

Transparency and Accountability in California's Regional Center System

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(i) Table of Abbreviations

Abbreviation	Term
ADA	Americans with Disabilities Act
AIPS	(National Core Indicators) Adult In-Person Survey
ARCA	Association of Regional Center Agencies
BCP	(California) Budget Change Proposal
CADDIS	California Developmental Disabilities Information System
CAP	Corrective Action Plan
CBO	Community-Based Organization
CDER	Child Development Evaluation Report
CDT	California Department of Technology
CMS	Centers for Medicare and Medicaid Services
CPRA	California Public Records Act
CRA	Client Rights Advocates
CY	Calendar Year
DC	Developmental Center
DDS	California Department of Developmental Services
DHCS	California Department of Health Care Services
DRC	Disability Rights California (formerly Protection and Advocacy, Inc.)
EDO	(California Department of Developmental Services') Enterprise Data Office
FY	Fiscal Year
HCBS	Home and Community-Based Services
HCBS Waiver	1915(c) HCBS Waiver
I/DD	Intellectual and Developmental Disabilit(ies)
IDEA	Individuals with Disabilities Education Act
IE	Independent Evaluation
IEE	Independent Educational Evaluation
IPP	Individual Program Plan
IT	Information Technology
LAO	Legislative Analyst's Office
MOU	Memorandum of Understanding
MLS	(National Core Indicators) Mover Longitudinal Study
M-R	Machine Readable
NCI	National Core Indicators
OAH	California Office of Administrative Hearings
OAL	California Office of Administrative Law
OCRA	Office of Clients' Rights Advocacy
POS	Purchase of Services
RC	Regional Center
S.B.	Senate Bill
SCDD	California State Council on Developmental Disabilities
SIDDLAPP	Stanford Intellectual and Developmental Disabilities Law and Policy Project
SIR	Special Incident Report
SLS	Supported Living Services
WIC	(California) Welfare and Institutions Code

I. Project Motivation and Overview

In 1969, California became the first state in the United States to grant individuals with intellectual and developmental disabilities (I/DD) the right to the services and supports they need to live more independent and normal lives. The Lanterman Developmental Disabilities Services Act (the Lanterman Act), now codified in the California Welfare and Institutions Code (WIC),¹ declared that “[a]n array of services and supports should be established which is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of life, and to support their integration into the mainstream life of the community.”² To this day, California is the only state in which the right of individuals with I/DD to be supported in the least restrictive environment is construed as a civil right and an individual entitlement, not merely a right to “take a number and wait in line” until sufficient state resources become available.³

To effectuate the goals of the Lanterman Act, California divides responsibility between the Department of Developmental Services (DDS), a state agency, and a network of twenty-one private, nonprofit corporations called “regional centers” that are funded by DDS through annual contracts. Each regional center (RC) serves a different area of the state, providing services and supports to individuals with I/DD in their local communities. DDS is responsible for monitoring the RCs and ensuring that they implement the Lanterman Act.

In the early years after the Act’s passage, DDS (and in turn, the RCs) were largely funded through the State’s General Fund. Since the mid-1980s, however, a sizable portion of funding has been provided by the federal government. The Centers for Medicare and Medicaid Services (CMS) fund a significant portion of the residential, day, and family supports and services that RC consumers receive.

As of this writing, California is not facing an imminent fiscal crisis and funding is relatively abundant. Given its relative prosperity at this historical juncture, the State is ideally positioned to shore up the service delivery system in a thoroughgoing fashion. Confronting each of the challenges that is threatening the system’s long-term viability will help safeguard the Lanterman Act’s beneficiaries from the effects of the next fiscal crisis if and when one materializes.

¹ The exact location of the Lanterman Act within the WIC is ambiguous. In the WIC, the Lanterman Act is demarcated as encompassing only division 4.5 (sections 4500 through 4585) of the WIC. CAL. WELF. & INST. CODE § 4500 (Deering, LEXIS through 2019 Sess.). However, a 1998 California Court of Appeals opinion cited a more expansive definition of the Act, including parts of division 4.7 in addition to 4.5. *Clemente v. Amundson*, 70 Cal. Rptr. 2d 1094, 1097 (Ct. App. 1998) (defining the Lanterman Act to encompass sections 4500 through 4905 of the WIC). In light of this ambiguity, we define the scope of our analysis to include WIC divisions 4.5 and 4.7, as well as WIC division 4.1 and title 13 of the California Government Code, which together constitute the “Lanterman Act and Related Laws” as defined by the Department of Developmental Services. *Lanterman Developmental Disabilities Act and Related Laws*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/transparency/laws-regulations/lanterman-act-and-related-laws/> (last visited Jan. 4, 2020) (listing sections considered the “Lanterman Act and Related Laws”).

² CAL. WELF. & INST. CODE § 4501 (Deering, LEXIS through 2019 Sess.).

³ HALEIGH MAGER-MARDEUSZ & GERALD F. KOMINSKI, UCLA CTR. FOR HEALTH POLICY RES., MORE THAN 400,000 CALIFORNIANS WITH DEVELOPMENTAL DISABILITIES REMAIN OUTSIDE THE STATE SAFETY NET 6 (2016), <http://healthpolicy.ucla.edu/publications/Documents/PDF/2016/DisabilityPN-nov2016.pdf> (last visited Jan. 23, 2020) (“California is the only state in the nation to have an entitlement to care for the developmentally disabled.”).

This report is part of a series issued by the Stanford Intellectual and Developmental Disabilities Law and Policy Project (SIDDLAPP) to explore steps that the State might take to protect the Lanterman Act entitlement in a reduced funding environment. Since its inception in September of 2017, the project has been carried forward by various Stanford-affiliated researchers—law students, research fellows, and undergraduates—under the direction of Alison Morantz, Director of SIDDLAPP and the James and Nancy Kelso Professor of Law.

SIDDLAPP researchers used several complementary approaches to investigate each issue considered in this report. First, they analyzed primary and secondary materials produced by each branch of government at the state and federal levels; such as statutes, regulations, administrative hearing decisions, responses to California Public Records Act requests, and judicial opinions. Second, they examined earlier reports on related issues released by nonprofit organizations, community task forces, the California State Controller’s Office, the California State Auditor, legislative analysts, and consultants. Third, the team arranged in-person meetings with a variety of individuals with pertinent personal and/or professional expertise, including consumers of RC services and their families, service providers, community activists, legislative staffers, and RC directors. Finally, the team sought to meet with various organizational entities that play leading roles in the development and analysis of state policy in the I/DD arena: Disability Rights California (DRC), The State Council on Developmental Disabilities (SCDD), DDS, the Department of Health Care Services (DHCS), the Legislative Analyst’s Office (LAO), Public Counsel, and the Association of Regional Center Agencies (ARCA). All of these individuals and organizations, with the exception of ARCA, accepted the team’s invitation to discuss the issues examined in these reports.

The project team wishes to gratefully acknowledge the input and assistance of the numerous individuals and organizations who provided the information, insights, and knowledge on which these reports are based.

The goal of this report, *Transparency and Accountability in California’s Regional Center System*, is to examine stakeholders’ capacity to obtain critical information on outcomes, and to hold the system accountable for those outcomes at the individual and systemic levels. First, we consider different institutional actors’ compliance with transparency statutes that mandate the disclosure of information to government and nonprofit entities; to the public on internet websites; and to the public upon request. Second, we assess the adequacy of current accountability provisions that empower individuals and institutions, respectively, to enforce key provisions of state law. Finally, we propose a number of reforms that we believe could improve overall levels of transparency and accountability in the regional center system, thus helping to safeguard the Lanterman Act’s historic legacy.

SIDDLAPP encourages dissemination of its publications. Additional reports in this series are available for download at <https://law.stanford.edu/siddlapp/>.

II. Executive Summary

In any large service delivery system, transparency and accountability go hand in hand. Systemic problems cannot be identified without a high level of transparency, and they cannot be corrected unless those in charge are held accountable for lapses. These concerns apply with special force to California’s regional center (RC) system, which serves hundreds of thousands of individuals with intellectual and developmental disabilities (I/DD). Taking measures to maximize transparency and accountability is an important way to safeguard the system’s long-term viability and equity.

Our examination of the I/DD service delivery system suggests that there is considerable room for improvement in both transparency and accountability. There are many areas in which the Department of Developmental Services (DDS) and/or the twenty-one RCs it oversees are not fully compliant with existing disclosure requirements. The inconsistent formats and time periods of mandated disclosures, and the relative scarcity of machine-readable data,⁴ pose additional barriers to data accessibility. Our research also suggests that DDS’s oversight of the RCs under its purview has been relatively limited. The Department has relied mostly on “soft” enforcement tools, such as specialized training and targeted grants, as well as targeted Corrective Action Plans (CAPs) in cases of clear misconduct. However, DDS has rarely used more incremental, outcome-driven strategies that reward RCs for advancing person-centered policy goals, or penalize them for falling short.

We propose a range of measures to improve systemic transparency. These include strengthening current disclosure requirements, especially those pertaining to the reporting of administrative hearing decisions; requiring all public disclosures of quantitative information to be provided in a machine-readable format; standardizing the location, format and content of RCs’ web-based disclosures; improving the methods used to classify consumers by ethnicity and community-based residence status; requiring RCs to report intake and assessment data; making RCs subject to the California Public Records Act; and creating a high-performance I/DD database.

To improve accountability and oversight, we suggest a number of reforms: explicitly permitting individuals who receive intake and assessment services to file complaints; requiring RCs to notify consumers in writing of all changes to services listed in their IPPs; deterring RCs from “deactivating” consumers who do not receive RC services for prolonged periods of time; allowing consumers to request independent assessments of service eligibility and to recover litigation costs if they prevail in disputes with RCs; protecting RC board members from retaliation; requiring DDS and RCs to publish corrective action plans as well as granular data on stakeholder quality assessment surveys and special incident reports; incentivizing RCs to improve person-centered outcomes; requiring independent evaluation of pilot projects designed to further key policy objectives; revising DDS’s budget allocation methodology to reduce geographic, racial and ethnic disparities; and creating an inspector general or other independent entity to oversee and monitor the RC system as a whole.

⁴ For a definition of “machine-readability,” see *infra* note 57.

III. Introduction

The guiding purpose of this report, like the others in this series,⁵ is to provide insights and tools to safeguard a system that, if history is any guide, will one day be threatened by another fiscal crisis. Regardless of whether the next crisis is triggered by a change in federal policy or a different precipitating event, it would throw important systemic challenges into stark relief.⁶ In this report, we consider the system’s readiness to cope with these challenges in ways that do not threaten the core of the Lanterman Developmental Disabilities Act (Lanterman Act) entitlement.

We start with three simple observations.

First, without the capacity to track and analyze key information at the state and individual RC levels, stakeholders cannot assess whether the Lanterman Act entitlement is being adequately preserved at any given moment in time.

Second, even if the State is capable of detecting problems, it cannot correct them unless it can hold RCs accountable for deficiencies. In other words, particularly in a system as large and complex as the one established by the Lanterman Act, transparency and accountability are interdependent; one operating in isolation is of little practical value.

Finally, systemic transparency and accountability are especially vital in times of resource scarcity. If overall funding to DDS begins to shrink, it is almost inevitable that RCs will be forced to take cost-cutting measures. The more potent the transparency and accountability tools at decision makers’ disposal, the better equipped the State will be to ensure that RCs save costs in ways that do not threaten the core of the entitlement.

With these insights in mind, we consider the following questions:

1. *Current Level of Systemic Transparency*: How transparent is the current system? How well equipped are DDS, the Legislature, and the public to identify existing deficiencies and track whether reforms are effective?
2. *Current Level of Systemic Accountability*: What accountability mechanisms are currently in place to correct those deficiencies that come to light? How effective are they?
3. *Suggested Reforms*: Are there measures that could enable the RC system to become more transparent and accountable to those it serves?

Our focus on the value of increasing transparency and accountability in California’s RC system is not new. In 2011, for example, the State Council on Developmental Disabilities (SCDD) identified “System Transparency/Oversight and Accountability” as a weakness of the system, observing that “the overall design of the developmental services system in California is meant to

⁵ See PETER VOGEL ET AL., STANFORD INTELLECTUAL & DEVELOPMENTAL DISABILITIES LAW & POLICY PROJECT, A FISCAL PRIMER ON CALIFORNIA’S REGIONAL CENTER SYSTEM (2018) [hereinafter LANTERMAN PRIMER]; LANE ZURAW ET AL., STANFORD INTELLECTUAL & DEVELOPMENTAL DISABILITIES LAW & POLICY PROJECT, THE SCOPE OF THE LANTERMAN ACT ENTITLEMENT (2018) [hereinafter LANTERMAN ENTITLEMENT REPORT]; CARLY HITE ET AL., STANFORD INTELLECTUAL & DEVELOPMENTAL DISABILITIES LAW & POLICY PROJECT, INCREASING UPTAKE OF MEDICAID FUNDING TO SUPPORT CALIFORNIA’S REGIONAL CENTER SYSTEM (2018) [hereinafter FEDERAL LANTERMAN FUNDING REPORT].

⁶ See LANTERMAN PRIMER, *supra* note 5, § V (discussing key challenges facing RC system).

be responsive and accountable to individuals and families through local implementation,” and contending that “the growth of the system over the past 40 years has created a need for additional transparency to the public and oversight and direction by the State of California.”⁷ In the decades since the Act’s passage, many other observers have reached broadly similar conclusions.⁸

In January of 2019, as part of the Governor’s FY 2019-2020 Budget, DDS submitted a Budget Change Proposal⁹ (BCP) for an additional \$8.1 million in appropriations, describing “increasing transparency and accountability in the Department’s programs and [the] RC system” as the purpose of the funding.¹⁰ These additional appropriations were approved by the Legislature¹¹ and signed into law with the passage of the Budget Act of 2019 on June 27, 2019.¹²

Our goal is to identify additional reform measures that we believe could build on DDS’s organizational expansion and bring about further improvements in systemic transparency and accountability.

Importantly, we do *not* present the recommendations in this report with the conviction that each and every one is worthy of immediate legislative enactment. Setting the bar that high would, we believe, do policymakers a disservice. Rather, we present a relatively broad array of proposals

⁷ STATE COUNCIL ON DEVELOPMENTAL DISABILITIES, SERVICES AND SUPPORTS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES IN CALIFORNIA: BRIEFING PAPER FOR GOVERNOR JERRY BROWN 5 (2011), www.acphd.org/media/95868/svcs_and_supports_individuals_with_devdis.pdf (last visited Jan. 7, 2020).

⁸ See, e.g., AMI SULLIVAN ET AL., A CONSOLIDATED DEVELOPMENTAL SERVICES QUALITY MANAGEMENT SYSTEM: ACHIEVING COMPREHENSIVE EFFICIENCY AND EFFECTIVENESS – DRAFT REPORT (2011) [hereinafter ACHIEVING COMPREHENSIVE EFFICIENCY]; CALIFORNIA AUDITOR GENERAL, CALIFORNIA’S REGIONAL CENTERS FOR THE DEVELOPMENTALLY DISABLED NEED BETTER FINANCIAL CONTROLS (1988); CHARLES GALLOWAY, ASSEMBLY OFFICE OF RESEARCH, KEEPING THE PROMISE OF THE LANTERMAN ACT, REPORT 1: QUALITY SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES 95–98 (1984); CITYGATE ASSOCIATES, INDEPENDENT EVALUATION OF THE DEPARTMENT OF DEVELOPMENTAL SERVICES’ COMMUNITY PLACEMENT PRACTICES: FINAL TECHNICAL REPORT IV-1–IV-14 (1998) [hereinafter CITYGATE INDEPENDENT EVALUATION]; PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING OF SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES (2017) [hereinafter PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING] <http://www.publiccounsel.org/tools/assets/files/0893.pdf> (last visited Jan. 8, 2020); PUBLIC COUNSEL, ADDRESSING FUNDING DISPARITIES IN SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES (2019) [hereinafter PUBLIC COUNSEL, ADDRESSING FUNDING DISPARITIES], https://www.lpfch.org/sites/default/files/field/publications/public_counsel_pos_disparity_report_-_complete_version.pdf#page20 (last visited Jan. 8, 2020).

⁹ Budget Change Proposals (BCPs) are formal documents required when a state agency or office “has a need for additional resources or a reduction in resources to change the level of service or funding for activities authorized by the Legislature, or to propose new program activities not currently authorized.” OFFICE OF HUMAN RES., *Budget Change Proposal*, DEP’T OF GEN. SERVS., <https://www.dgs.ca.gov/OHR/Resources/Page-Content/Office-of-Human-Resources-Resources-List-Folder/Personnel-Operations-Manual/Budget-Change-Proposal#@ViewBag.JumpTo> (last visited Jan. 14, 2020). In June of the year prior to the budget’s enactment, each BCP is presented to the Department of General Services’ Executive Management Team for approval, at which point a formal version of the BCP is prepared and, if subsequently approved by the Department of Finance or the Governor’s Office (in the case of disagreements between the two prior agencies), included in the Governor’s Budget released on January 10th. *Id.*

¹⁰ CAL. DEP’T OF DEVELOPMENTAL SERVS., FY 2019/20 BUDGET CHANGE PROPOSAL 6 (2019), https://esd.dof.ca.gov/Documents/bcp/1920/FY1920_ORG4300_BCP2742.pdf (last visited Dec. 24, 2019).

¹¹ See 2019-20 BCPs, CAL. DEP’T OF FIN., <https://esd.dof.ca.gov/dofpublic/viewBcp.html?yr=1920> (last visited Jan. 17, 2020) (specifying that “BCPs that are not approved in full by the Legislature are indicated as “Legislature Modified”... BCPs fully rejected by the Legislature are shown as “Legislature Rejected”[, and] BCPs fully approved by the Legislature do not have a notation at the end of the BCP title,” and subsequently listing the aforementioned BCP, see CAL. DEP’T OF DEVELOPMENTAL SERVS., *supra* note 10, without any demarcation to note that it was not accepted in full, under the search results for “Developmental Services” through the link labeled “Headquarters Restructure and Reorganization”).

¹² Budget Act of 2019, ch. 23, 2019 Cal. Legis. Serv. 91 (West).

that we believe exceed a minimum threshold of credibility, feasibility and potential efficacy. Our hope is that enlarging the scope of potential reforms will enrich public debate on the strengths and weaknesses of the RC system, spurring improvements that will enhance the system's long-term efficacy, equity and stability.

IV. Current Levels of Systemic Transparency

Since the passage of the Lanterman Act, the Legislature has imposed numerous reporting requirements on DDS and RCs, respectively. For our purposes, it is useful to group these requirements into three categories. First, the Legislature has directed DDS and RCs to provide various types of qualitative and quantitative information to each other, other (quasi-) governmental entities, and nonprofit organizations. Second, the Legislature requires DDS and RCs to publish certain types of data on their respective websites. Finally, the Legislature has mandated that certain types of information be provided to the public “upon request,” such as in response to California Public Records Act¹³ (CPRA) requests. This section analyzes each type of mandated disclosure in turn.

A. Mandated Disclosures to Government & Nonprofit Entities

DDS’s and RCs’ reporting obligations to other (quasi-)governmental and nonprofit entities are varied and extensive. For example, each RC is required to inform DDS within two working days of any circumstance in which a Special Incident Report (SIR) was, or should have been, submitted to the RC by a service provider.¹⁴ (SIRs are generally required whenever a RC consumer disappears or experiences a crime, serious injury or accident, unexpected hospitalization, or apparent instance of abuse or neglect.)¹⁵

DDS and RCs are also required to make numerous disclosures to Disability Rights California (DRC), the private nonprofit organization designated by the governor to protect and advocate for the rights of persons with disabilities,¹⁶ or the Office of Clients’ Rights Advocacy (OCRA), a DDS-funded division of DRC that provides advocacy assistance to RC consumers and their families.¹⁷ For example, OCRA must be notified of any comprehensive assessments of consumers residing in developmental centers (DCs) who meet certain criteria;¹⁸ the date, time and location of any Individual Program Plan (IPP) meetings in which such assessments are

¹³ The California Public Records Act is codified in sections 6250-6270.5 of the California Government Code. CAL. GOV’T CODE §§ 6250-6270.5 (Deering, LEXIS through 2019 Sess.).

¹⁴ See CAL. CODE REGS. tit. 17, § 54327.1(a)-(b) (2019) (noting, in section titled “Requirements for Special Incident Reporting by Regional Centers,” that RCs must report special incidents to DDS within two working days of learning of them either through receipt of Special Incident Reports or indirectly).

¹⁵ See CAL. CODE REGS. tit. 17, § 54327 (2019) (enumerating specific circumstances in which special incident reporting is required).

¹⁶ See *Our History*, DISABILITY RIGHTS CAL., <https://www.disabilityrightsca.org/who-we-are/our-history> (last visited Jan. 7, 2020) (noting that in 1978 the Governor designated DRC, then known as Protection & Advocacy, Inc., as California’s federally-mandated protection and advocacy agency).

¹⁷ See *Office of Clients’ Rights Advocacy (OCRA)*, DISABILITY RIGHTS CAL., <https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra> (last visited Jan. 7, 2020) (noting that through a contract with DDS, OCRA has been providing a variety of services to consumers since 1999). OCRA has a “Clients’ Rights Advocate (CRA) designated for each regional center catchment area” to assist with “legal problems, conduct[ing] trainings, and investigat[ing] denials of rights.” *Id.*

¹⁸ CAL. WELF. & INST. CODE § 4418.25(c)(2)(D) (Deering, LEXIS through 2019 Sess.) (establishing that assessments must be provided to the Clients’ Rights Advocate of the RC that conducts the assessment).

discussed or updated;¹⁹ outcome data on the assessment process;²⁰ the number of consumers from each RC admitted to each developmental center and the legal basis for these admissions;²¹ “progress in the development of needed statewide specialty services and supports, including regional community crisis options”;²² progress in reducing admissions to out-of-state placements and mental health facilities that are ineligible for federal Medicaid funding;²³ information on the use of facilities serving consumers with “challenging service needs that utilize delayed egress devices and secured perimeters”;²⁴ and any recommendations regarding additional rate exceptions that may be necessary “to meet the needs of consumers with challenging service needs.”²⁵ In addition, DRC must be notified directly of any cases in which an unexpected or suspicious death, incident of alleged sexual assault, or incident of alleged physical abuse occurs at a DC or a DDS-operated facility;²⁶ and is vested with the authority to access all relevant records and investigate any allegations of abuse and neglect.²⁷

Finally, a great deal of information, such as the status of DC operations and the progress of efforts to reduce DC populations,²⁸ the implementation of new programing,²⁹ and the outcome of efforts to reduce purchase of service (POS) disparities,³⁰ must be reported by DDS directly to legislative committees.

¹⁹ *Id.* WELF. & INST. § 4418.25(c)(2)(E) (LEXIS).

²⁰ *Id.* WELF. & INST. § 4418.25(f)(3) (LEXIS).

²¹ *Id.* WELF. & INST. § 4418.25(f)(1) (LEXIS).

²² *Id.* WELF. & INST. § 4418.25(f)(4) (LEXIS).

²³ *Id.* WELF. & INST. § 4418.25(f)(5) (LEXIS); *see also id.* WELF. & INST. § 4418.25(h) (LEXIS) (requiring each Institution for Mental Disease to provide OCRA with detailed information on each RC consumer admitted to the facility during the preceding year).

²⁴ *Id.* WELF. & INST. § 4418.25(f)(6) (LEXIS).

²⁵ *Id.* WELF. & INST. § 4418.25(f)(7) (LEXIS).

²⁶ California Welfare and Institutions Code (WIC) section 4427.5(b)(1) requires reporting of incidents involving a resident of a developmental center or DDS-operated facility to the “agency described in subdivision (i) of [s]ection 4900.” CAL. WELF. & INST. § 4427.5(b)(1) (Deering, LEXIS through 2019 Sess.). Similarly, section 4659.2(b) requires RC vendors to report incidents to the “agency described in subdivision (i) of [s]ection 4900.” CAL. WELF. & INST. § 4659(b) (Deering, LEXIS through 2019 Sess.). Section 4900(i) identifies this agency as the “private nonprofit corporation designated by the Governor ... for the protection and advocacy of the rights of persons with developmental disabilities,” CAL. WELF. & INST. CODE § 4900(i) (Deering, LEXIS through 2019 Sess.), which in 1978 was designated as DRC. *See* DISABILITY RIGHTS CAL., *supra* note 16 and accompanying text.

²⁷ *See* CAL. WELF. & INST. CODE § 4902 (Deering, LEXIS through 2019 Sess.) (authorizing the protection and advocacy agency, defined in California Welfare and Institutions Code (WIC) section 4900(i), to “[i]nvestigate any incident of alleged abuse or neglect of any person with a disability”). WIC section 4900(i) identifies this agency as the “private nonprofit corporation designated by the Governor ... for the protection and advocacy of the rights of persons with developmental disabilities,” CAL. WELF. & INST. CODE § 4900(i) (Deering, LEXIS through 2019 Sess.), which in 1978 was designated as DRC. *See* DISABILITY RIGHTS CAL., *supra* note 16 and accompanying text.

²⁸ *See* CAL. WELF. & INST. CODE § 4474.1 (Deering, LEXIS through 2019 Sess.) (reports regarding DC closure); CAL. WELF. & INST. CODE § 4474.12(d) (Deering, LEXIS through 2019 Sess.) (reports regarding DC residents moving into the community); CAL. WELF. & INST. CODE § 4474.2(b) (Deering, LEXIS through 2019 Sess.) (reports regarding DDS-directed activities to expand community placement).

²⁹ *See, e.g.,* CAL. WELF. & INST. CODE §§ 4429-4432 (Deering, LEXIS through 2019 Sess.) (ongoing DDS reporting requirements); *see also* WELF. & INST. § 4418.25(f) (LEXIS) (DDS outcome reporting requirements); CAL. WELF. & INST. CODE § 4436(e) (Deering, LEXIS through 2019 Sess.) (reports regarding enhanced behavioral supports homes); CAL. WELF. & INST. CODE § 4685.8(z)(2) (Deering, LEXIS through 2019 Sess.) (reports regarding the Self-Determination Program); CAL. WELF. & INST. CODE § 4696.1(f) (Deering, LEXIS through 2019 Sess.) (reports regarding cooperation with county mental health agencies); CAL. WELF. & INST. CODE § 4836 (Deering, LEXIS through 2019 Sess.) (reports regarding community-living continuums).

³⁰ CAL. WELF. & INST. CODE § 4519.5(a)-(d), (g)(2) (Deering, LEXIS through 2019 Sess.).

Because most of the latter provisions require public entities to share information with each other without public disclosures, we could not analyze comprehensively the extent to which DDS and RCs have complied with them. We note, however, that the Legislative Analyst’s Office (LAO), which provides nonpartisan fiscal and policy advice to the Legislature, has periodically opined that DDS’s disclosures to the Legislature are insufficiently granular to enable the Legislature to determine whether statutory goals are being met.³¹

B. Mandated Disclosures on Public-Facing Websites

(1) NCI Survey Data

California Welfare and Institutions Code (WIC) section 4571, originally enacted in 2009,³² is intended to “[e]nable the department and regional centers to compare the performance of California’s developmental services system against other states’ developmental services systems and to assess quality and performance among all of the regional centers.”³³ In particular, DDS is required to conduct a “nationally validated, benchmarked, consistent and reliable” Quality Assessment³⁴ that uses “outcome-based measures” as points of comparison.³⁵ The Quality Assessment must provide statewide data and data broken down by RC.³⁶

To comply with this mandate, DDS has chosen to administer five National Core Indicators (NCI) surveys, developed in partnership with the Human Services Research Institute, the National Association of State Directors of Developmental Disabilities Services, and the University of California, Davis.³⁷ The first survey, called the Adult In-Person Survey (AIPS), is conducted by the SCDD through in-person interviews with adult consumers receiving RC services.³⁸ Three additional surveys are mailed to the families (or conservators) of RC consumers: the Family Guardian Survey (mailed to family members of adult consumers living *outside* the family home); the Adult Family Survey (mailed to family members of adult consumers living *in* the family

³¹ See MAC TAYLOR, LEGISLATIVE ANALYST’S OFFICE, SEQUESTERING SAVINGS FROM THE CLOSURE OF DEVELOPMENTAL CENTERS 15 (2018) [hereinafter SEQUESTERING SAVINGS], <https://lao.ca.gov/reports/2018/3735/sequestering-savings-013118.pdf> (last visited Jan. 8, 2020) (“DDS lacks a standardized method for understanding [] gaps [in services] on a systemwide basis.”); see also MAC TAYLOR, LEGISLATIVE ANALYST’S OFFICE, THE 2016–17 BUDGET: ANALYSIS OF THE DEPARTMENT OF DEVELOPMENTAL SERVICES BUDGET 14 (2017), <https://lao.ca.gov/reports/2016/3382/developmental-services-analysis-030416.pdf> (last visited Jan. 8, 2020) (emphasizing the need for greater transparency in DDS’s disclosures to the Legislature regarding the use of Community Placement Plan funding).

³² Act of Jul. 28, 2009, ch. 9, § 9, 2009 Cal. Legis. Serv. 5144, 5155-56 (codified as amended at CAL. WELF. & INST. CODE § 4571 (2019)).

³³ CAL. WELF. & INST. CODE § 4571(b)(2) (Deering, LEXIS through 2019 Sess.).

³⁴ *Id.* WELF. & INST. § 4571 (LEXIS). The title of section 4571 uses the phrase “quality assessment,” while the body of the statute uses the phrase “quality assurance instrument.” *Id.* WELF. & INST. § 4571 (LEXIS). For clarity’s sake, we use the term “Quality Assessment” throughout this report.

³⁵ *Id.* WELF. & INST. § 4571(a) (LEXIS).

³⁶ *Id.* WELF. & INST. § 4571(e) (LEXIS).

³⁷ *National Core Indicators*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/nci/> (last visited Dec. 25, 2019) [hereinafter *DDS NCI Webpage*] (“The survey was developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services.”); *Mover Longitudinal Study*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/nci/mover-longitudinal-study-reports/> (last visited Dec. 25, 2019) [hereinafter *MLS Webpage*] (“[T]he MLS was designed by the University of California, Davis.”).

³⁸ *Regional Center Oversight Dashboard*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/dashboard/> (last visited Dec. 25, 2019) [hereinafter *Performance Dashboard*] (describing survey methodology in the “NCI Report” tab).

home); and the Child Family Survey (mailed to family members of minor consumers living at home).³⁹ A fifth survey, the Mover Longitudinal Study (MLS), was developed to provide additional information on consumers transitioning from DCs into the community.⁴⁰ These five surveys differ in the timing and frequency of their administration. The AIPS is conducted every three years; the most recent survey took place in FY 2017-18.⁴¹ The three family surveys are also conducted every three years, but on inconsistent schedules⁴²: the Family Guardian Survey and Adult Family Survey were last conducted in FY 2016-17, whereas the Child Family Survey was last conducted in FY 2018-19.⁴³ The reporting frequency for the MLS is less clear.⁴⁴ Although the study was initiated in January 2016,⁴⁵ no reports have been posted to DDS’s website.⁴⁶

The reporting requirements for the NCI survey data are codified in two different sections of the WIC. Section 4571 states that all RC-specific reports shall be published on the RCs’ websites,⁴⁷ and that all other reports shall be made publicly available, without indicating whether the disclosures must be placed on DDS’s public-facing websites, or need only be made available upon request.⁴⁸ Meanwhile, section 4572(a) requires DDS to publish “[r]ecognized quality and access measures” on its public-facing online Performance Dashboard.⁴⁹ Although the latter

³⁹ *DDS NCI Webpage, supra* note 37 (detailing the survey methodology in the “Survey Results/Reports” tab).

⁴⁰ *MLS Webpage, supra* note 37 (“MLS was designed by the University of California, Davis (UCD) to provide needed information to stakeholders and help DDS answer questions about how and why changes in services occur over time for people who move from a DC to the community.”). The MLS is not the first survey implemented by DDS to observe these outcomes; in FY 2009-10, DDS began an annual interview of individuals who moved from Lanterman Developmental Center, as well as a cohort of individuals who had transitioned from any DC within the previous five years. *See DDS NCI Webpage, supra* note 37 (detailing past surveys of people transitioning out of DCs in the “Individuals Transitioning” tab). Individuals from Lanterman Developmental Center were to be interviewed every year until FY 2018-19, while the remaining cohort of individuals were subsequently absorbed into the Mover Longitudinal Study (MLS). *Id.*

⁴¹ *See DDS NCI Webpage, supra* note 37 (detailing the schedule for all California NCI surveys in the “Survey Schedule” in the “Survey Results/Reports” tab).

⁴² *See id.*

⁴³ *See id.*

⁴⁴ WIC section 4474.12 (governing the implementation of the MLS) does not detail a set schedule for reporting of results. CAL. WELF. & INST. CODE § 4474.12 (Deering, LEXIS through 2019 Sess.). There is also ambiguity as to whether WIC section 4571(i) requires MLS reports to be made publicly available. WIC section 4571(i) only requires the reporting of survey results “pursuant to [section 4571],” CAL. WELF. & INST. CODE § 4571(i) (Deering, LEXIS through 2019 Sess.), and while section 4474.12(b) explicitly demarcates the study as “one element of the quality assurance instrument required pursuant to [s]ection 4571,” CAL. WELF. & INST. CODE § 4474.12(b) (Deering, LEXIS through 2019 Sess.), MLS’s implementation and the accompanying reports are detailed in section 4474.12, not section 4571. *Id.* WELF. & INST. § 4474.12(d) (LEXIS).

⁴⁵ CAL. DEP’T OF DEVELOPMENTAL SERVS., NCI LONGITUDINAL STUDY, https://www.dds.ca.gov/wp-content/uploads/2019/02/NCI_MLSFAQ_20180208.pdf (last visited Jan. 7, 2020) (“The Longitudinal Study will begin to survey individuals who have moved from a Developmental Center in January, 2016.”).

⁴⁶ The DDS NCI Webpage provides results for the prior version of the MLS, the Developmental Center Mover and Lanterman Developmental Center Mover Survey, for FY 2012-13 and FY 2013-14. *DDS NCI Webpage, supra* note 37 (listing all survey reports in the “Self Advocates” tab). However, it contains no more recent reports, either relating to the Lanterman Movers—who were to be interviewed until FY 2018-19—or the broader sample of movers from any developmental center, who were to be incorporated into the MLS in 2016. *See DDS NCI Webpage, supra* note 37 (detailing past the survey schedule of people transitioning out of DCs in the “Individuals Transitioning” tab). Additionally, the dedicated MLS Webpage contains no results at all from the study. *MLS Webpage, supra* note 37.

⁴⁷ CAL. WELF. & INST. CODE § 4571(h)(2) (Deering, LEXIS through 2019 Sess.).

⁴⁸ CAL. WELF. & INST. CODE § 4571(i) (Deering, LEXIS through 2019 Sess.).

⁴⁹ CAL. WELF. & INST. CODE § 4572(a) (Deering, LEXIS through 2019 Sess.). For the sake of clarity, we choose to refer to the webpage in which DDS fulfills the requirements of section 4572(a), *see id.* WELF. & INST. § 4572(a) (LEXIS), as the “Performance Dashboard.” This represents a slight deviation from the statute itself, in which it is referred to as the

provision does not state explicitly that the “quality measures” referenced are the same as the Quality Assessment referenced in section 4571 (which in turn corresponds to the NCI survey data), this seems to be the only plausible interpretation.

DDS has chosen to fulfill these reporting requirements by posting NCI data in two separate locations, but the content of its disclosures are incomplete in several important regards. First, on a webpage entitled “National Core Indicators” (DDS NCI Webpage), DDS provides links to some results of the five NCI surveys, broken down by RC as well as statewide.⁵⁰ Yet the DDS NCI Webpage includes no results from the 2016-17 Family Guardian Survey; no results from the 2016-17 Adult Family Survey; and no results from any year of the MLS.⁵¹ DDS’s Performance Dashboard likewise includes an “NCI Report” tab, but the disclosures on this page are even more sparse: they only include results from five survey questions in a single year (the 2014-2015 AIPS),⁵² and omit results from the FY 2017-18 AIPS despite the latter’s inclusion on the DDS NCI Webpage.⁵³

Moreover, several factors limit the utility of the NCI data that DDS does report. First, the content of the AIPS has changed between survey years, making it difficult to track California’s performance relative to other states over time. For example, in the FY 2014-15 AIPS (the second most recent edition of the AIPS), respondents were asked, “If you call and leave a message, does your case manager/service coordinator take a long time to call you back, or does s/he call you back right away?”⁵⁴ The percentage of California respondents who answered “[c]alls back right away” lagged behind the national average by 13 percentage points.⁵⁵ Yet this question was dropped from the FY 2017-18 AIPS, making it impossible to track progress on this performance metric.⁵⁶

“performance dashboard,” *see id.* WELF. & INST. § 4572(a) (LEXIS), as well as the webpage itself, which is titled the “Regional Center Oversight Dashboard,” *see Performance Dashboard, supra* note 38.

⁵⁰ *See DDS NCI Webpage, supra* note 37 (Self Advocates).

⁵¹ *See id.* The lack of information pertaining to the FY 2016-17 Adult Family and Family Guardian Surveys is especially concerning given that the state-level results for California (although not broken down by RC) are available on the NCI’s own webpage. *See California, NAT’L CORE INDICATORS*, <https://www.nationalcoreindicators.org/states/CA/>, (last visited Dec. 13, 2019) (Additional Reports). Though the 2018-19 Child Family Survey has been completed, *see DDS NCI Webpage, supra* note 37 (Survey Results/Reports), the survey data have not yet been compiled into a report, *see Reports 2018-19, NAT’L CORE INDICATORS*, <https://www.nationalcoreindicators.org/resources/reports/#reports-child-family-survey-state-reports> (last visited Jan. 8, 2020) (Child Family Survey State Reports).

⁵² *Performance Dashboard, supra* note 38 (National Core Indicators). The webpage displays graphically RC performance across five of the metrics from the FY 2014-2015 AIPS, although these graphs do not include information on the statewide or national average. *Id.*

⁵³ *See DDS NCI Webpage, supra* note 37 (Self Advocates).

⁵⁴ CAL. DEP’T OF DEVELOPMENTAL SERVS., ADULT CONSUMER SURVEY: CALIFORNIA STATEWIDE REPORT FISCAL YEAR 2014-2015 86 (2016), https://www.dds.ca.gov/wp-content/uploads/2019/09/NCI_adultConsumerSurvey3FY14_15.pdf [sic] (last visited Dec. 25, 2019).

⁵⁵ *Id.* at 86 tbl.69 (reporting that 61% of California consumers answered that if they call and leave a message, their case manager/service coordinator “[c]alls back right away,” compared to 74% nationwide).

⁵⁶ CAL. DEP’T OF DEVELOPMENTAL SERVS., IN PERSON SURVEY: CALIFORNIA ADULT CONSUMER SURVEY 2017-18 vii-xi (2019) [hereinafter 2017-18 AIPS], https://www.dds.ca.gov/wp-content/uploads/2019/11/adultConsumerSurvey4FY17_18.pdf (last visited Jan. 7, 2020) (listing content of survey, which does not include any questions on whether service coordinators return the calls of respondents right away if they leave a voicemail).

Secondly, the manner in which DDS reports the AIPS results limits their practical utility. DDS does not present the NCI AIPS data in machine-readable format,⁵⁷ such as Microsoft Excel, but only in the form of a 240-page PDF document.⁵⁸ As a consequence, the only way to systematically compare California's performance to that of other states would be to manually convert each table into a machine-readable format, thereby rendering the data suitable for empirical analysis.⁵⁹ Moreover, because DDS does not make available the *underlying* respondent-level survey data and respondent characteristics, it is impossible to break the data down into more granular categories to explore whether trends differ by consumer type. Though the NCI's own website likewise lacks respondent-level microdata, it does include a tool with which users can break down AIPS results by state, question, and demographic group.⁶⁰ To allow users to disaggregate California's NCI results in a similar fashion, DDS could make a comparable tool available on its website.

In short, DDS's compliance with the Quality Assessment reporting requirements could be improved in several regards. The Department has made results from some NCI surveys available on two webpages, but many survey years are missing, even if they are available elsewhere on

⁵⁷ Throughout this report, we describe a given disclosure as "machine-readable" if it contains numeric information presented in extensive markup language (either XML or JSON), or else is saved in a format suited to tabular display (CSV, XLS or XLSX). Numeric data displayed in graphics that cannot be easily exported to such a format, or that are only provided in the form of a PDF table, are not machine-readable. This definition aligns with that used by the U.S. federal government, OFFICE OF MGMT. & BUDGET, CIRCULAR NO. A-11, § 200 pp. 21-22 (2019), <https://www.whitehouse.gov/wp-content/uploads/2018/06/a11.pdf> (last visited Jan. 3, 2020) ("Traditional word processing documents, hypertext markup language (HTML) and portable document format (PDF) files are easily read by humans but typically are difficult for machines to interpret. Other formats such as extensible markup language (XML), (JSON), or spreadsheets with header columns that can be exported as comma separated values (CSV) are machine readable formats."), the European Union, *see Can individuals ask to have their data transferred to another organization?*, EUR. COMM'N, https://ec.europa.eu/info/law/law-topic/data-protection/reform/rules-business-and-organisations/dealing-citizens/can-individuals-ask-have-their-data-transferred-another-organisation_en (last visited Jan. 3, 2020) (providing XML, JSON, and CSV as examples of machine-readable format and noting that a PDF would not necessarily be sufficient to meet the requirement), the United Nations, *see Open Data Portal*, U.N., <https://peacekeeping.un.org/en/open-data-portal> (last visited Jan. 3, 2020) ("The Peacekeeping Open Data Portal provides data in machine-readable formats (e.g., CSV, XLS)."), and all other academic, governmental, and popular reference sources of which we are aware. *See, e.g., Open Data Handbook*, OPEN DATA FOUND., <https://opendatahandbook.org/glossary/en/terms/machine-readable/> (last visited Jan. 3, 2020) (defining machine-readable as data stored in a format that can be automatically read and processed by a computer, such as CSV, JSON, or XML); JIM HENDLER & THERESA A. PARDO, *A Primer on Machine Readability for Online Documents and Data*, DATA.GOV, (Sept. 24, 2012), <https://www.data.gov/developers/blog/primer-machine-readability-online-documents-and-data> (last visited Jan. 3, 2020) (identifying CSV as the most common machine-readable format and highlighting that it is not sufficient to only provide reports on information in pdf, jpg, or html formats). In some cases, it may be possible to use software programs such as PDFTables to convert PDF files to machine-readable formats, yet such programs are often proprietary. *See* PDFTABLES, <https://pdftables.com/> (last visited Dec. 13, 2019) (pricing). Moreover, converting the files in this fashion requires a baseline programming proficiency that is likely out of most stakeholders' reach. Finally, if PDF files have been scanned by hand from hard copies, or saved in "protected" format, copying over each number by hand is likely the only way to extract and analyze the information they contain.

⁵⁸ *See* 2017-18 AIPS, *supra* note 56.

⁵⁹ *See supra* note 57 and accompanying text.

⁶⁰ *NCI Charts (2016-17)*, NAT'L CORE INDICATORS, <https://www.nationalcoreindicators.org/charts/2016-17/> (last visited Dec. 11, 2019). The most recent NCI Charts tool available is for FY 2016-17, a year in which California did not participate in the NCI AIPS. *DDS NCI Webpage*, *supra* note 37 (detailing the schedule for all the NCI surveys as well as their most recent implementation date in the table labeled "Survey Schedule" under the "Survey Results/Reports" tab). For this reason, the user cannot use the tool to disaggregate the most recent AIPS data for California. The user can, however, select data from California's participation in the 2014-15 AIPS and break it down by more granular characteristics. *NCI Charts (2014-15)*, NAT'L CORE INDICATORS, <https://www.nationalcoreindicators.org/charts/2014-15/> (last visited Dec. 11, 2019).

DDS’s own website or on the NCI’s own website. Moreover, the facts that the survey questions are inconsistent over time, and that the data are only made available in PDF format at a high level of aggregation, limit their utility.

Finally, it is important to note that the recent passage of California Senate Bill 81 (S.B. 81), effective June 27, 2019, expanded the reporting requirements relating to the NCI survey data;⁶¹ as mentioned earlier, WIC section 4571(h) now specifies that “[e]ach regional center shall annually present data collected from, and the findings of, the quality assurance instrument... at a public meeting of its governing board” and that all RC-specific reports generated pursuant to section 4571(h) must “be made publicly available on the regional center’s internet website in a machine-readable format.”⁶² Yet as just discussed, some of these same data are already available on DDS’s website, albeit not in machine-readable format.⁶³ Because the statute requires RCs to make all RC-specific reports pursuant to section 4571(h) available on their websites, RCs presumably must publish data from *all* surveys and years in which NCI survey data was collected. Yet the statute does not specify any deadline by which RCs must meet these new statutory requirements. Because S.B. 81 took effect so recently and lacks a clear compliance deadline, we do not analyze RCs’ level of compliance with its provisions in this report.

(2) Online Disclosures Required by Statute

The Legislature has required DDS and/or RCs to post numerous forms of data online. To identify these requirements, we reviewed the Lanterman Act as well as the California code sections that DDS considers “related laws.”⁶⁴ Our review yielded forty-eight discrete statutory provisions that require online disclosure of system-wide and/or RC-level outcomes.⁶⁵ To assess the extent to which DDS and the 21 RCs are fulfilling these requirements, we visited DDS’s website, as well as the website of each RC, to determine their respective levels of compliance with each provision.⁶⁶

⁶¹ Act of Jun. 27, 2019, ch. 28, sec. 10 § 4571, 2019 Cal. Legis. Serv. 1270, 1284-1285 (West) (reclassifying CAL. WELF. & INST. CODE § section 4571(h) as CAL. WELF. & INST. CODE § 4571(i) and subsequently adding new statutory language surrounding the disclosure of RC-level outcomes).

⁶² CAL. WELF. & INST. CODE § 4571(h)(1)-(2) (Deering, LEXIS through 2019 Sess.).

⁶³ *Regional Center National Core Indicator Reports*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/nci/reports/> (last visited Dec. 25, 2019) (providing RC-level reports for the most recent iterations of the NCI Child Family, Family Guardian, and Adult Family Surveys, but not the most recent (FY 2017-18) AIPS, and providing no reports in machine-readable format).

⁶⁴ See CAL. DEP’T OF DEVELOPMENTAL SERVS., *supra* note 1 (listing sections classified as “Lanterman Act and Related Laws,” which include divisions 4.1, 4.5, and 4.7 of the CAL. WELF. & INST. CODE and title 14 of CAL. GOV’T CODE).

⁶⁵ We do not include requirements established by 2019 legislation, as RCs have had little time to comply with those requirements as of this writing. A list of *all* required online disclosures, including those that were recently enacted as of this writing, can be downloaded at this link: <https://law.stanford.edu/master-spreadsheet-of-dds-rc-web-disclosure-compliance-2019/>. If a given requirement applies to both RCs and DDS, we treat it as *two* provisions. Our review of divisions 4.1, 4.5, and 4.7 of the WIC and title 14 of the Government Code yielded 24 provisions that require DDS to publish information online, and 24 provisions that require RCs to publish information online. Four of these provisions are “double counted” in that they apply to both DDS *and* RCs. To the best of our knowledge, the provisions analyzed here include most, if not all, of the transparency requirements contained in Lanterman Act and related laws, *see id.*

⁶⁶ For a complete description of the compliance rating procedure, including the timing of each compliance review, *see infra* note 74.

Table 1: Summary of DDS’s Compliance with Online Disclosure Requirements

#	WIC Section ⁶⁷	Summary of Required Disclosure	High	Med.	Low	% M-R ⁶⁸
1	4436.5(c)(1)	Instances of physical restraint		✓		0.0
2	4436.5(c)(2)	Instances of chemical restraint		✓		0.0
3	4437(a)(1)	Estimated DC budgets	✓			0.0
4	4437(a)(2)	Supplemental budget info by RC		✓		0.0
5	4474.11(a)	Plans to close DC(s)	✓			NA
6	4474.15(b)	Residential capacity by RC	✓			100.0
7	4519.5(d)	POS demographic breakdown [†]		✓		4.8
8	4519.5(d)	Rare language IPP requests [†]			✓	0.0
9	4519.5(d)	Demographics of consumers with no POS [†]		✓		4.8
10	4519.5(f)(2)	POS disparities meeting reports [†]		✓		NA
11	4519.5(h)(6)	Disparities grant information	✓			33.3
12	4572(a)	Quality and access measures ⁶⁹		✓		0.0
13	4572(b)	HCBS compliance measures			✓	0.0
14	4572(c)	Integrated employment trends		✓		0.0
15	4572(d)	4731 Complaints rate by RC		✓		33.3
16	4572(e)	Fair hearing rate by RC		✓		0.0
17	4629.5(c)	Transparency Portal ⁷⁰		✓		NA
18	4629.5(d)	List of RC services [†]	✓			NA
19	4631(c)	Budget & expenditures by RC		✓		0.0
20	4639.75(a)	Work incentive program info	✓			NA
21	4652.5(d)(2)	Vendor audit compliance		✓		0.0
22	4679(e)	Links to community resource development proposals [†]			✓	NA
23	4689(p)(1)	SLS ⁷¹ questionnaire	✓			NA
24	4783(i)	Family Cost Particip. Plan	✓			NA
TOTAL			33.3%	54.2%	12.5%	11.0%

† = Information required to be disclosed by both DDS and RCs (i.e. in both Tables 1 and 2)

⁶⁷ The WIC sections listed in this column mandate the online *disclosure* of the specified information, but do not necessarily pertain to the *collection* of the data in question. For example, section 4519.5(d) requires DDS to “post the information described in [section 4519.5]”—including a POS demographic breakdown, the number of rare language IPP requests, and the demographics of consumers not receiving POS—on its internet website. CAL. WELF. & INST. CODE § 4519.5(d) (Deering, LEXIS through 2019 Sess.). The provisions that require this information to be *collected*, however, include sections 4519.5(a)(1)-(5), 4519.5(a)(6), and 4519.5(b). *Id.* WELF. & INST. CODE § 4519.5(a)-(b) (LEXIS).

⁶⁸ See *supra* note 57 and accompanying text (defining machine-readability). For provisions that require DDS to post numerical data already published by RCs (provision numbers 7, 8, and 9) the “% M-R” value is the percentage of RCs that have data in machine-readable format for at least one year. For all other provisions, the “% M-R” value is the percentage of years for which DDS publishes data in machine-readable format.

⁶⁹ The provision does not state explicitly which “quality and access measures” DDS is required to disclose. CAL. WELF. & INST. CODE § 4572 (Deering, LEXIS through 2019 Sess.). As explained above, however, the “quality and access measures” referenced in WIC section 4572 are equivalent to the Quality Assessment referenced in WIC section 4571, which in turn corresponds to the NCI survey data. See discussion *supra* § IV. B. 1. (discussing the quality assurance instrument and DDS’s choice to fulfill this requirement through the NCI Surveys).

⁷⁰ The Transparency Portal includes a link to the RCs’ websites, biannual fiscal audits of the RCs, vendor audits, biannual HCBS waiver reviews, biannual targeted case management program and federal nursing home reform program reviews, Early Start program reviews, RC annual performance contracts (Performance Contracts), and RC year-end Performance Contract reports. CAL. WELF. & INST. CODE § 4629.5(c)(1)-(7) (Deering, LEXIS through 2019 Sess.).

⁷¹ “SLS” refers to Supported Living Services.

Table 2: Summary of RCs’ Compliance with Online Disclosure Requirements

#	WIC Section ⁷²	Summary of Required Disclosure	% High	% Med	% Low	% M-R ⁷³
1	4519.5(c)	POS demographic breakdown [†]	76.2	23.8	0.0	4.8
2	4519.5(c)	Rare language IPP requests [†]	0.0	4.8	95.2	0.0
3	4519.5(c)	Demographics of consumers with no POS [†]	81.0	19.0	0.0	4.8
4	4519.5(f)(2)	POS disparities meeting reports [†]	33.3	66.7	0.0	NA
5	4622(g)(3)	Training for board members	38.1	28.6	33.3	NA
6	4629.5(b)(1)	Annual independent audits	19.0	81.0	0.0	NA
7	4629.5(b)(2)	Biannual DDS audits	33.3	66.7	0.0	NA
8	4629.5(b)(4)	Contract awards	23.8	71.4	4.8	0.0
9	4629.5(b)(5)	Service policies	90.5	9.5	0.0	NA
10	4629.5(b)(6)	Service vendor information	95.2	0.0	4.8	0.0
11	4629.5(b)(7)	Board meeting minutes & agendas	4.8	95.2	0.0	NA
12	4629.5(b)(8)	Board bylaws	100.0	0.0	0.0	NA
13	4629.5(b)(9)	Annual Performance Contracts	9.5	85.7	4.8	NA
14	4629.5(b)(10)	Biannual HCBS Waiver reviews	28.6	71.4	0.0	NA
15	4629.5(b)(11)	Transparency/public info policy	100.0	0.0	0.0	NA
16	4629.5(b)(12)	Conflict of interest policy	100.0	0.0	0.0	NA
17	4629.5(b)(14)	List of RC services [†]	28.6	9.5	61.9	NA
18	4629.5(b)(15)	Managerial salaries and benefits	47.6	28.6	23.8	0.0
19	4629.5(b)(3)	Salary schedules	4.8	90.5	4.8	0.0
20	4629.5(b)(3)	Administrative expenditures	4.8	90.5	4.8	0.0
21	4629.5(b)(13)	2017 benefits and salary reports	4.8	0.0	95.2	NA
22	4679(c)	Comm. resource development priorities	47.6	42.9	9.5	NA
23	4679(e)	Comm. resource development proposals [†]	14.3	52.4	33.3	0.0
24	4704.6	Link to appeals procedure	57.1	28.6	14.3	NA
TOTAL			43.5%	40.3%	16.3%	1.1%

† = Information required to be disclosed by both DDS and RCs (i.e. in both Tables 1 and 2)

A condensed version of our findings is presented above in Tables 1 and 2. We use a three-level scale to rate each entity’s level of compliance with each statutory requirement. Entities that reported *all* required information for *all* years are rated as “high.” Entities that reported *no* required information for *any* year are marked as “low.” Entities rated as “medium” were partially compliant, in that they reported some information for at least some years, but with substantive omissions and/or temporal gaps in coverage.⁷⁴ Expanded versions of Tables 1 and 2, including

⁷² The WIC sections listed in this column mandate the online *disclosure* of the specified information, but do not necessarily pertain to the *collection* of the data in question. For example, section 4519.5(c) requires RCs to “post the information described in [section 4519.5]”—including a POS demographic breakdown, the number of rare language IPP requests, and the demographics of consumers not receiving POS—on its internet website. CAL. WELF. & INST. CODE § 4519.5(c) (Deering, LEXIS through 2019 Sess.). The provisions that require this information to be *collected*, however, include sections 4519.5(a)(1)-(5), 4519.5(a)(6), and 4519.5(b). *Id.* WELF. & INST. CODE § 4519.5(a)-(b) (LEXIS).

⁷³ See *supra* note 57 and accompanying text (defining machine-readability). The “% M-R” value in Table 2 refers to the percentage of RCs with disclosures available in machine-readable information for at least one year.

⁷⁴ To rate an entity as a “high,” “medium,” or “low” for a given requirement, two successive pairs of recent college graduates, all of whom were employed as full-time research fellows at Stanford Law School, spent at least 15 minutes apiece attempting to locate the required information on the reporting entity’s website. The first pair of research fellows conducted their review between August 1st and August 21st, 2018, and the second pair conducted a follow-up review

comprehensive information on each provision’s statutory enactment, effective date, and verbatim wording, can be downloaded at the following link: <https://law.stanford.edu/master-spreadsheet-of-dds-rc-web-disclosure-compliance-2019/>. A more customizable, interactive version of the same information that enables detailed comparisons of specific provisions and/or reporting entities is available at the following link: <https://law.stanford.edu/siddlapp/lanterman-transparency-tracker/>.

As shown in Table 1, DDS is fully compliant with 33.3% (8 out of 24) of the statutory disclosure provisions analyzed in our study. These eight provisions pertain to DC budgets;⁷⁵ plans to close DCs;⁷⁶ data on the RCs’ respective residential capacities;⁷⁷ information on grants awarded to reduce POS disparities;⁷⁸ a list and description of services purchased by RCs, work incentive programs, and the Family Cost Participation Plan, respectively;⁷⁹ and the standardized Supported Living Services (SLS) form used in the IPP process.⁸⁰ Yet as of this writing, DDS has not complied fully,⁸¹ if at all, with the remaining 16 disclosure requirements.⁸² The latter provisions mandate disclosure of the number of instances of physical and chemical restraint, respectively;⁸³ supplemental budget information related to RCs;⁸⁴ data on disparities in POS expenditures and reports about RC stakeholder meetings related to these disparities, respectively;⁸⁵ the numbers of requests for IPPs in uncommon (“non-threshold”) languages by RC;⁸⁶ the numbers and percentages of eligible consumers not receiving POS by RC and demographic group;⁸⁷ the

between July 15th and August 27th, 2019, to update and verify their predecessors’ initial determinations. The second pair of research fellows also conducted a final review of DDS’s compliance between January 2, 2020 and January 14, 2020 after the Department substantially redesigned its website. For each set of reviews, if neither member of a given pair could find the information they sought within this time period, they concluded that it was either nonexistent, or sufficiently well-hidden that most stakeholders would likewise be unable to find it.

⁷⁵ CAL. WELF. & INST. CODE § 4437(a)(1) (Deering, LEXIS through 2019 Sess.).

⁷⁶ CAL. WELF. & INST. CODE § 4474.11(a) (Deering, LEXIS through 2019 Sess.).

⁷⁷ CAL. WELF. & INST. CODE § 4474.15(b) (Deering, LEXIS through 2019 Sess.).

⁷⁸ CAL. WELF. & INST. CODE § 4519.5(h)(6) (Deering, LEXIS through 2019 Sess.).

⁷⁹ CAL. WELF. & INST. CODE §§ 4629.5(d), 4639.75(a), 4783(i) (Deering, LEXIS through 2019 Sess.).

⁸⁰ CAL. WELF. & INST. CODE § 4689(p)(1) (Deering, LEXIS through 2019 Sess.).

⁸¹ See *supra* note 74 and accompanying text (explaining the process through which entities were rated as being in “high,” “medium,” or “low” compliance).

⁸² This low rate of compliance is partly attributable to DDS’s redesign of its website in December of 2019. Before the redesign, DDS was fully compliant with two of the Performance Dashboard requirements (the rate of 4731 Complaints and OAH fair hearing requests per RC). The new version of the Performance Dashboard, however, lacks data from FY 2015-16 for both requirements. Compare 4731 Complaints, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/dashboard/4731-complaints/> (last visited Jan. 3, 2020) (the redesigned Performance Dashboard providing complaints data through FY 2016-17), with 4731 Complaints, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www3.dds.ca.gov/RCOversight/4731Complaints.cfm> (last visited Jan. 3, 2020) (the archived version of the Performance Dashboard providing complaints data through FY 2015-16); compare Fair Hearings, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/dashboard/fair-hearings/> (last visited Jan. 3, 2020) (the redesigned Performance Dashboard providing fair hearings data through FY 2016-17), with FAIR HEARINGS, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www3.dds.ca.gov/RCOversight/FairHearing.cfm> (last visited Jan. 3, 2020) (the archived version of the Performance Dashboard providing fair hearing data through FY 2015-16). Since WIC section 4572 (the statute governing Performance Dashboard disclosures) provides no indication that only data from recent years must be disclosed, see CAL. WELF. & INST. CODE § 4572 (Deering, LEXIS through 2019 Sess.), we downgraded DDS’s compliance with these two disclosure requirements from “high” to “medium.” See *supra* Table 1.

⁸³ CAL. WELF. & INST. CODE § 4436.5(c)(1)-(2) (Deering, LEXIS through 2019 Sess.).

⁸⁴ CAL. WELF. & INST. CODE § 4437(a)(2) (Deering, LEXIS through 2019 Sess.).

⁸⁵ CAL. WELF. & INST. CODE § 4519.5(a)(1)-(5), (f)(1) (Deering, LEXIS through 2019 Sess.).

⁸⁶ *Id.* WELF. & INST. § 4519.5(a)(6) (LEXIS).

⁸⁷ *Id.* WELF. & INST. § 4519.5(b) (LEXIS).

required Performance Dashboard disclosures (respective measures of service quality and access, compliance with the HCBS Final Settings Rule, 4731 Complaints filed, fair hearings requested, and trends in integrated employment by RC);⁸⁸ various disclosures on a “transparency portal”;⁸⁹ RC budget and expenditure reports;⁹⁰ vendors’ compliance with audits;⁹¹ and links to approved community resource development proposals.⁹²

As Table 2 reveals, RCs are slightly more likely to be fully compliant with transparency provisions than DDS, with a mean (high) compliance rate of 43.5%.⁹³ Yet of twenty-four disclosure provisions, there are only eight with which a majority of RCs are fully compliant. These eight provisions pertain to data on disparities in POS expenditures;⁹⁴ the numbers and percentages of eligible consumers not receiving POS by demographic group;⁹⁵ POS policies;⁹⁶ service vendor information;⁹⁷ board bylaws;⁹⁸ transparency and conflict of interest policies;⁹⁹ and providing a link to DDS’s webpage describing fair hearing and complaint procedures.¹⁰⁰ The remaining sixteen provisions, with which a majority of RCs are not fully compliant, concern the numbers of requests for IPPs in uncommon (“non-threshold”) languages;¹⁰¹ reports about stakeholder meetings related to POS disparities;¹⁰² information about board member trainings;¹⁰³ board and committee meeting agenda and minutes;¹⁰⁴ annual independent and biannual DDS audits, as well as biannual HCBS Waiver reviews;¹⁰⁵ information on awarded contracts;¹⁰⁶ annual performance contracts (Performance Contracts);¹⁰⁷ providing a link to DDS’s list of services purchased by RCs;¹⁰⁸ information on RC administrative expenditures and staff salaries;¹⁰⁹ information on managerial salaries and benefits following 2017 budget increases specifically;¹¹⁰ and community resource development priorities and approved proposals, respectively.¹¹¹

⁸⁸ CAL. WELF. & INST. CODE § 4572(a)-(e) (Deering, LEXIS through 2019 Sess.).

⁸⁹ CAL. WELF. & INST. CODE § 4629.5(c) (Deering, LEXIS through 2019 Sess.); *see also supra* note 70 and accompanying text (listing the seven disclosures that must be included on the Transparency Portal).

⁹⁰ CAL. WELF. & INST. CODE § 4631(c) (Deering, LEXIS through 2019 Sess.).

⁹¹ CAL. WELF. & INST. CODE § 4652.5(d)(2) (Deering, LEXIS through 2019 Sess.).

⁹² CAL. WELF. & INST. CODE § 4679(e) (Deering, LEXIS through 2019 Sess.).

⁹³ *See supra* note 74 and accompanying text (describing our rating methodology).

⁹⁴ CAL. WELF. & INST. CODE § 4519.5(a)(1)-(5) (Deering, LEXIS through 2019 Sess.).

⁹⁵ *Id.* WELF. & INST. § 4519.5(b) (LEXIS).

⁹⁶ CAL. WELF. & INST. CODE § 4629.5(b)(5) (Deering, LEXIS through 2019 Sess.).

⁹⁷ *Id.* WELF. & INST. § 4629.5(b)(6) (LEXIS).

⁹⁸ *Id.* WELF. & INST. § 4629.5(b)(8) (LEXIS).

⁹⁹ *Id.* WELF. & INST. § 4629.5(b)(11)-(12) (LEXIS).

¹⁰⁰ CAL. WELF. & INST. CODE § 4704.6 (Deering, LEXIS through 2019 Sess.).

¹⁰¹ CAL. WELF. & INST. CODE § 4519.5(a)(6) (Deering, LEXIS through 2019 Sess.).

¹⁰² *Id.* WELF. & INST. § 4519.5(f)(1) (LEXIS).

¹⁰³ CAL. WELF. & INST. CODE § 4622(g)(3) (Deering, LEXIS through 2019 Sess.).

¹⁰⁴ CAL. WELF. & INST. CODE § 4629.5(b)(7) (Deering, LEXIS through 2019 Sess.).

¹⁰⁵ *Id.* WELF. & INST. § 4629.5(b)(1)-(2), (10) (LEXIS).

¹⁰⁶ *Id.* WELF. & INST. § 4629.5(b)(4) (LEXIS).

¹⁰⁷ *Id.* WELF. & INST. § 4629.5(b)(9) (LEXIS).

¹⁰⁸ *Id.* WELF. & INST. § 4629.5(b)(14) (LEXIS).

¹⁰⁹ CAL. WELF. & INST. CODE § 4639.5(a)-(b) (Deering, LEXIS through 2019 Sess.).

¹¹⁰ *Id.* WELF. & INST. § 4639.5(d) (LEXIS).

¹¹¹ CAL. WELF. & INST. CODE § 4679(c), (e) (Deering, LEXIS through 2019 Sess.).

As with the NCI data, only a small fraction of quantitative disclosures—11% of DDS’s disclosures, and 1.1% of all RC disclosures—are available in a machine-readable format.¹¹² The vast majority of disclosures are provided in the form of PDF documents or web pages with embedded graphs and tables. The scarcity of machine-readable data is a significant barrier to systemic transparency. For instance, DDS dedicates a webpage to POS disparity data,¹¹³ in compliance with WIC section 4519.5(a).¹¹⁴ Yet this webpage merely links to each RC’s reports, all of which are in PDF format. Thus to track POS disparities across years and RCs, one would need to visit each RC’s website, scrutinize its annual disclosures for each demographic group, and enter each data point into a data-processing program.¹¹⁵ Making all mandated disclosures available in machine-readable format would greatly improve the ease with which stakeholders could identify patterns over time and between RCs.

Prior to 2019, no WIC provisions required DDS or RCs to publicly disclose information in machine-readable format. Yet following the recent passage of S.B. 81,¹¹⁶ which took effect on June 27, 2019, DDS is required to publish the disclosures on its existing Performance Dashboard—which includes “[q]uality and access measures,”¹¹⁷ HCBS Waiver compliance measures, trends in integrated employment, 4731 Complaint rates, and fair hearing rates¹¹⁸—in machine-readable format.¹¹⁹ As mentioned previously, S.B. 81 also amended the Lanterman Act to require RCs to publish RC-specific NCI survey results on their respective websites in machine-readable format.¹²⁰ Since the passage of S.B. 81, DDS has substantially redesigned its

¹¹² Machine-readability is pertinent only to statutory requirements that require DDS and RCs to report numeric information. For non-numeric disclosures, we do not score the reporting entity for machine-readability but mark the relevant box with “NA.” For our definition of machine-readability, see *supra* note 57 and accompanying text.

¹¹³ *Purchase of Service Data*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/purchase-of-service-data/> (last visited Jan. 16, 2020).

¹¹⁴ CAL. WELF. & INST. CODE § 4519.5(a)(1)-(5) (Deering, LEXIS through 2019 Sess.).

¹¹⁵ See *supra* note 57 and accompanying text (defining machine-readability and noting that some unprotected pdfs can be converted into machine-readable format with requisite programming skills and software).

¹¹⁶ Act of Jun. 27, 2019, ch. 28, 2019 Cal. Legis. Serv. 1270 (West).

¹¹⁷ The provision does not state explicitly which “quality measures” DDS is to disclose. CAL. WELF. & INST. CODE § 4572 (Deering, LEXIS through 2019 Sess.). Yet as explained above, the “quality measures” referenced in WIC section 4572 are likely the same as the Quality Assessment referenced in WIC section 4571 (which in turn corresponds to the NCI Survey data). See discussion *supra* pp. 14-15.

¹¹⁸ DDS had been required to publish these data, although not in machine-readable format, on its Performance Dashboard since 2016. Act of Jun. 27, 2016, ch. 26, § 8, 2016 Cal. Legis. Serv. 937, 946 (codified as amended at CAL. WELF. & INST. CODE § 4572 (2019)) (requiring DDS to annually publish a performance dashboard including data on quality and access measures, HCBS Waiver compliance measures, trends in integrated employment, 4731 Complaint rates, and fair hearing rates).

¹¹⁹ Act of Jun. 27, 2019 sec. 11, § 4572 (amending CAL. WELF. & INST. CODE § 4572 to require DDS to post the annual Performance Dashboard in machine-readable format). S.B. 81 also adds the requirement that RCs publish their own Performance Dashboards, although the statutory language does not clearly specify whether or not these Performance Dashboards must also be in machine-readable format. Act of Jun. 27, 2019 sec. 11, § 4572 (amending CAL. WELF. & INST. CODE § 4572 to require RCs to publish their own Performance Dashboards); see also *supra* note 57 and accompanying text (providing a full definition of machine-readability).

¹²⁰ Act of Jun. 27, 2019 sec. 10, § 4571(h)(1)-(2) (Requiring RCs to collect and annually report in machine-readable format the results of the quality assurance instrument). While the statute references only reports relating to a “quality assurance instrument,” DDS and RCs have chosen to comply with this requirement by reporting the results of the NCI Surveys. See discussion *supra* § IV. B. 1. (discussing the quality assurance instrument and DDS’s choice to fulfill this requirement through the NCI surveys).

Performance Dashboard. For each metric for which data are presented,¹²¹ the Dashboard now provides the required information in the form of an interactive graphics display so that it can be more easily interpreted by assistive technologies, an important step toward making data more accessible to a broad array of consumers and stakeholders.¹²² Yet as of this writing, the underlying data are only available in machine-readable format for one disclosure requirement for one year,¹²³ severely limiting stakeholders' capacity to analyze trends in systemic performance.

Finally, the data that DDS and RCs *do* report frequently contain internal inconsistencies and ambiguities. First, in some contexts, it is unclear whether data that RCs report on a fiscal year (FY) basis aligns with the fiscal year defined by the State Comptroller.¹²⁴ Moreover, some RCs will post data on a calendar year (CY) basis, while others—for the same reporting requirement—will post data by FY.¹²⁵ Secondly, even for a given statutory requirement, the earliest year for which data are disclosed and the calendar months included in each disclosure can vary widely across RCs.¹²⁶ Third, for some RCs, the list of audit reports listed on DDS's

¹²¹ At the time of this writing, the HCBS waiver compliance page is still blank. *Home and Community-Based Services Waiver Compliance*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/dashboard/hcbs-waiver-compliance/> (last visited Jan. 2, 2020).

¹²² See *Performance Dashboard*, *supra* note 38 (providing links to the webpages of each specific disclosure requirement). This represents a step toward compliance with the Web Content Accessibility Guidelines (WCAG), with which all California state agencies are required to comply as a result of the 2017 passage of A.B. 434, Act of Oct. 14, 2017, ch. 780, 2017 Cal. Legis. Serv. 5956 (codified as amended at CAL. GOV'T CODE § 11546.7 (2019)) (requiring that before July, 1 2019, and biennially thereafter, all state agencies certify that their websites are in compliance WCAG 2.0, or a subsequent version, at a minimum Level AA success criteria), with which DDS has asserted that its redesigned website is in compliance, *Accessibility*, CAL DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/general/accessibility/> (last visited Jan. 21, 2020) (“[The DDS] website was developed in compliance with California Government Code Section 11135.”).

¹²³ At the bottom of the graphic displaying the rate of 4731 Complaints for each RC, there is a widget (in the shape of a box intersected by a downward facing arrow) which allows users to download the graphic's underlying data as a CSV file. However, this functionality only makes available complaints data from the graphic's most recent year (FY 2018-2019). *4731 Complaints*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/dashboard/4731-complaints/> (last visited Jan. 2, 2020). The other two years of data (from FY 2017-18 and FY 2016-17) are available only through the graphic, cannot be exported into data processing software in one of the standard file formats, and therefore do not meet the standards of machine-readability employed in existing legislation. See *supra* note 57 (describing the implementation of machine-readability requirements by the U.S. federal government, the European Union, and the United Nations). For all of the other Performance Dashboard disclosure requirements analyzed in Table 1, there was no apparent way to obtain the underlying data used to create the graphics displayed on the Dashboard.

¹²⁴ For example, in compliance with the statutory requirement to post POS expenditure data online, CAL. WELF. & INST. CODE § 4519.5(c) (Deering, LEXIS through 2019 Sess.), Alta RC provides POS expenditure reports on a FY basis. See, e.g., ALTA REG'L CTR., REGIONAL CENTER PURCHASE OF SERVICES (POS) DATA, https://www.altaregional.org/sites/main/files/file-attachments/pos_data2011_12.pdf?1491328057 (last visited, Jan. 8, 2020) (providing POS data for FY 2011-12). However, there is no information in this report about whether Alta RC's definition of a fiscal year, see *id.*, aligns with the California Office of the Controller's definition, which starts on July 1 of a given year and ends June 30 of the following year, see Press Release, Office of the Cal. State Controller, CA Controller Reports Revenues \$2.68 Billion Short of 2016-17 Budget Act (July 10, 2017), https://www.sco.ca.gov/PDF-Var/eo_pressrel_18596.pdf (last visited Jan. 9, 2020) (defining the fiscal year as beginning July 1 and ending June 30).

¹²⁵ For example, in compliance the statutory requirement to post awarded contracts online, CAL. WELF. & INST. CODE § 4629.5(b)(4) (Deering, LEXIS through 2019 Sess.), Far Northern Regional Center reports contract awards on a CY basis, see *Awarded RFPs*, FAR N. REG'L CTR., <https://www.farnorthernrc.org/about-us/transparency/awarded-rfps/> (last visited Dec. 17, 2019), whereas San Gabriel/Pomona RC reports data on a FY basis, see SAN GABRIEL/POMONA REG'L CTR., CONT. AWARDS (2018), <https://www.sgprc.org/home/showdocument?id=3049> (last visited Dec. 24, 2019).

¹²⁶ For example, in compliance with the statutory requirement to post biannual HCBS Waiver program reviews, WELF. & INST. § 4629.5(b)(10) (LEXIS), Redwood Coast RC makes available HCBS audit reports dating to FY 2010-11, *Audit Documents*, REDWOOD COAST REG'L CTR., <http://redwoodcoastrc.org/transparency/audit-documents> (last visited Dec. 17, 2019) (RCRC Home & Community Based Services Waiver- Monitoring Reports), with the scope of the oldest report

website differs from the list of audit reports available on the RC's website, making it difficult to assess whether the RCs in question are fully compliant with audit requirements.¹²⁷ Finally, for given RCs, there appear to be inconsistencies in the length of time encompassed by a single disclosure. For example, in compliance with the statutory requirement to post DDS biannual fiscal audits online,¹²⁸ San Andreas RC provides hyperlinks to PDF copies of the relevant audits dating to FY 2003-04.¹²⁹ However, while certain audit reports encompass information from four fiscal years, others only report information from two.¹³⁰ The prevalence of such inconsistencies complicates the task of making “apples to apples” comparisons across different regions and time periods.

In short, the incompleteness of many web-based disclosures, their often inconsistent formatting and content, and the fact that numeric data are hardly ever provided in machine-readable format, make it difficult to track trends over time (and across regions) in the quality of service provision.

encompassing August 1, 2010 through July 31, 2011, CAL. DEP'T OF DEVELOPMENTAL SERVS. & CAL. DEP'T OF HEALTH CARE SERVS., REDWOOD COAST REGIONAL CENTER HOME AND COMMUNITY-BASED SERVICES WAIVER MONITORING REVIEW REPORT (2011), http://redwoodcoastrc.org/sites/default/files/u2/Audit_2011_HCBS_Final.pdf (labeled on RC website as “FY 2010-2011”). Conversely, Alta RC only provides HCBS audit reports dating to FY 2014-15. *Home and Community Based Services Waiver Review*, ALTA REG'L CTR., <https://www.altaregional.org/post/home-and-community-based-services-waiver-review> (last visited Dec. 17, 2019), with the scope of the oldest report encompassing the period from June 1, 2014 through May 31, 2015, CAL. DEP'T OF DEVELOPMENTAL SERVS. & CAL. DEP'T OF HEALTH CARE SERVS., ALTA CALIFORNIA REGIONAL CENTER HOME AND COMMUNITY-BASED SERVICES WAIVER MONITORING REVIEW REPORT (2015), https://www.altaregional.org/sites/main/files/file-attachments/hcbs_review_june_2014-may_2015_0.pdf?1473265583 (last visited Jan. 8, 2020) (labeled on RC website as “Home & Community Based Waiver Review 6/2014 - 5/2015”).

¹²⁷ For example, a FY 2014-15 and 2015-16 audit report is provided on Valley Mountain RC's website, but not on DDS's website. Conversely, a FY 2010-11 and 2011-12 audit report is provided on DDS's website, but not on Valley Mountain RC's. *Compare Regional Centers Biannual Fiscal Audit Reports*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/transparency/monitoring-reports/regional-centers-biannual-fiscal-audit-reports/> (last visited Jan. 4, 2020) (making available a FY 2010-11 and 2011-12 Valley Mountain RC audit report but not the FY 2014-15 and 2015-16 Valley Mountain RC audit report), *with Public Disclosures*, VALLEY MOUNTAIN REG'L CTR., <https://www.vmmc.net/public-disclosures/> (last visited Jan. 4, 2020) (listing past biannual DDS audits for Valley Mountain RC under “Biannual Fiscal Audits” and including the audit report for FY 2014-15 and 2015-16 but not the audit report for FY 2010-11 and 2011-12).

¹²⁸ WELF. & INST. § 4629.5(b)(2) (LEXIS).

¹²⁹ *Department of Developmental Services Audit*, SAN ANDREAS REG'L CTR., <http://www.sanandreasregional.org/reports-policies/#biannual-fiscal-audits> (last visited, Dec. 17, 2019).

¹³⁰ *Compare* CAL. DEP'T OF DEVELOPMENTAL SERVS., AUDIT OF THE SAN ANDREAS REGIONAL CENTER FOR FISCAL YEARS 2003-04, 2004-05, 2005-06, 2006-07 (2009), <http://www.sanandreasregional.org/app/uploads/2019/10/DDS-Audit-2003-2007.pdf> (last visited Jan. 7, 2020) (describing results of the DDS independent audit of San Andreas RC for the *four year* period of July 1st, 2003, to June 30th, 2007), *with* CAL. DEP'T OF DEVELOPMENTAL SERVS., AUDIT OF THE SAN ANDREAS REGIONAL CENTER FOR FISCAL YEARS 2015-16 AND 2016-17 (2019), <http://www.sanandreasregional.org/app/uploads/2019/11/DDS-Audit-Report-FY-15-16-16-17.pdf> (last visited Jan. 7, 2020) (describing results of the DDS independent audit of San Andreas RC for the *two year* period of July 1st, 2015, to June 30th, 2017).

C. Mandated Disclosures to the Public “Upon Request”

To the best of our knowledge, there are fifteen statutory provisions that require the production of specific information “upon request.”¹³¹ These provisions are presented in Table 3, below.

These fifteen required disclosures comprise the following: data on RCs’ compliance with community placement plans and consumers’ transitions to and from DCs;¹³² efforts to keep high-risk consumers in the community;¹³³ interagency Medi-Cal protocols;¹³⁴ summaries of RC service coordinator caseload ratios;¹³⁵ RC contracts with staff and contractors;¹³⁶ evaluations of RC projects that have received DDS funds;¹³⁷ Letters of Noncompliance sent by DDS to RCs not fulfilling contractual obligations;¹³⁸ written or recorded testimonies from RC board meetings and other RC board meeting materials, respectively;¹³⁹ recommendations made to DDS to reduce RCs’ reporting and recording requirements;¹⁴⁰ memoranda of understanding (MOUs) between RCs and respective county mental health agencies;¹⁴¹ evaluations of the administrative law judges that preside over Office of Administrative Hearing (OAH) fair hearings related to the Lanterman Act;¹⁴² redacted copies of all fair hearing decisions issued by OAH relating to the Lanterman Act;¹⁴³ breakdowns of the respective characteristics and outcomes of OAH fair hearing requests;¹⁴⁴ and the number of complaints filed each year for each RC and state developmental center catchment area, the subject matter of each complaint, and a summary of each decision.¹⁴⁵

¹³¹ The California Public Records Act subsumes a much broader scope of information, *see* CAL. GOV. CODE §§ 6250-6276.48 (Deering, LEXIS through 2019 Sess.).

¹³² CAL. WELF. & INST. CODE § 4418.25(d) (Deering, LEXIS through 2019 Sess.).

¹³³ CAL. WELF. & INST. CODE § 4418.7(f) (Deering, LEXIS through 2019 Sess.).

¹³⁴ CAL. WELF. & INST. CODE § 4474.4 (Deering, LEXIS through 2019 Sess.).

¹³⁵ CAL. WELF. & INST. CODE § 4640.6(e) (Deering, LEXIS through 2019 Sess.).

¹³⁶ *Id.* WELF. & INST. § 4640.6(k)(1) (LEXIS).

¹³⁷ CAL. WELF. & INST. CODE § 4513 (Deering, LEXIS through 2019 Sess.).

¹³⁸ CAL. WELF. & INST. CODE § 4635(b)(2) (Deering, LEXIS through 2019 Sess.).

¹³⁹ CAL. WELF. & INST. CODE §§ 4661(b), 4665 (Deering, LEXIS through 2019 Sess.).

¹⁴⁰ CAL. WELF. & INST. CODE § 4669.2(a)(4) (Deering, LEXIS through 2019 Sess.).

¹⁴¹ CAL. WELF. & INST. CODE § 4696.1(e) (Deering, LEXIS through 2019 Sess.).

¹⁴² CAL. WELF. & INST. CODE § 4712(n) (Deering, LEXIS through 2019 Sess.).

¹⁴³ CAL. WELF. & INST. § 4712.5(d) (Deering, LEXIS through 2019 Sess.).

¹⁴⁴ CAL. WELF. & INST. CODE § 4714(b) (Deering, LEXIS through 2019 Sess.).

¹⁴⁵ CAL. WELF. & INST. CODE § 4731(d) (Deering, LEXIS through 2019 Sess.).

Table 3: Statutes Requiring RCs and/or DDS to Provide Data to the Public Upon Request¹⁴⁶

#	WIC Section	Affected Entity	Summary of Required Disclosure
1	4418.25(d)	DDS	Data on RCs' compliance with community placement plans & transfers to/from developmental centers
2	4418.7(f)	DDS	Efforts to keep at-risk consumers in the community
3	4474.4	DDS and RCs ¹⁴⁷	Inter-agency protocols on Medi-Cal participation by RC consumers leaving developmental centers
4	4640.6(e)	DDS	Summary of RCs' service coordinator caseload data
5	4640.6(k)(1)	RCs	RC staff and contractor employment contracts
6	4513	DDS	Evaluations of RC projects funded through DDS RFPs
7	4635(b)(2)	DDS	Noncompliance letters sent by DDS to noncompliant RCs
8	4661(b)	RCs	Testimony in RC board meetings
9	4665	RCs	RC board meeting materials
10	4669.2(a)(4)	DDS	Joint recommendations by RCs and other stakeholders on ways to reduce RCs' reporting and recording requirements
11	4696.1(e)	DDS	MOUs between RCs and county mental health agencies
12	4712(n)	DDS	Biennial evaluations of OAH hearing officers
13	4712.5(d)	DDS	Redacted copies of all OAH decisions
14	4714(b)	DDS	Data on OAH hearings, including issues & outcomes
15	4731(d)	DDS	Data on section 4731 Complaints by RC & DC

Although submitting CPRA requests for all fifteen of these requirements was beyond the scope of our study, we prioritized the final three provisions (13-15) for analysis because they play special roles in enhancing systemic transparency and oversight. WIC sections 4712.5(d) and 4714(b) pertain to administrative fair hearings conducted by the OAH,¹⁴⁸ to which consumers can appeal adverse decisions by RCs. Since judicial case law on the meaning of the Lanterman Act entitlement is very scant,¹⁴⁹ with most adjudications being conducted by OAH hearing officers rather than judges, OAH opinions shed important light on the day-to-day interpretation of the Act. WIC section 4731(d), meanwhile, pertains to complaints alleging a violation of consumers' rights filed against RCs or vendors.¹⁵⁰ Analysis of these data helps to illuminate the extent to which the complaint process is being utilized, the range of concerns being raised, how complaints are investigated, and whether there are significant variations in complaint filing behavior over time and across RCs.

¹⁴⁶ Two additional provisions, WIC sections 4639.5(a) and 4639.5(b), require RCs to provide salary schedules and administrative expenditure information to the public upon request. CAL. WELF. & INST. CODE § 4639.5(a)-(b) (Deering, LEXIS through 2019 Sess.). However, a different provision, WIC section 4629.5(b)(3), requires the exact same information to be published online, CAL. WELF. & INST. CODE § 4629.5(b)(3)(Deering, LEXIS through 2019 Sess.). Since section 4629.5(b)(3) is analyzed in Table 2 and the aforementioned sections superfluous, we omit them from the table.

¹⁴⁷ WIC section 4474.4 requires the Secretary of the Department of Health and Human Services (HHS) to “verify that the State Department of Developmental Services (DDS) and the State Department of Health Care Services (DHCS) have established protocols in place between the departments, as well as with the regional centers . . .” CAL. WELF. & INST. CODE § 4474.4 (Deering, LEXIS through 2019 Sess.). The section then goes on to require that the protocols “be made available to the public upon request.” *Id.* WELF. & INST. § 4474.4 (LEXIS). We construe this provision as requiring that all three affected entities—DHCS, DDS, and RCs—provide the protocols upon request.

¹⁴⁸ WELF. & INST. CODE §§ 4712.5(d), 4714(b) (LEXIS).

¹⁴⁹ LANTERMAN ENTITLEMENT REPORT, *supra* note 5, § III.

¹⁵⁰ WELF. & INST. CODE § 4731(d) (LEXIS).

(1) Timeliness, Completeness, and Accuracy of DDS Compliance with CPRA

To analyze compliance with the three transparency statutes prioritized for analysis that require data to be provided “upon request,” we submitted a series of requests to DDS under the California Public Records Act (CPRA).¹⁵¹ The sections that follow analyze the extent to which the disclosures DDS produced in response to those requests meet the statutory requirements and serve their intended goal of enhancing systemic transparency. Our efforts to obtain these data from DDS, however, raised overarching concerns regarding the Department’s compliance with CPRA. Under CPRA, a state agency or department must determine within 10 calendar days¹⁵² of the date of receipt of the request whether identifiable public records may be disclosed; notify the requester of its determination; and state the estimated time and date when the records will be available for inspection or copying.¹⁵³ In “unusual circumstances,”¹⁵⁴ this initial response window may be extended for up to 14 days through written notice setting forth the reasons for the extension and the date on which the initial determination is to be made.¹⁵⁵

In our experience, DDS was not fully compliant with CPRA’s requirements in several regards. First, the agency did not always respond to our inquiry within ten days, or even within twenty-four days (the sum of the initial ten-day window plus the additional period of up to fourteen days permitted in “unusual circumstances.”).¹⁵⁶ Secondly, the content of the agency’s initial communication often fell short of the statutory requirements.¹⁵⁷ Finally, the data produced by

¹⁵¹ CAL. GOV’T CODE §§ 6250-6276.48 (Deering, LEXIS through 2019 Sess.).

¹⁵² *The California Public Records Act*, CITY OF SANTA CRUZ, <http://www.cityofsantacruz.com/government/city-departments/city-clerk/public-records-request/the-california-public-records-act> (last visited Dec. 23, 2019) (specifying that the affected agency must respond within 10 calendar, and not business, days).

¹⁵³ CAL. GOV’T CODE § 6253(c) (Deering, LEXIS through 2019 Sess.).

¹⁵⁴ These circumstances include the need to search for records in field facilities or other separate establishments; the need to collect and review a voluminous amount of separate and distinct records; the need to consult with other state or local agenc(ies) that have a substantial interest in the request; and, in the case of electronic records, the need to compile data, write programming language or a computer program, or construct a computer report to extract data. *Id.* GOV’T CODE § 6253(c)(1)-(4) (LEXIS).

¹⁵⁵ *Id.* GOV’T CODE § 6253(c) (LEXIS).

¹⁵⁶ For example, of the four CPRA requests we submitted to DDS in CY 2019, in only two cases did the Department respond in ten days with a determination about the availability of the requested records. *See* E-mail from Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep’t of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Nov. 26, 2019) (on file with authors) (responding within ten days to a CPRA request filed on Nov. 18, 2019, with requested data); E-mail from Joy Rosenquist, Assistant Chief Counsel, Cal. Dep’t of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Nov. 27, 2019) (on file with authors) (responding within ten days to a CPRA request filed on Nov. 18, 2019, with a determination about the availability of the records). The remaining two determination letters arrived 13 and 41 days, respectively, after the CPRA requests were received. *See* E-mail from Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep’t of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Aug. 21, 2019) (on file with authors) (responding 13 days later to a CPRA request filed on Aug. 8, 2019, with requested data); E-mail from Joy Rosenquist, Assistant Chief Counsel, Cal. Dep’t of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Sept. 18, 2019) (on file with authors) (responding 41 days later to a CPRA request filed on Aug. 8, 2019, with a determination about the availability of the records).

¹⁵⁷ As noted above, *supra* note 156 and accompanying text, we submitted four CPRA requests to DDS in CY 2019. In all four cases, DDS eventually (although often belatedly) provided us with a determination letter (or e-mail) that specified whether the requested documents were available. However, in both instances in which DDS did not respond within the ten-day deadline, the communication did not specify the reasons for the delay, as is required by section 6253 of the California Government Code, CAL. GOV’T CODE § 6253(c) (Deering, LEXIS through 2019 Sess.). *See* E-mail from

DDS in response to CPRA requests was sometimes (at least initially) incomplete,¹⁵⁸ internally contradictory,¹⁵⁹ and/or formatted inconsistently over time.¹⁶⁰

Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Aug. 20, 2019) (on file with authors) (responding to a CPRA request filed on Aug. 8, 2019, without explaining the delay in determining the availability of the requested records); E-mail from Joy Rosenquist, Assistant Chief Counsel, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Sept. 5, 2019) (on file with authors) (informally responding to a CPRA request filed on Aug. 8, 2019, without explaining the delay in determining the availability of the requested records).

¹⁵⁸ As noted above, *supra* note 156 and accompanying text, we have submitted four CPRA requests with DDS in CY 2019. In one case, DDS determined that the information we requested was not available. *See* E-mail from Joy Rosenquist to Alison Morantz (Sept. 18, 2019), *supra* note 156. In another case, DDS determined that the information was available, and at the time of this writing, we are still awaiting the relevant records. *See* E-mail from Joy Rosenquist to Alison Morantz (Nov. 27, 2019), *supra* note 156. In the remaining two cases, DDS initially responded to our request with incomplete data. *See* E-mail from Alexandra Sanders to Alison Morantz (Nov. 26, 2019), *supra* note 156 (attaching yearly 4731 Complaints data broken down by RC, but omitting Westside RC from the FY 2014-15 data and East Bay RC from the FY 2018-19 data); E-mail from Alexandra Sanders to Alison Morantz (Aug. 21, 2019), *supra* note 156 (attaching OAH fair hearing request data, but omitting the filing date and RC for all OAH appeals, both of which we explicitly requested). However, in both cases DDS responded to follow up requests for corrected versions of the datasets within 2-4 weeks. *See* E-mail from Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Dec. 26, 2019) (on file with authors) (responding to follow up request for corrected data in 29 days by attaching excel spreadsheets on WIC section 4731 Complaints received from FY 2011-12 through Dec. 26, 2019 for all RCs for all years); E-mail from Joy Rosenquist, Assistant Chief Counsel, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Dec. 18, 2019) (responding to follow up request for corrected data in 14 days by attaching excel spreadsheets on the OAH fair hearing request data with requests filed between Jan. 1, 2018, and July 31, 2019, complete with the previously missing fields for filing date and RC).

¹⁵⁹ For example, as mentioned above, *supra* note 158 and accompanying text, there were two cases in which DDS produced datasets in response to CPRA requests that we filed during CY 2019. In both cases, the data requested were updates to data we had acquired previously from DDS. Yet in one of these instances, which involved data on complaints filed under WIC section 4731, the datasets contained internal inconsistencies. As discussed previously, *see supra* note 158 and accompanying text, we received two 4731 Complaints datasets in 2019 in addition to a prior version of the 4731 Complaints data that we had received in February 2018. *See* E-mail from Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep't of Developmental Servs., to Lane Zuraw, J.D. Candidate, Stanford Law School (Feb. 1, 2018) (on file with authors) (attaching data for WIC section 4731 Complaints filed from FY 2012-13 through Jan. 16, 2018). These three datasets differed in three salient ways: (1) some complaints were included in one or more datasets but were missing from others, even though their filing dates were encompassed by all three; (2) the final determination (i.e. violation or no violation) for a given complaint sometimes differed between datasets; and (3) the second and third datasets included two fields, "Date CAP Issued" and "Date CAP Completed," that were not included in the first dataset. These discrepancies were especially concerning given the fact that inconsistencies existed not only between the first dataset and the latter two (which were received nearly two years later), but also between the second and third datasets, which were received only a month apart. In the second case, in which we received updated OAH fair hearing data, DDS simply augmented their previous data, and as such, there were no overlapping time frames for which we could compare the content of the two datasets. *See* E-mail from Joy Rosenquist to Alison Morantz (Dec. 18, 2019), *supra* note 158 (augmenting previous OAH case data, from CY 1998-2017, with cases filed between Jan. 1, 2018, and July 31, 2019).

¹⁶⁰ For example, as noted above, *supra* note 159 and accompanying text, there were two instances in 2019 when we requested that DDS update a dataset they sent to us previously. In one of these cases, the old and new versions of the dataset were provided in different format. *Compare* E-mail from Alexandra Sanders to Lane Zuraw (Feb. 1, 2018), *supra* note 159 (providing data in Excel format), *with* E-mail from Alexandra Sanders to Alison Morantz (Nov. 26, 2019), *supra* note 156 (providing data as PDF files in "protected" format, which not only prevented their conversion into machine-readable format, but even precluded the cutting and pasting of individual data elements). In response to an additional follow-up request, *see* E-mail from Alison Morantz, Dir. of SIDDLAPP, Stanford Law School, to Alexandra Sanders, Appeals, Complaints & Projects, Cal. Dep't of Developmental Servs. (Nov. 27, 2019) (on file with authors) (requesting the 4731 Complaints data in machine-readable format), DDS provided the data in the same machine-readable format (Excel) in which it had originally been provided. *See* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158 (responding to Nov. 27 follow-up request by attaching excel spreadsheets on WIC section 4731 Complaints received from FY 2011-12 through Dec. 26, 2019).

Because we have only submitted twelve CPRA requests to DDS since the inception of this project, we cannot assess whether the shortfalls we observed in DDS's CPRA compliance are typical or exceptional. Moreover, even if such shortfalls are relatively common, we have no way to compare the agency's track record to that of other state or local agencies covered by CPRA. Yet at the very least, our experience suggests that the timeliness, completeness and accuracy of DDS's disclosures under CPRA cannot be taken for granted.

(2) Information on OAH Fair Hearing Requests and Decisions

We submitted several CPRA requests¹⁶¹ to DDS to assess its compliance with the transparency requirements that pertain to OAH fair hearings. Our goal was to analyze, respectively, the completeness and accuracy of the summary data on OAH fair hearing requests that DDS must produce pursuant to WIC section 4714(b);¹⁶² and to check whether all of the underlying decisions were being made available to the public as required by WIC section 4712.5(d).¹⁶³

In response to our CPRA requests, DDS provided several Excel spreadsheets with detailed information (file date, case outcome, issues, etc.) on 29,790 unique OAH fair hearing requests filed between January 1st, 1998 and July 31st, 2019.¹⁶⁴ However, DDS did not make any of the underlying decisions available. When we requested an explanation, a DDS representative informed us that OAH maintains a public website with a search tool, where one can search for OAH decisions by case ID.¹⁶⁵

¹⁶¹ Request to Inspect Public Record from Lane Zuraw, J.D. Candidate, Stanford Law School, to Cal. Dep't of Developmental Servs. (Jan. 12, 2018), <https://www-cdn.law.stanford.edu/wp-content/uploads/2019/02/a1-1.12.18-PRA-Request-for-OAH-and-4731-complaint-data.pdf>; E-mail from Lane Zuraw, J.D. Candidate, Stanford Law School, to Cal. Dep't of Developmental Servs. (Mar. 9, 2018), <https://www-cdn.law.stanford.edu/wp-content/uploads/2019/12/a7-Follow-Up-to-First-OAH-PRA-Request-03-09-2018.pdf> (requesting data on OAH fair hearing request outcomes); Request to Inspect Public Record from Alison Morantz, Dir. of SDDLAPP, Stanford Law School, to Cal. Dep't of Developmental Servs. (Aug. 8, 2019), <https://www-cdn.law.stanford.edu/wp-content/uploads/2019/12/a4-8.8.19-PRA-Request-for-OAH-and-4731-complaint-data-2.pdf> (requesting data on OAH fair hearing request outcomes, for requests filed since the prior CPRA).

¹⁶² CAL. WELF. & INST. CODE § 4714(b) (Deering, LEXIS through 2019 Sess.).

¹⁶³ CAL. WELF. & INST. CODE § 4712.5(d) (Deering, LEXIS through 2019 Sess.).

¹⁶⁴ The excel sheets included the following set of fields for all years: Filing Date, Regional Center, Case ID, Issue(s), Date Signed/Closed, Outcome, Case Narrative, Mediation Date, Mediation Decision, Informal Hearing Date, Informal Hearing Decision, Mediation Declined by RC. E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SDDLAPP, Stanford Law School (Mar. 30, 2018) (on file with authors) (providing data in Excel format for OAH fair hearing requests filed from January 1, 1998 to Dec. 31, 2017); E-mail from Alexandra Sanders to Alison Morantz (Aug. 21, 2019), *supra* note 158 (providing data in Excel format for OAH fair hearing requests filed from Jan. 1, 2018 to July, 2019, without including fields for regional center and filing date); E-mail from Joy Rosenquist to Alison Morantz (Dec. 18, 2019), *supra* note 158 (providing data in Excel format for OAH fair hearing requests filed from Jan. 1, 2018 to July, 2019, including fields for regional center and filing date). To view and download these data, see *Data on California's Regional Center System Serving People with I/DD*, STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW & POLICY PROJECT, <https://law.stanford.edu/siddlapp/data-on-californias-regional-center-system-serving-people-with-idd/> (providing OAH fair hearing request data in Excel format from 1998 to July 31, 2019).

¹⁶⁵ E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SDDLAPP, Stanford Law School (Aug. 20, 2018) (on file with authors); *see also infra* note 178 (describing DDS's assertion that comprehensive records of decisions might also be obtained through in person inspections of DDS or OAH records and our reasons to believe that this not likely to be the case).

In response to a separate e-mail inquiry to OAH requesting information on decision outcomes, a representative clarified that fair hearing requests with “Granted,” “Denied,” or “Split” outcomes should always generate written decisions, whereas “Withdrawn” and “Dismissed” requests do not.¹⁶⁶ Thus, for the purpose of assessing DDS’s compliance with WIC section 4712.5(d) (which requires DDS to make redacted copies of all OAH fair hearing decisions publicly available), we confine our analysis to fair hearing requests that are classified as “Granted,” “Denied” or “Split.”¹⁶⁷

We used a two-pronged approach to assess the completeness of DDS’s compliance with the disclosure requirements surrounding OAH fair hearing requests, codified in WIC sections 4714(b) and 4712.5(d).

Our first goal was to assess whether written decisions were available for the subset of OAH fair hearing requests that were heard by OAH administrative law judges and resulted in written opinions.¹⁶⁸ To complete this task, we first accessed the DDS Decisions Search Page (OAH Search Tool), operated by the California Department of General Services; this was the resource to which the DDS representative had directed us that ostensibly included all decisions filed during the prior five years.¹⁶⁹ Next, we identified all fair hearing requests in DDS’s CPRA response that were filed since January 1, 2013,¹⁷⁰ and for which the outcomes were recorded as granted, denied, or split.¹⁷¹ Finally, we used the OAH Search Tool to determine how many of these (1,485) cases had written decisions posted online.¹⁷²

Our second goal was to determine whether DDS’s CPRA response was complete, i.e., whether it included *all* of the OAH fair hearing requests posted online that were filed from January 1, 1998 to July 31, 2019. Since the OAH Search Tool included only one fair hearing request filed before

¹⁶⁶ E-mail from Vanessa Leach, Cal. Office of Admin. Hearings, to Evan Lehmann, Research Fellow, Stanford Law School (Sept. 16, 2019) (on file with authors). On a subsequent telephone call the OAH official further clarified that fair hearing requests are considered “Dismissed” if the administrative law judge issues a Dismissal Order, and because Dismissal Orders are distinct from decisions, “Dismissed” requests should not generate written decisions. Telephone Call with Vanessa Leach, Cal. Office Of Admin. Hearings (Dec. 17, 2019).

¹⁶⁷ The representative we spoke to was not familiar with “Administratively Closed” outcomes. Telephone Call with Vanessa Leach, *supra* note 166. Because we could not obtain a clear definition of “Administratively Closed,” and because “Administratively Closed” outcomes are infrequent in our dataset and only occur between years 1998-2000, we exclude those fair hearing requests from our analysis of DDS’s compliance with WIC section 4712.5(d).

¹⁶⁸ See *supra* notes 166-167 and accompanying text (clarifying which fair hearing request outcomes generate written decisions).

¹⁶⁹ *DDS Decisions Search*, CAL. DEP’T OF GEN. SERVS., <https://www.dgs.ca.gov/OAH/Case-Types/General-Jurisdiction/Resources/DDS-Decisions#@ViewBag.JumpTo> (last visited Jan. 20, 2020) [hereinafter *OAH Search Tool*] (specifying in a subtitle that “[u]sers can search decisions from Department of Developmental Services hearings for the past seven years” without clarifying whether cases from prior years had been removed). Careful investigation revealed that in fact, decisions *were* available for appeals filed since at least 2012. We err on the side of caution in focusing exclusively on fair hearing requests filed since January 1, 2013.

¹⁷⁰ See *id* (explaining our choice to focus on fair hearing requests filed since January 1, 2013).

¹⁷¹ See *supra* notes 166-167 and accompanying text (clarifying which fair hearing request outcomes generate written decisions).

¹⁷² To determine which cases were available through the OAH Search Tool, we ran a webscraping program in **R**, a free software environment for statistical computing, which extracted the Case ID (or Case IDs in instances where multiple fair hearing requests were consolidated into the same hearing) from each PDF decision provided through the OAH Search Tool. We then compared the list of webscraped Case IDs to the dataset of fair hearing requests provided by DDS in response to our CPRA request. This analysis was conducted on Dec. 23, 2019 and the R Markdown file used is on file with the authors and available to interested readers upon request.

2012,¹⁷³ we could not comprehensively evaluate this question. Yet to obtain at least a partial answer, we extracted the case IDs of *all* decisions from *all* years (since 1998) available through the OAH Search Tool, then determined which (if any) of these fair hearing requests were not disclosed in DDS’s CPRA response.

The results of these analyses are summarized in Table 4, below. As is shown in the table, only about 64% of all relevant OAH fair hearing requests (943 out of 1,485) in DDS’s response to our CPRA request had written decisions available online. Moreover, 101 fair hearing requests (from CY 2012-2019) were not included in DDS’s response to our CPRA Request, even though their corresponding written decisions were available online through the OAH Search Tool.

Table 4: DDS Compliance with OAH Fair Hearing Transparency Requirements¹⁷⁴

<i>Fair Hearings in DDS’s CPRA Response that Generated Written Decisions</i>	#	%
<i>All Outcomes (“Granted,” “Denied,” and “Split”)</i>	1,485	[100]
Written decisions available online	943	63.5%
<i>Outcome “Granted”</i>	359	[100]
Written decisions available online	237	66.0%
<i>Outcome “Denied”</i>	991	[100]
Written decisions available online	620	62.6%
<i>Outcome “Split”</i>	135	[100]
Written decisions available online	86	63.7%
<i>Fair Hearing Requests Missing from DDS’s CPRA Response for which Written Decisions Are Available Online through OAH Search Tool¹⁷⁵</i>	101	[100]
Decisions Dated after Jan. 1, 2019 ¹⁷⁶	5	5%
Decisions Dated CY 2018	40	40%
Decisions Dated CY 2017	10	10%
Decisions Dated CY 2016	7	7%
Decisions Dated CY 2015	11	11%
Decisions Dated CY 2012-15	28	28%

¹⁷³ The OAH Search Tool makes available the decision from one fair hearing, OAH Case ID #2010060679, that was filed in 2010 and decided in 2011. This finding was the result of webscraping analysis. *See id.*

¹⁷⁴ WIC section 4714(b) requires DDS to make publicly available summary data on *all* OAH fair hearing requests. CAL. WELF. & INST. CODE § 4714(b) (Deering, LEXIS through 2019 Sess.). Meanwhile, WIC section 4712.5(d) requires that *all* decisions produced in response to OAH fair hearings be made publicly available. CAL. WELF. & INST. CODE § 4712.5(b) (Deering, LEXIS through 2019 Sess.). Our analysis of DDS’s compliance with section 4714(b) was limited to fair hearing requests filed from January 1st, 2013 (due to the limitations of the OAH Search Tool, *see supra* note 169) through July 31st, 2019 (due to the limited timeframe of our CPRA requests, *see supra* note 164). Similarly, our analysis of DDS’s compliance of 4714(b) was limited to those fair hearings whose decisions were available through the OAH Search Tool, which contained only one fair hearing decided before 2012. *See supra* note 173. Both analyses were performed using the web-scraping procedure described above, *supra* note 172, on December 23rd, 2019.

¹⁷⁵ Because these fair hearing requests were not included in our CPRA response we lacked information on the date each request was originally filed. Therefore, we were forced to use the date associated with the decision. In cases where the OAH decision was signed and dated, we used this date; however, for certain cases the administrative law judge left this field blank. In such cases we used the date upon which “[t]he record was closed and the matter submitted for decision.” This date was available for all remaining decisions available online.

¹⁷⁶ Since our CPRA request to DDS only extended through July 31st, 2019, *see* Request to Inspect Public Record from Alison Morantz to Cal. Dep’t of Developmental Servs. (Aug. 8, 2019), *supra* note 164, this number only includes fair hearings that were missing from DDS’s CPRA response and were filed *before* August 1, 2019.

In short, our analysis suggests that DDS’s reliance on OAH to effectuate its compliance with the transparency provisions relating to fair hearings is misplaced. Although WIC section 4714(b) requires DDS to provide summary data on all OAH fair hearing requests, as of this writing, dozens of recent fair hearing requests were (evidently) missing from DDS’s internal database.¹⁷⁷ Meanwhile, although WIC section 4712.5(b) requires DDS to “make copies of the decisions available to the public upon request,” approximately 36 percent of OAH decisions from recent years were unavailable.¹⁷⁸ DDS should hold OAH and the Department of General Services¹⁷⁹ strictly accountable for making all decisions available through the Search Tool, or else the Legislature should devise an alternative method to bring DDS into compliance with WIC sections 4712.5(d) and 4714(b).

(3) Summary Data on Consumer Complaints

Under WIC section 4731, “[e]ach consumer or any representative acting on behalf of any consumer or consumers, who believes that any right to which a consumer is entitled has been abused, punitively withheld, or improperly or unreasonably denied by a RC, developmental center, or service provider, may pursue a complaint as provided in this section.”¹⁸⁰ Yet a key transparency provision associated with section 4731 is ambiguously worded. Subdivision (d) states that “[t]he department shall annually compile the number of complaints filed, by each regional center and state developmental center catchment area, the subject matter of each complaint, and a summary of each decision. Copies shall be made available to any person upon request.”¹⁸¹ The word “copies” in the final sentence could refer either to the complaints themselves, or only to the annual summary compilations. We know of no pertinent case law, administrative rulings, statutory language, or legislative history that would resolve this textual ambiguity. As we discuss below, however, DDS has chosen to adopt the narrower interpretation,

¹⁷⁷ We take this to be the most likely explanation for the absence of these fair hearing requests from DDS’s CPRA response, although we cannot rule out the possibility that these fair hearing requests are contained in DDS’s internal database but were inadvertently omitted from its CPRA response.

¹⁷⁸ In response to a follow-up query, a DDS official responded that the latter decisions, if unavailable online, potentially could be found through on-site inspection of records at either DDS’s or OAH’s offices. *See* E-mail from Jason Scott to Alison Morantz (Aug. 20, 2018) *supra* note 165. However, our experience indicated that the latter approach would be unlikely to bear fruit, since neither agency appears to keep comprehensive records of fair hearing decisions. For example, in response to a request for a written decision for a fair hearing resolved in October, 2000, OAH responded that the document had “been destroyed in the ordinary course of business pursuant to the Office of Administrative Hearings’ records retention schedule.” E-mail from Nicole Buckoski, Staff Counsel, Cal. Office of Admin. Hearings, to Joshua Altman, Research Fellow, Stanford Law School (Sept. 17, 2018) (on file with authors). Similarly, after a prior version of this analysis revealed that DDS had omitted over 100 hearing requests in its response to our initial CPRA request for data on fair hearing requests filed from 1998 to 2017, *see* Request to Inspect Public Record (Aug. 8, 2019), *supra* note 161 (listing in an excel table all fair hearings that had been omitted from the CY 1998-2017 data produced in response to a prior CPRA request), we informed DDS of the omission and requested that these hearing requests be included as part of their response to our updated CPRA request. *See id.* (requesting that the updated OAH hearings dataset include “any OAH cases that were inadvertently omitted from your response to our prior [C]PRA request”). However, DDS evidently was unable to comply with this request, as their response only provided data on fair hearing requests filed *after* 2017, and did not revise the dataset provided for prior years. *See* E-mail from Alexandra Sanders to Alison Morantz (Aug. 21, 2019), *supra* note 156 (attaching OAH fair hearing data for requests filed from Jan. 1, 2018 to Jul. 31, 2019).

¹⁷⁹ Although OAH oversees the fair hearings process, the fair hearing decisions are posted on the Department of General Services’ website. *See OAH Search Tool*, *supra* note 169.

¹⁸⁰ Cal. WELF. & INST. CODE § 4731(a) (Deering, LEXIS through 2019 Sess.).

¹⁸¹ *Id.* WELF. & INST. § 4731(d) (LEXIS).

making public only the annual summary compilations of complaints (not the complaints themselves).

To analyze DDS’s compliance with transparency provisions surrounding these complaints (4731 Complaints), we submitted CPRA requests for information on *all* 4731 Complaints filed with DDS,¹⁸² information that WIC section 4731(d) requires DDS to compile and release upon request.¹⁸³ In response to the CPRA requests, DDS forwarded Excel spreadsheets containing basic summary data on each 4731 Complaint,¹⁸⁴ an approach that it justified by claiming that the underlying complaints and decisions contained confidential information.¹⁸⁵ For all complaints, the spreadsheets contain the following fields: Regional Center, Date Received, DB # [database number], Description of Complaint(s), Findings, and Date Closed. In cases where a violation was found, the spreadsheets also list Date CAP [Corrective Action Plan] Issued and Date CAP Completed.¹⁸⁶ Table 5, below, provides a few illustrative examples.

Table 5: Illustrative Examples of DDS Disclosures Regarding Section 4731 Complaints¹⁸⁷

#	Regional Center	Date Received	DB#	Description of Complaint(s)	Findings	Date Closed	Date CAP Issued	Date CAP Completed
1	[RC name]	7/11/13	13-018	“1) [RC] <u>has not provided documents in Spanish.</u> [. . . .]”	“1) [RC] did not provide written notice in a language that the consumer and family could comprehend [. . . .]”	6/9/14	6/9/2014	8/9/14
2	[RC name]	7/3/2015	15-026	“[. . . .] 2) [RC] <u>is not staffed or trained properly to supervise service coordinators or caseloads.</u> 3) [RC] <u>does not have an appropriate</u>	“[. . . .] 2) No violation. 3) No violation. 4) No violation. [. . . .] 8) No violation.”	9/22/15		

¹⁸² Request to Inspect Public Record from Lane Zuraw (Jan. 12, 2018), *supra* note 161; Request to Inspect Public Record from Alison Morantz, Director of SIDDLAPP, Stanford Law School, to Cal. Dep’t of Developmental Servs. (Nov. 18, 2019), <https://law.stanford.edu/wp-content/uploads/2019/12/b4-11.18.19-PRA-Request-4731-complaint-data-1.pdf>.

¹⁸³ WELF. & INST. § 4731(d) (LEXIS).

¹⁸⁴ E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158 (attaching 4731 Complaint data, which is on file with the authors).

¹⁸⁵ E-mail from Jason Scott to Alison Morantz (Aug. 20, 2018), *supra* note 165.

¹⁸⁶ While not required by statute, DDS’s policy is to issue a CAP if a violation is found following a 4731 Complaint. *See infra* note 398 and accompanying text (describing DDS policy with regard to CAPs).

¹⁸⁷ The illustrative complaints presented in this table were selected from a dataset of 256 WIC section 4731 Complaints which had been filed from July 1st, 2011 to December 26th 2019. We received these data from DDS on December 26th, 2019 in response to a prior CPRA request, *see* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158. All emphases (i.e., underlines) have been added. The names of individual regional centers specified in the original spreadsheet have been replaced with “[RC].” Ellipses, including those in brackets, indicate words, phrases or complaint “counts” that have been omitted from the table. To conserve space, the dates of years have been shortened to two-digit format (for example, “4/25/2016” in the original spreadsheet has been shortened to “4/25/16”).

				<p><u>interpretation of intake policy.</u> 4) <u>[RC] does not have operational contingencies for sudden departure of a service coordinator.</u> [. . . .] 8) <u>[RC] does not foster collaboration and growth with families."</u></p>				
3	[RC name]	12/6/15	15-032	<p>"1) <u>[RC] did not file incident reports with CCL.</u> 2) <u>[RC] did not enforce the completion of a corrective action plan with the vendor.</u> 3) <u>[RC] did not address substantial inadequacies, impose sanctions or audit the vendor."</u></p>	"1) No violation. 2) No violation. 3) Outside the scope of §4731."	1/6/16		
4	[RC name]	4/25/16	16-004	<p>"1) Vendor allowed the consumer to become ill with influenza and sustain bruises and scrapes while at a day program. 2) <u>Vendor does not have a policy for management of health and safety.</u> 3) <u>[RC] did not have a policy to ensure consumer health and safety.</u> 4) [RC] did not follow-up on reports from the complainant regarding injuries the consumer sustained at day program."</p>	"1) No violation. 2) No violation. 3) No violation. 4) No violation."	6/27/16		
5	[RC name]	8/8/16	16-016	<p>"[. . . .] 2) [RC] staff warned the consumer and his family that they should not allow [RC] to perform a behavioral assessment because [RC] could manipulate the results to deny or revoke services. 3) <u>[RC] is not following the fair</u></p>	"[. . . .] 2) No violation. 3) [RC] did not provide written notice confirming the agreed upon date, time, and place for the informal meeting . . . [RC] provided a written decision, six working days	9/26/16	9/30/16	9/30/16

				<u>hearing (FH) process specified by DDS, creating a potential bias in the outcome of the FH proceedings.</u> "	after the informal meeting date, which exceeds the amount of time allowed by statute. [. . .]"			
6	[RC name]	9/26/18	18-034	1) [RC] did not provide transportation services as reflected on the IPP. 2) [RC] did not <u>provide resources and supports to individuals with developmental disabilities in the North Tahoe/Truckee areas.</u> [. . .]"	"1) [RC] did not provide services reflected in the consumer's IPP . . . 2) The allegation is not a consumer rights issue. [. . .]"	11/27/18	3/6/19	5/9/19
7	[RC name]	1/30/19	19-004	"[. . .] 4) The vendor does not train staff. 5) [RC]'s <u>Cardio Pulmonary Resuscitation and Crisis Prevention Institute (CPI) credentials are not renewed timely.</u> "	"[. . .] 4) No violation. 5) Outside the scope of §4731."	3/14/19	3/26/19	On Hold
8	[RC name]	6/19/19	19-019	"1) [RC] changed agreed upon services created by Fairview Developmental Center (FDC). [. . .] 7) Residential services provider staff (RSP) did not accompany the consumer during transport to Psychiatric Crisis Unit. 8) RSP does not communicate with the conservators."	"1) Outside the scope of §4731, referred to fair hearing. 2 through 8) First level allegations and were returned to SARC for resolution."	7/10/19		

Although arguably compliant with the statutory requirements, the 4731 Complaint data are of limited practical value for several reasons. First, although CAPs are routinely issued in cases where violations are found,¹⁸⁸ the CAPs themselves are not made publicly available. Therefore, there is no way for the public to assess the breadth or adequacy of measures taken by the vendor and/or RC to correct the identified problems. This concern carries special force in contexts where

¹⁸⁸ Telephone Call with Tom Blythe, Appeals, Complaints & Projects, Cal. Dep't of Developmental Servs. (Dec. 23, 2019) (clarifying that although it is DDS's practice to issue CAPs in instances where violations are found through the 4731 Complaint process, this is not mandated by statute).

at least part of a 4731 Complaint (such as the underlined portions of those listed in Table 5) alleges more systemic problems that may affect not just the named consumer(s), but also other individuals served by a particular vendor or RC. Secondly, in cases where no violation is found, the spreadsheet provides no details or rationale. Therefore, it is unclear whether the allegations, even if true, are insufficient to constitute a rights violation; whether the allegations were factually unsupported; or some combination thereof. Third, in cases where a case is deemed outside the scope of the statute but not referred to fair hearing, it is unclear from the data provided what alternative channels, if any, the complainant can pursue to address the problem. For example, in Examples #3, #6, and #7 above (involving, respectively, a RC's alleged failure to impose sanctions or audits on a vendor; a RC's alleged failure to serve consumers in a particular region of the state; and a RC's alleged failure to timely renew its credentials with an emergency care facility), the complaint was deemed "outside the scope" of section 4731 or "not a human rights issue." It is unclear what recourse, if any, was available to these complainants. Finally, the information we received includes *only* complaints that were referred to DDS in writing pursuant to WIC section 4731(c);¹⁸⁹ those that were resolved internally by RCs pursuant to WIC Section 4731(b) are not included.¹⁹⁰

In short, our examination of two important transparency measures that require DDS to provide data to the public "upon request" paint a mixed picture. On one hand, the Department's compliance with WIC sections 4712.5(d) and 4714(b) is quite limited, with only about sixty-four percent of OAH decisions filed since January 1, 2013 available online, and dozens of fair hearing decisions available online omitted from DDS's response to our CPRA request. On the other hand, assuming that DDS's interpretation of the relevant statutory provision is correct, the summary data that we received on 4731 Complaints appears to be technically compliant with the statute. Yet the 4731 data are also provided in a form that sheds very little light on the Department's decision-making criteria or investigatory processes. Additionally, the way that DDS has construed the scope of section 4731 may leave some complainants—including those who raise more pervasive or systemic concerns—with no apparent recourse.

¹⁸⁹ See E-mail from Tom Blythe, Appeals, Complaints & Projects Section, Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Jan. 15, 2019) (on file with authors) (explaining the contents of the 4731 Complaint data provided to us by DDS).

¹⁹⁰ S.B. 81, which took effect on June 27, 2019, requires DDS to start collecting and posting on its website information about *all* consumers' rights complaints filed with RCs, including those that are never referred to DDS. Act of Jun. 27, 2019, ch. 28, § 8, 2019 Cal. Legis. Serv. 1270, 1281-82 (codified as amended at CAL. WELF. & INST. CODE § 4519.2 (2019)). Given the statute's recent vintage, however, we do not analyze DDS's compliance with it in this report.

V. Current Levels of Systemic Accountability

Strong transparency alone cannot preserve the Lanterman entitlement unless it is buttressed by robust oversight and accountability, so that concerned stakeholders can correct problems when they arise. After surveying private oversight mechanisms that enable individual consumers and their families to hold RCs accountable for failing to address their needs, we shift to a discussion of public oversight mechanisms.

A. Private Accountability Mechanisms

As discussed earlier, the Lanterman Act provides two different mechanisms for individual stakeholders to hold the I/DD system accountable for errors: the filing of 4731 Complaints alleging violations of consumers' rights,¹⁹¹ and the filing of requests for administrative fair hearings under WIC section 4714(a). Section 4731 Complaints are initially handled by RC directors, who must offer a proposed resolution in writing within 20 working days.¹⁹² If a RC director does not resolve a complaint to the satisfaction of the complainant, the complaint may be referred to the Director of DDS, who must respond, in writing, with a proposed resolution within 45 days receipt.¹⁹³ The proposed resolution must then be sent to the complainant, the director of the RC, and (if applicable) the service provider.¹⁹⁴

In contrast, the “fair hearing” process enables consumers and their representatives to request OAH adjudication of disputes with RCs regarding determinations of eligibility or the provision of services and supports. The Lanterman Act specifies:

[A]ny applicant for or recipient of services, or authorized representative of the applicant or recipient, who is dissatisfied with any decision or action of the service agency which he or she believes to be illegal, discriminatory, or not in the recipient's or applicant's best interests, shall, upon filing a request within 30 days after notification of the decision or action complained of, be afforded an opportunity for a fair hearing.¹⁹⁵

The hearing must be held within 50 days of the date when the hearing request form is received by the service agency (unless the claimant is granted a continuance),¹⁹⁶ and the hearing officer must render a written decision “in ordinary and concise language” within 80 days of the date the hearing request form is received.”¹⁹⁷ DDS contracts with OAH to conduct fair hearings on its

¹⁹¹ CAL. WELF. & INST. CODE § 4731(a) (Deering, LEXIS through 2019 Sess.); *see also* discussion *supra* § IV. C. (discussing in detail the 4731 Complaint process).

¹⁹² *Id.* WELF. & INST. § 4731(b) (LEXIS).

¹⁹³ *Id.* WELF. & INST. § 4731(c) (LEXIS).

¹⁹⁴ *Id.* WELF. & INST. § 4731(c) (LEXIS).

¹⁹⁵ CAL. WELF. & INST. CODE § 4710.5(a) (Deering, LEXIS through 2019 Sess.).

¹⁹⁶ CAL. WELF. & INST. CODE § 4712(a) (Deering, LEXIS through 2019 Sess.).

¹⁹⁷ CAL. WELF. & INST. CODE § 4712.5(b) (Deering, LEXIS through 2019 Sess.).

behalf,¹⁹⁸ and claimants may not file claims in state court without first exhausting their administrative remedies through the fair hearing process.¹⁹⁹

From a policy standpoint, it is helpful to know how frequently these two accountability mechanisms are actually used. With this question in mind, we requested data from DDS on all complaints and fair hearing requests filed pursuant to WIC sections 4731 and 4710.5(a), respectively.

Table 6: Frequency of Section 4731 Complaints Referred in Writing to DDS, by RC (Jul. 1st, 2011 – Dec. 26th, 2019)²⁰⁰

RC	Total Complaints (Jul. 1st, 2011 – Dec. 26th, 2019)	Annual Complaints per 1,000 Consumers
ACRC	32	0.15
CVRC	5	0.03
ELARC	2	0.02
FDLRC	15	0.15
FNRC	1	0.01
GGRC	11	0.13
HRC	10	0.07
IRC	29	0.09
KRC	10	0.13
NBRC	10	0.11
NLACRC	31	0.12
RCEB	10	0.05
RCOC	12	0.06
RCRC	0	0.00
SARC	16	0.10
SCLARC	9	0.05
SDRC	17	0.07
SGPRC	4	0.03
TCRC	10	0.07
VMRC	12	0.09
WRC	10	0.12
Total	256	0.08

As shown in Table 6, above, very few 4731 Complaints are referred in writing to DDS. Between July 1, 2011 and December 26, 2019, DDS received only 256 complaints statewide, with no RC exceeding (and most falling well below) a rate of 1 complaint per 5,000 consumers per year.²⁰¹

¹⁹⁸ *About Department of Developmental Services Case Type*, CAL. DEP'T OF GEN. SERVS., <https://www.dgs.ca.gov/OAH/CASE-TYPES/GENERAL-JURISDICTION/ABOUT/PAGE-CONTENT/ABOUT-DDS#@VIEWBAG.JUMPTO> (last visited Dec. 18, 2019).

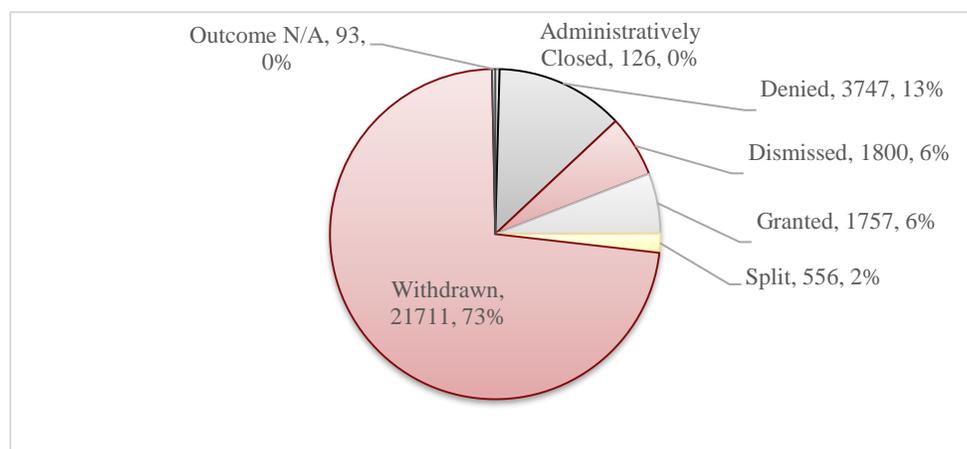
¹⁹⁹ *Gulbransen v. Far Northern Regional Center*, No. C075375, 2017 WL 4533965, at *3 (Cal. Ct. App. Oct. 11, 2017).

²⁰⁰ *Id.*

²⁰¹ Data on the number of complaints filed against each RC and ultimately referred to the Department was provided by DDS in response to a CPRA request. *See* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note

As of this writing, no data are publicly available on how many 4731 Complaints are resolved internally by RC directors. That information, when it becomes publicly available,²⁰² will shed light on how often the complaint process is being utilized at the local level. It is possible that the complaints referred to DDS constitute only a small fraction of the total number. Nevertheless, the facts (discussed earlier)²⁰³ that no information is available on the content of Corrective Action Plans (CAPs); that no rationale is given in situations where no violation is found; and that complaints are sometimes deemed “outside the scope” of the statute with no indication of an alternative recourse or remedy, remain significant barriers to transparency and accountability. Thus although section 4731 may help to resolve civil rights violations in individual cases, it seems ill-equipped to address more broad-based or systemic deficiencies.

Figure 1: Disposition of Fair Hearing Requests (Filed January 1st, 1998 – July 31st, 2019)²⁰⁴
(Total Fair Hearing Requests = 29,790)



As is shown in Figure 1, above, fair hearing requests are far more common than 4731 Complaints that are referred to DDS.²⁰⁵ Since 1998, about 1,400 fair hearing requests related to

158. Data on the total number of eligible consumers served by each RC was collected from each RC’s POS disparity tables for FY 2017-18. See *Regional Center Purchase of Service Data*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/purchase-of-service-data/> (last visited Jan. 3, 2020) (providing hyperlinks to each RC’s POS disparity data). For each RC, the annual complaint rate is calculated by summing the RC’s total number of complaints, dividing that sum by 8.49 years to reflect the total observation period, dividing that quotient by the number of eligible consumers, and finally multiplying that quotient by 1,000.

²⁰² See *supra* note 190 (discussing the reform enacted in June of 2019, which requires DDS to post data on *all* 4731 complaints, including those resolved internally by RCs).

²⁰³ See discussion *supra* pp. 35-36.

²⁰⁴ Data on fair hearing requests (filed from January 1st, 1998 – July 31st, 2019) and their resulting outcomes were obtained from DDS through several PRA requests. See *supra* notes 161, 164 and accompanying text.

²⁰⁵ Again, it is important to bear in mind that the two procedures encompass different types of issues. Unlike the fair hearing process, which is designed for consumers to challenge a change in, or denial of, services, CAL. WELF. & INST. CODE § 4710.5(a) (Deering, LEXIS through 2019 Sess.), the 4731 Complaint process pertains to situations in which a consumer believes that his/her rights have been “abused, punitively withheld, or improperly or unreasonably denied by a regional center, developmental center, or service provider,” CAL. WELF. & INST. CODE § 4731(a) (Deering, LEXIS through 2019 Sess.) (describing the purpose of section 4731 Complaints).

disputes with RCs have been filed each year.²⁰⁶ However, as shown in Figure 1, above, few requests that are filed ever reach the fair hearing stage. Of the 29,790 requests filed between January 1st, 1998 and July 31st, 2019, 73% (21,837) were administratively closed or withdrawn prior to adjudication.²⁰⁷ Of the 7,953 appeals that were not withdrawn or administratively closed, only 29% (2,313) resulted in at least a partial victory for the claimant (i.e., received a granted or split decision).

As is shown in Table 7, below, there is also considerable diversity across RCs in the frequency and typical resolution of fair hearing requests. For example, between 1998 and 2019 the annual number of hearing requests per 1,000 consumers varied widely across RCs (from 1.78-11.99), as did the respective percentages of hearing requests that were withdrawn (59-84%), dismissed (3-13%), granted (1-13%), and denied (6-25%).

Yet it is difficult to draw any clear conclusions from variations in frequency alone. A low rate of fair hearing requests in a given RC could mean that most consumers' needs are being met; for example, staff may choose to settle many cases in consumers' favor before fair hearing requests are even filed. Yet a low rate of requests could also indicate that structural impediments—such as a lack of familiarity with the process, language barriers, or inability to afford an attorney—are deterring many justifiably aggrieved consumers from filing.

Another empirical uncertainty is why so many fair hearing requests—a majority in all RCs—are withdrawn. If most requests are withdrawn because the RC acquiesces to the consumer's request before the hearing takes place, one might infer that most consumers' needs are being adequately met. If, on the other hand, most requests are withdrawn because consumers cannot find (or afford) legal representation, one might reach a very different conclusion.

Either way, it is important to bear in mind that most fair hearing requests are resolved (or withdrawn) outside the public eye. Although procedural mechanisms that deter or impede judicial adjudication raise equity concerns in many areas of law,²⁰⁸ such concerns arguably carry

²⁰⁶ Data on fair hearing requests (filed from January 1st, 1998 – July 31st, 2019) and their resulting outcomes were obtained from DDS through several PRA requests. *See supra* notes 161, 164 and accompanying text. We calculated the annual rate of fair hearing requests by dividing the total number of requests for this time period (29,790) by 21.583 years to reflect the total observation period.

²⁰⁷ Consumers may request either an informal meeting or mediation with a service agency before proceeding to a fair hearing. CAL. WELF. & INST. CODE § 4710.5(a) (Deering, LEXIS through 2019 Sess.). If the consumer or his or her representative is satisfied with the service agency's decision following the voluntary meeting, or if the two parties reach a resolution in the mediation, then the consumer or his or her representative shall withdraw the request for a fair hearing. CAL. WELF. & INST. CODE § 4710.9 (Deering, LEXIS through 2019 Sess.).

²⁰⁸ *See, e.g.,* Cara Van Dorn, *When Joining Means Enforcing: Giving Consumer Protection Agencies Authority to Ban the Use of Class Action Waivers*, 17 WAKE FOREST J. BUS. INTELL. PROP. L. 245, 266 (2017) (noting that bans on class actions impede access to justice because only those plaintiffs with damages high enough to justify the costs of resolving their claim on an individual basis will bring claims); Theodore Eisenberg et al., *Arbitration's Summer Soldiers: An Empirical Study of Arbitration Clauses in Consumer and Nonconsumer Contracts*, 41 U. MICH., J. L. REFORM 871, 876 (2008) (concluding, on basis of empirical study, that to the extent that mandatory arbitration clauses are successful in preventing access to courts, they "eliminate any effective consumer remedy for defective products or services"); Alexander J.S. Colvin, *Mandatory Arbitration and Inequality of Justice in Employment*, 35 BERKELEY J. EMP. & LAB. L. 71, 90 (2014) (arguing that the declining access to courts brought about by the rise of mandatory arbitration increases inequality in workplace).

particular force in this context since, as discussed earlier, so many administrative decisions are not publicly available.²⁰⁹

Table 7: Frequency and Disposition of Fair Hearing Requests by Regional Center, (Filed January 1st, 1998 – July 31st, 2019)²¹⁰

Regional Center	Fair Hearing Requests per 1,000 Consumers per Year ²¹¹	% Withdrawn	% Dismissed	% Granted	% Denied
ACRC	2.51	67%	13%	5%	12%
CVRC	2.15	83%	5%	2%	9%
ELARC	6.85	59%	7%	10%	20%
FDLRC	4.30	69%	9%	5%	13%
FNRC	4.38	75%	6%	1%	15%
GGRC	2.62	68%	8%	5%	17%
HRC	4.72	66%	3%	13%	12%
IRC	5.30	76%	4%	5%	13%
KRC	6.43	78%	4%	7%	11%
NBRC	3.03	68%	4%	6%	18%
NLACRC	3.24	73%	6%	5%	13%
RCEB	2.13	75%	4%	5%	14%
RCOC	3.08	84%	4%	2%	7%
RCRC	3.64	61%	4%	7%	25%
SARC	1.78	77%	4%	4%	12%
SCLARC	3.58	68%	7%	8%	13%
SDRC	1.83	73%	4%	8%	13%
SG/PRC	5.01	70%	5%	9%	13%
TCRC	1.94	82%	5%	5%	6%
VMRC	3.73	79%	8%	2%	10%
WRC	11.99	73%	10%	6%	9%

The public’s inability to access all fair hearing decisions impedes access to justice in two ways. First, the more opaque the fair hearing process and the less certain the odds of success, the less

²⁰⁹ See *supra* Table 4 (presenting the number of OAH decisions not found online); see also *supra* § IV. C. 2. (discussing DDS’s compliance with the reporting requirements surrounding OAH decisions more broadly).

²¹⁰ Data on fair hearing requests (filed from January 1st, 1998 – July 31st, 2019) and their resulting outcomes were obtained from DDS through several PRA requests. See *supra* notes 161, 164 and accompanying text. To view and download these data, see *Data on California’s Regional Center System*, *supra* note 164. Note that the four outcome categories presented in the table are not comprehensive (we do not present the percentages of requests that have a split outcome, were administratively closed, or do not have an outcome listed), and as such the percentages may not necessarily sum to 100%.

²¹¹ Data on fair hearing requests (filed from January 1st, 1998 – July 31st, 2019) and resulting outcomes were obtained from DDS through several PRA requests. See *supra* notes 161, 164 and accompanying text. Data on the total number of eligible consumers served by each RC was collected from each RC’s POS disparity tables for FY 2017-18. See *Regional Center Purchase of Service Data*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/purchase-of-service-data/> (last visited Jan. 4, 2020) (providing hyperlinks to each RC’s POS disparity data). For each RC, the annual rate of OAH fair hearing requests was calculated by summing the RC’s total number of requests, dividing that sum by 21.583 years to reflect the total observation period, dividing that quotient by the number of eligible consumers, and finally multiplying that quotient by 1,000.

willing claimants with meritorious claims may be to hire attorneys or try to represent themselves. Secondly, even the most sophisticated consumers and family members are typically one-shot players in OAH hearings, whereas RCs and their attorneys are repeat players whose prior experience and familiarity with the process are likely to confer competitive advantages.²¹² The absence of full and complete public information on the outcomes of prior fair hearings will, if anything, tend to exacerbate these disparities by magnifying informational asymmetries between consumers and RCs.

In sum, our survey of the two private enforcement mechanisms for promoting systemic accountability raises some questions but leaves others unanswered. Although only a handful of consumer complaints are referred in writing to DDS pursuant to WIC section 4731, as of this writing, it is unknown whether many more are resolved at the initial stage by RC directors. Either way, the relatively narrow scope of the statute and the scant data available on CAPs, discussed earlier, makes section 4731 an awkward and relatively opaque mechanism to remedy civil rights violations. Meanwhile, although well over a thousand requests for fair hearing are filed (on average) each year, the vast majority of them are withdrawn before trial, and the reasons for these withdrawals are not recorded (or at least, not provided to the public). Most importantly, over a third of fair hearing decisions are not publicly available.²¹³ Without access to more granular data on outcomes, it is difficult to assess whether the administrative hearings performed by OAH are serving their intended role of ensuring consumers' access to needed services and supports.

B. Public Accountability Mechanisms

The operational autonomy of RCs, which the architect of the Lanterman Act hoped would make RCs more responsive to their local communities, was a cornerstone of the Act at the time of its passage, and remains so to this day.²¹⁴ The California Supreme Court has made clear that the responsibility of DDS “does not extend to the control of the manner in which [regional centers] provide services or in general operate their programs.”²¹⁵ The Department's role is not to participate directly in the determination of individual needs or in the provision of services and supports to consumers, but rather to “ensure that the regional centers operate in compliance with

²¹² See, e.g., Lisa Blomgren Amsler (formerly Bingam), *Employment Arbitration: The Repeat Player Effect*, 1 EMP. RTS. EMP. POL'Y J. 189, 189–220 (1997) (finding substantial repeat player bias in commercial and arbitration awards); Alexander J.S. Colvin, *An Empirical Study of Employment Arbitration: Case Outcomes and Processes*, 8 J. EMPIRICAL LEGAL STUD. 1, 1–23 (2011) (finding substantial repeat-employer bias in arbitration of employment disputes).

²¹³ See *supra* Table 4 and accompanying text.

²¹⁴ See, e.g., FRANK D. LANTERMAN REG'L CTR., STRENGTHENING THE COMMITMENT...REINVESTING IN THE SYSTEM: A JOURNEY OF COMMUNITY PARTNERSHIP: HISTORY OF THE REGIONAL CENTERS IN CALIFORNIA 6 (2016), [https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6\(Blue\)\(web\)_final.pdf](https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf) (last visited, Jan. 9, 2020) (noting that in decade of the Lanterman Act's passage, the creation of a “public-private partnership was aimed at establishing a system of community-based services for people with mental retardation that [would] offer alternatives to state institutions. Because parents [were] suspicious of the capacity of the state bureaucracy to know what is best for their children, they demand[ed] that these regional centers be locally governed.”).

²¹⁵ *Ass'n for Retarded Citizens v. Dep't of Developmental Servs.*, 38 Cal.3d 384, 389–390 (1985); see also CAL. WELF. & INST. CODE § 4633 (Deering, LEXIS through 2019 Sess.) (“[DDS] shall not require regional centers to provide or purchase any services beyond the level of the funding appropriation for such services.”).

federal and state law[s] and regulation[s], and provide services and supports to consumers in compliance with the principles of [the Lanterman Act].”²¹⁶

Broadly speaking, the Legislature has granted DDS two types of tools with which to exercise its oversight authority. The first type, which comprises the vast majority of tools, aims to promote conformity with the more procedural aspects of RCs’ operations (such as vendoring, billing, accounting, and recordkeeping), while nudging RCs toward improvements in consumer outcomes. DDS’s authority encompasses a fairly wide array of such discrete statutory provisions, such as ones empowering DDS to collect and disseminate data on RCs’ compliance with online transparency requirements,²¹⁷ to establish best practices for accounting and administrative management,²¹⁸ and to authorize the payment of “negotiated” rates that fall outside the ordinary statutory ranges.²¹⁹ Additionally, DDS has the authority to establish equitable rates for non-residential services and supports;²²⁰ standardize IPP formats;²²¹ audit a random sample of IPPs biennially;²²² audit RCs’ finances on a biennial basis;²²³ request periodic progress reports from RCs on the implementation of special projects;²²⁴ and review data on the caseloads of RCs’

²¹⁶ CAL. WELF. & INST. CODE § 4434(a) (Deering, LEXIS through 2019 Sess.); *see also* CAL. WELF. & INST. CODE § 4629(b) (Deering, LEXIS through 2019 Sess.) (“[RC] contracts shall include a provision requiring each regional center to render services in accordance with applicable provision of state laws and regulations.”).

²¹⁷ *See, e.g.*, CAL. WELF. & INST. CODE § 4519.5(a) (Deering, LEXIS through 2019 Sess.) (requiring DDS and RCs to annually collaborate to produce POS disparity data); CAL. WELF. & INST. CODE § 4571 (Deering, LEXIS through 2019 Sess.) (unified quality assessment system); CAL. WELF. & INST. CODE § 4629.5(c) (Deering, LEXIS through 2019 Sess.) (requiring DDS to post a link to the data provided by each RC in compliance with WIC section 4629.5(b)); CAL. WELF. & INST. CODE § 4652.5(d)(2) (Deering, LEXIS through 2019 Sess.) (requiring DDS to compile, broken down by RC, data on vendor compliance with audit reports and the opinions resulting from vendor audit reports and to publish these data annually on its Performance Dashboard).

²¹⁸ *See* CAL. WELF. & INST. CODE § 4620.3 (Deering, LEXIS through 2019 Sess.) (approving dissemination of DDS best practices around administrative management); *see also* CAL. WELF. & INST. CODE § 4631(a) (Deering, LEXIS through 2019 Sess.) (empowering DDS to prescribe a uniform accounting, budgeting and encumbering system; a systemic approach to administrative practices and procedures; and a uniform reporting system).

²¹⁹ *See, e.g.*, CAL. WELF. & INST. CODE § 4681.6(a)(1) (Deering, LEXIS through 2019 Sess.) (requiring RCs to gain DDS authorization for negotiated rates with residential services providers if they are higher than the rate in effect on June 30, 2008); CAL. WELF. & INST. CODE § 4689.8(a)(1) (Deering, LEXIS through 2019 Sess.) (requiring RCs to gain DDS authorization for negotiated rates with living services providers if they are higher than the rate in effect on June 30, 2008); CAL. WELF. & INST. CODE § 4691.9(a)(1) (Deering, LEXIS through 2019 Sess.) (requiring RCs to gain DDS authorization for negotiated rates higher than the rate in effect on June 30, 2008).

²²⁰ *See* CAL. WELF. & INST. CODE § 4690 (Deering, LEXIS through 2019 Sess.) (empowering the DDS director to “establish, maintain, and revise, as necessary” an equitable rate-setting process for nonresidential services); *see also* CAL. WELF. & INST. CODE § 4680 (Deering, LEXIS through 2019 Sess.) (empowering DDS to establish an equitable vendor payment system).

²²¹ *See* CAL. WELF. & INST. CODE § 4646.5(c)(1)-(2) (Deering, LEXIS through 2019 Sess.) (empowering DDS to prepare training materials and a standard format and instructions for the preparation of IPPs).

²²² *Id.* WELF. & INST. § 4646.5(c)(3) (LEXIS) (“The department shall biennially review a random sample of IPPs at each regional center to ensure that these plans are being developed and modified in compliance with section 4646 and [section 4646.5].”).

²²³ CAL. WELF. & INST. CODE § 4780.5 (Deering, LEXIS through 2019 Sess.) (“[DDS] is responsible for the processing, audit, and payment of funds made available to regional centers under [division 4.5 of the WIC].”). While not explicit in statute, WIC section 4780.5 is cited as the authority for DDS’s biannual fiscal audits of each RC. *See, e.g.*, CAL. DEP’T OF DEVELOPMENTAL SERVS., AUDIT OF THE EASTERN LOS ANGELES REGIONAL CENTER FOR FISCAL YEARS 2011-12 AND 2012-13 4 (2014), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_EastLA111213_20190228.pdf (last visited Dec. 26, 2019) (Authority).

²²⁴ CAL. WELF. & INST. CODE § 4513(c) (Deering, LEXIS through 2019 Sess.).

service coordinators to ensure they meet statutory requirements.²²⁵ Such measures have promoted some standardization of, and compliance with, the more formal and procedural provisions of the Lanterman Act.

In some cases, these tools may also help promote the Act's core policy goals. For example, the capacity to authorize negotiated rates²²⁶ may help RCs find providers willing to serve consumers in high-cost or underserved areas. Additionally, DDS's standardized IPP format may prompt service coordinators to understand and discuss the consumer's life goals,²²⁷ a process consistent with the Act's focus on individual empowerment and person-centered planning. In areas where RCs are known to be falling short, DDS also has the authority to provide additional materials,²²⁸ sponsor training,²²⁹ and fund pilot programs.²³⁰

The second type of tools at DDS's disposal are meant to address serious or chronic deficiencies in RCs' performance. For example, if DDS concludes that a RC is breaching its contractual duties (for instance, by engaging in accounting improprieties), DDS "shall make reasonable efforts to resolve the problem within a reasonable period of time with the cooperation of the regional center, including . . . renegotiation of the contract."²³¹ If the problems persist, DDS "shall issue a letter of noncompliance," "establish a specific timeline for the development and implementation of a corrective action plan [CAP]," and subsequently monitor the RC's implementation of the CAP.²³² If DDS finds that the RC "continues to fail in fulfilling its contractual obligations after reasonable efforts have been made, finds that other regional centers are able to fulfill similar obligations under similar contracts, and finds that it will be in the best interest of the persons being served by the regional center," the Department "shall take steps to terminate the contract," including finding another governing board willing and able to provide RC services in the same catchment area.²³³ Yet because terminating a RC's contract (or

²²⁵ CAL. WELF. & INST. CODE § 4640.6(e) (Deering, LEXIS through 2019 Sess.). DDS is subsequently required to verify these reports as part of its biannual fiscal audit. *See id.* WELF. & INST. § 4640.6(e) (LEXIS).

²²⁶ *See supra* note 219 and accompanying text; *see also, e.g., Vendorization & Rates Frequently Asked Questions*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/vendor-provider/vendorization-process/vendorization-rates-frequently-asked-questions/> (last visited Dec. 25, 2019) [hereinafter *Vendorization & Rates Frequently Asked Questions*] (noting that the rate of pay for some services, including Supported Living, are negotiated between vendors and RCs).

²²⁷ CAL. WELF. & INST. CODE § 4646.5(a)(1) (Deering, LEXIS through 2019 Sess.) (requiring that the IPP planning process include "[g]athering information and conducting assessments to determine the life goals, capabilities and strengths, preferences, barriers, and concerns or problems of the person with developmental disabilities").

²²⁸ *Id.* WELF. & INST. § 4646.5(c)(1)-(2) (LEXIS) (IPP training materials).

²²⁹ CAL. WELF. & INST. CODE § 4643.3(b) (training program for autism diagnosis procedures); CAL. WELF. & INST. CODE § 4659(f)(1) (Deering, LEXIS through 2019 Sess.) (authorizing DDS to train RCs on how to exhaust generic resources); CAL. WELF. & INST. CODE § 4511(c) (Deering, LEXIS through 2019 Sess.) (authorizing DDS to train RCs on facilitating the transition of consumers from DCs to the community); *see also* CAL. WELF. & INST. CODE § 4519.5(g) (Deering, LEXIS through 2019 Sess.) (requiring DDS to identify barriers to equitable access of RC services across different racial/ethnic groups, including lack of cultural competency training).

²³⁰ *See Disparity Funds Program: Grant Structure*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/disparities/disparity-funds-program/grant-structure/> (last visited Dec. 26, 2019) (noting that DDS received \$11 million in 2016 to fund projects aimed at reducing POS disparities); *see also Disparity Funds Program: Awarded Projects*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/disparities/disparity-funds-program/awarded-projects/> (last visited Dec. 26, 2019) (listing the projects that DDS has funded in its efforts to reduce POS disparities).

²³¹ CAL. WELF. & INST. CODE § 4635(b)(1) (Deering, LEXIS through 2019 Sess.).

²³² *Id.* WELF. & INST. § 4635(b)(2) (LEXIS).

²³³ *Id.* WELF. & INST. § 4635(c)-(d) (LEXIS).

threatening to do so) is such a drastic step, it is almost never used, except in cases of clear malfeasance or mismanagement.²³⁴

Notably absent from DDS's regulatory toolkit are accountability measures that reward or penalize individual RCs for their progress (or lack thereof) in implementing laws and regulations designed to empower, educate, and better support consumers and their families.

The absence of concrete performance incentives does not reflect any disinterest on the Legislature's part in measuring systemic outcomes. Legislation passed in 2016, for example, required DDS to "evaluate, and improve the quality of community-based services [provided by RCs] through the use of a performance dashboard."²³⁵ Moreover, in compliance with WIC section 4629.5(c)(7),²³⁶ DDS posts annually on its website its Performance Contracts with each RC.²³⁷ These materials are prefaced with the following introduction:

DDS establishes contracts with regional centers that include specific, measurable, performance objectives, which are reviewed by the public on an annual basis. The annual performance contracts are designed to help consumers achieve quality of life, reach meaningful progress above current baselines, and developed [sic] services and supports to meet consumer's needs. Every year, DDS reviews each regional center's performance data for compliance with their contracts.²³⁸

²³⁴ There has been only one instance in which DDS cancelled a RC contract, which took place in the late 1970s and involved Loma Prieta Regional Center, subsequently renamed San Andreas Regional Center. See E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Sept. 12, 2018) (identifying Loma Prieta as the "one instance of a regional center contract termination") (on file with authors). Beginning in approximately 2014, however, DDS also took some of the preliminary steps outlined in the statute in response to systemic problems at Kern Regional Center. See Letter from Nancy Bargmann, Director, Cal. Dep't of Developmental Servs., to Kurt Van Sciver, President, Kern Reg'l Ctr. (Apr. 6, 2017), https://docs.wixstatic.com/ugd/7b3c6a_b6c1897dc0d84216b5dc03f638a0f214.pdf (last visited Jan. 7, 2020) ("[I]n the event KRC is not in significant compliance with the provisions of the [Special Contract Language] within six months, the Department will proceed with termination of KRC's contract.>").

²³⁵ Act of Jun. 27, 2016, ch. 26, § 8, 2016 Cal. Legis. Serv. 937, 946-947 (codified as amended at CAL. WELF. & INST. CODE § 4572 (2019)) (requiring the Performance Dashboard to be published annually and include, at a minimum, all of the following: "(a) Recognized quality and access measures. (b) Measures to indicate the movement toward compliance with the federal Home and Community-Based Services Waiver rules (CMS 2249-F and CMS 2296-F). (c) Measures to evaluate the changes in the number of consumers who work in competitive integrated employment. (d) The number of complaints referred to the department pursuant to subdivision (c) of section 4731, for every 1,000 consumers served, by each regional center. (e) The number of administrative fair hearings held pursuant to Article 3 (commencing with section 4710) of Chapter 7, separated by eligibility and service issues, for individuals ages three and over, for every one thousand consumers served, by each regional center").

²³⁶ CAL. WELF. & INST. CODE § 4629.5(c)(7) (Deering, LEXIS through 2019 Sess.). This disclosure is part of the broader requirement that DDS maintain a transparency portal on its website to provide stakeholders with information on providers and RCs. WELF. & INST. § 4629.5(c) (LEXIS); see also *supra* note 70 (describing in full the disclosures required as part of DDS's Transparency Portal). Note that RCs are also required to post their Performance Contracts with DDS as part of a separate provision. WELF. & INST. § 4629.5(b)(9) (LEXIS).

²³⁷ *Regional Center Performance Contracts*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/disparities/data/regional-center-performance-contracts/> (last visited Dec. 23, 2019); see also *supra* Table 1 (rating DDS's compliance with disclosure requirements).

²³⁸ CAL. DEP'T OF DEVELOPMENTAL SERVS., *supra* note 237.

Performance Contracts generally list activities that RCs intend to implement to improve outcomes on various observable performance measures. These activities can relate to consumers' living situations, such as the percentage of minors living with families and the percentage of adult consumers living in home settings;²³⁹ budgetary, auditing, and recordkeeping practices, such as whether or not expenditures stay within the year's operational budget;²⁴⁰ consumer employment, such as the percentage of those aged 16-64 with earned income;²⁴¹ and racial/ethnic disparities in service delivery.²⁴² The content and structure of the Performance Contracts, however, vary considerably by RC. For example, the listed performance measures differ between RCs,²⁴³ and while some Performance Contracts present RC-specific outcome measures alongside statewide averages, others do not.²⁴⁴

DDS also posts Performance Contract Year-End Reports (Year-End Reports) for each RC that compare end-of-year outcomes relating to the reduction of POS disparities and other RC goal areas to outcomes from the prior year.²⁴⁵ The Year-End Reports do not, however, typically

²³⁹ See, e.g., NORTH L.A. COUNTY REG'L CTR., PERFORMANCE CONTRACT (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_NLACAPR2018_20190228.pdf (last visited Dec. 26, 2019); WESTSIDE REG'L CTR., WESTSIDE REGIONAL CENTER PERFORMANCE CONTRACT 2018 (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_WSAPR2018_20190228.pdf (last visited Dec. 26, 2019).

²⁴⁰ See, e.g., FRANK D. LANTERMAN REG'L CTR., FRANK D. LANTERMAN REGIONAL CENTER 2018 PERFORMANCE PLAN (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_FDLAPR2018_20190228.pdf (last visited Dec. 26, 2019); EASTERN L.A. REG'L CTR., EASTERN LOS ANGELES REGIONAL CENTER PERFORMANCE CONTRACT 2018 (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_ELAPR2018_20190228.pdf (last visited Dec. 26, 2019).

²⁴¹ See, e.g., KERN REG'L CTR., PERFORMANCE CONTRACT PLAN (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_KRCAPR2018_20190228.pdf (last visited Dec. 26, 2019); REG'L CTR. OF ORANGE COUNTY, PERFORMANCE CONTRACT 2018 (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_RCOCAPR2018_20190228.pdf (last visited Dec. 26, 2019).

²⁴² See, e.g., SAN ANDREAS REG'L CTR., 2018 PERFORMANCE CONTRACT: PROPOSED OUTCOMES AND ACTIVITIES (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_SAAPR2018_20190228.pdf (last visited Dec. 26, 2019); CENTRAL VALLEY REG'L CTR., CENTRAL VALLEY REGIONAL CENTER PERFORMANCE CONTRACT – 2018 (2018), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_CVAPR2018_20190228.pdf (last visited Dec. 19, 2019).

²⁴³ Compare ALTA CALIFORNIA REG'L CTR., 2018 PERFORMANCE CONTRACT (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_AltaAPR2018_20190228.pdf (last visited Dec. 26, 2019) (including the “[n]umber and percent of adults in facilities serving greater than 6 people” in its outcome measures), with SAN DIEGO REG'L CTR., 2018 PERFORMANCE CONTRACT PLAN OUTCOMES AND ACTIVITIES (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_SDAPR2018_20190228.pdf (last visited Dec. 26, 2019) (not including the number and percent of adults in facilities serving greater than 6 people in its outcome measures).

²⁴⁴ Compare NORTH BAY REG'L CTR., PERFORMANCE PLAN 2018 (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_NBAPR2018_20190228.pdf (last visited Dec. 26, 2019) (presenting the RC's outcome data from past years alongside statewide averages relating to measures of interest), with INLAND REG'L CTR., INLAND REGIONAL CENTER 2018 PERFORMANCE CONTRACT PLAN (2017), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_IRCAPR2018_20190228.pdf (last visited Dec. 26, 2019) (presenting measures of interest and proposed actions, but not offering current or past outcome data, at either the RC or state-level, for these measures).

²⁴⁵ See, e.g., FRANK D. LANTERMAN REG'L CTR., [2017] PERFORMANCE REPORT FOR FRANK D. LANTERMAN REGIONAL CENTER (2018), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_FDLPCYR2017_20190228.pdf (last visited Dec. 26, 2019) (presenting data for CY 2017). Not all goals listed in the Performance Contracts are addressed in the Year-End Reports. Compare ALTA REG'L CTR., 2017 PERFORMANCE CONTRACT (2016), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_AltaAPR2017_20190228.pdf (last visited Jan. 23, 2020) (including the “number of clients who are . . . victims of abuse” in its outcome measures), with ALTA REG'L CTR., [2017] PERFORMANCE REPORT FOR ALTA CALIFORNIA REGIONAL CENTER (2018), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_AltaPCYR2017_20190228.pdf (last visited Jan. 23, 2020) (failing to report the number of clients who were victims of abuse in that year); compare HARBOR REG'L CTR., HARBOR REGIONAL CENTER

indicate whether the RC followed through on the planned activities enumerated in the prior year's contract.

The function of Performance Contracts and Year-End Reports is mostly informational, in that RCs' budgets are not tied in any concrete way to their reported success or failure in furthering key policy goals, such as reducing the number of consumers in restrictive environments, increasing competitive integrated employment, or mitigating racial/ethnic disparities. For this reason, the statement on DDS's website that Performance Contracts are "reviewed by the public on an annual basis" in a way that incentivizes RCs to "reach meaningful progress above current baselines"²⁴⁶ seems largely aspirational.

To be sure, under the Lanterman Act, each RC is formally accountable to a board of directors, at least half of whose members must be "persons with developmental disabilities or their parents or legal guardians."²⁴⁷ Each board is authorized to review and approve their RC's budget, policies, procedures, and Performance Contracts; and may appoint advisory committee(s) that include consumers and providers.²⁴⁸ Moreover, each board "may provide recommendations to the director of the regional center based on the results of that review."²⁴⁹ Yet in practice, it may be difficult for board members to synthesize enough information about their RC's performance to hold its executives meaningfully accountable for their performance. After all, unlike DDS officials, board members have no control over the size of the RC's total budget; serve on a volunteer basis;²⁵⁰ cannot readily obtain granular data on statewide outcomes (besides statewide averages); and if they are consumers (or family members),²⁵¹ may feel reluctant to publicly criticize an organization upon which they rely for services and supports. Thus as a practical matter, RC boards may not be well equipped to ensure that RCs are held accountable for their success in promoting key policy objectives.

In short, the Legislature has not yet granted DDS explicit authority to impose monetary rewards or penalties to RCs based on their relative success or failure in expanding community-based services, promoting community inclusion, increasing competitive integrated employment, and enhancing overall consumer satisfaction.²⁵² Yet as of this writing, there are indications that the

PERFORMANCE PLAN 2017 (2016), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_HRCAPR2017_20190228.pdf (last visited Jan. 23, 2020) (including "accuracy of POS projections" in its outcome measure), *with* HARBOR REG'L CTR., [2017] PERFORMANCE REPORT FOR HARBOR REGIONAL CENTER (2018), https://www.dds.ca.gov/wp-content/uploads/2019/03/Transparency_HRCPCYR2017_20190228.pdf (last visited Jan. 23, 2020) (failing to report whether or not Harbor Regional Center's POS projections were accurate for that year).

²⁴⁶ See CAL. DEP'T OF DEVELOPMENTAL SERVS., *supra* note 237.

²⁴⁷ CAL. WELF. & INST. CODE § 4622(e) (Deering, LEXIS through 2019 Sess.).

²⁴⁸ See, e.g., *Board of Directors FAQs*, EASTERN L.A. REG'L CTR., <http://www.elarc.org/governance/board-of-directors/board-of-directors-faqs> (last visited Dec. 26, 2019).

²⁴⁹ WELF. & INST. § 4622(j)(2) (LEXIS).

²⁵⁰ See, e.g., *Board of Directors*, REG'L CTR. OF ORANGE COUNTY, <http://www.rcocdd.com/board-of-directors/> (last visited Dec. 26, 2019) ("Board members volunteer their time").

²⁵¹ See, e.g., REG'L CTR. OF ORANGE COUNTY, FAST FACTS FOR PROSPECTIVE BOARD MEMBERS, http://www.rcocdd.com/wp-content/uploads/about/bod/RCOC_Board_Recruitment_Flyer.pdf (last visited Jan. 7, 2020) (noting that Orange County Regional Center's board "is comprised of up to 19 unpaid, volunteer residents of Orange County – many of whom are adults serviced by RCOO and family members [sic]").

²⁵² To the best of our knowledge, DDS has only issued Letters of Noncompliance (and CAPs) to RCs in cases of clear malfeasance, such as mismanagement of funds, not in cases where RCs have simply failed to show meaningful improvement on the person-centered outcomes reported in Performance Contracts. As discussed later in this report, *see*

State is becoming more open to this possibility.²⁵³ If these efforts gain traction, they could pave the way for reforms that (if effectively implemented) could significantly enhance systemic accountability.

C. Assessing the Adequacy of Current Oversight Measures

While there is no straightforward way to ascertain whether current accountability measures are efficacious or sufficient, two important benchmarks arguably shed some light on this question. First, one can explore data on the system-wide *adequacy* of the services and supports received by Lanterman Act beneficiaries. Secondly, one can analyze available evidence regarding the *equity* of the RC system as a whole.

To assess the adequacy of the service delivery system, it is reasonable to start by asking how California's spending on I/DD services compares to that of other states. Although reliant upon somewhat outdated data, the results of this inquiry are not encouraging. In FY 2016-17 (the most recent year for which per capita figures are available as of this writing), California's per capita spending on 1915(c) Waivers for persons with I/DD was \$83.66, whereas the comparable figure for the country as a whole was \$104.41.²⁵⁴ This disparity is even clearer when one limits the comparison to Waiver program participants.²⁵⁵ At \$26,200 per enrollee, California's (state and federal) FY 2016-17 expenditures on HCBS 1915(c) Waiver services lagged considerably behind the nationwide average of \$44,200 per enrollee.²⁵⁶ Cross-state comparisons utilizing different

infra text accompanying note 426, the Governor's Budget for FY 2020-21 includes a novel proposal from DDS whereby RCs that meet an "advanced tier of performance measures and outcomes," in alignment with their respective Performance Contracts, would receive additional "incentive payments," at an estimated total cost of \$78 million. See CAL. DEP'T OF DEVELOPMENTAL SERVS., FY 2020-21 GOVERNOR'S BUDGET K-27 (2020) [hereinafter FY 2020-21 GOVERNOR'S BUDGET], https://www.dds.ca.gov/wp-content/uploads/2020/01/Budget_RCDCEstimate20202021.pdf (last visited Jan. 14, 2020).

²⁵³ *Id.*

²⁵⁴ Total Spending on 1915(c) HCBS Waiver Programs for I/DD residents in FY 2016-17 was \$3,296,300,000 in California compared to \$33,950,000,000 nationwide. MARYBETH MUSUMECI ET AL., KAISER FAMILY FOUND. & WATTS HEALTH POLICY CONSULTING, MEDICAID HOME AND COMMUNITY-BASED SERVICES ENROLLMENT AND SPENDING 13 (2019), <http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending> (last visited, Jan. 9, 2020). On July 1, 2017, the population of California was estimated at 39,399,349 compared to 325,147,121 nationwide. *Annual Estimates of Resident Population: Apr. 1 2010 to Jul. 1, 2018*, U.S. CENSUS BUREAU, POPULATION DIV., https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2018_PEPANNRES&prodType=t able (last visited Jan. 13, 2020). Dividing the former set of figures by the latter produces the result that California's per capita spending on 1915(c) Waivers for persons with I/DD was \$83.66 in FY 2016-17, while the comparable figure for the country as a whole was \$104.41.

²⁵⁵ Such comparisons may be complicated, to some extent, by the fact that California is the only state to offer an entitlement under state law to *all* residents who qualify as RC clients, see MAGER-MARDEUSZ & KOMINSKI, *supra* note 3, and is one of only a few that provides services to undocumented I/DD residents. See SHAWN FREMSTAD ET AL., KAISER COMM'N ON MEDICAID & THE UNINSURED, KAISER FAMILY FOUND., COVERING NEW AMERICANS: A REVIEW OF FEDERAL AND STATE POLICIES RELATED TO IMMIGRANTS' ELIGIBILITY AND ACCESS TO PUBLICLY FUNDED HEALTH INSURANCE 17 tbl.2 (Nov. 2004), <https://www.kff.org/wp-content/uploads/2013/01/covering-new-americans-a-review-of-federal-and-state-policies-related-to-immigrants-eligibility-and-access-to-publicly-funded-health-insurance-report.pdf> (last visited Jan. 7, 2020) (counting states as potentially offering I/DD services to undocumented immigrants as those states that are indicated as offering "Elderly & Disabled People" services at least on a limited basis and offer services to immigrants "residing under the color or law" (PRUCOLs) and/or regardless of immigration status. Applying these standards, states that potentially offer such I/DD services include CA, DC, ME, MA, NJ, NM, NY, PA, RI, WA).

²⁵⁶ MUSUMECI ET AL., *supra* note 254, at 14.

budgetary metrics tend to reach similar conclusions. For example, in 2015 (again, the most recent year for which data are available), thirty-six U.S. states spent a higher fraction of statewide personal income on disability services than did California,²⁵⁷ and while California spent \$3.50 of every \$1,000 on services for people with I/DD, the average across all 50 states was \$4.30.²⁵⁸

An alternative, and arguably more compelling, way to assess the adequacy of current oversight measures is to compare the (self-reported) experiences and satisfaction levels of consumers in California with those of consumers in other states. The NCI AIPS data, discussed earlier, reports a variety of self-reported outcomes among Medicaid beneficiaries with I/DD across the U.S.²⁵⁹ Based on AIPS data collected in 2017–18,²⁶⁰ California’s performance is unimpressive. Across the 91 performance metrics analyzed,²⁶¹ California significantly²⁶² outperformed the national average on nine metrics (10% of the total),²⁶³ including four that relate to service coordination and access.²⁶⁴ Yet California performed significantly worse than the national average on 33

²⁵⁷ DAVID BRADDOCK ET AL., *THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: 2017 14* (11th ed. 2017).

²⁵⁸ *Id.* at 14.

²⁵⁹ The AIPS report is preceded by a brief introductory section, entitled “*Message from the California Department of Developmental Services*,” which states, “This report does not compare California’s data to the data of other states. This is because California’s DDS service system is unique among states.” 2017-18 AIPS, *supra* note 56, at iii. It then lists seven factors that ostensibly make California unique: (1) the Lanterman Act; (2) laws that mandate intake, evaluation and assessment with 120 days; (3) a broad definition of eligibility; (4) statutory limitations on caseload size for certain mandated services; (5) service obligations that extend “from pre-conception to death”; (6) the autonomous functioning and governance structure of each RC; and (7) consumers’ right to “call a team meeting at any time to request a change in service.” *Id.* Even if California is in fact “unique” in these seven regards, it is unclear why comparing its average outcomes to those reported in other states, as the statute requires, is invalid or uninformative.

²⁶⁰ *Id.* at xii.

²⁶¹ In addition to demographic information about survey respondents, DDS’s report on the 2017-18 AIPS includes 116 different metrics. Of these metrics, 9 were California-specific and therefore could not be compared against a national benchmark. An additional 16 metrics could not clearly be construed as shedding light on the quality of the service delivery system. (For example, tables 45 and 46 asked respondents to detail in what industry they were currently employed. *Id.* at 54-55. A fuller description of California’s performance across the 91 metrics selected for analysis, as well as the full list of excluded metrics, is available from the authors upon request.

²⁶² The AIPS does not provide a margin of error for each component question in the survey; however, it does note that “[e]ach state is instructed to attempt to complete a minimum of 400 surveys” to guarantee “a 95% confidence level and a margin of error of +/- 5%, no matter how large the service population size.” *Id.* at 11. Given that California achieved this sample size for *each* RC, and therefore had a total sample size of 8,280, *id.* at 13, the estimates for California would be subject to considerably lower sampling error than those of other states. With these considerations in mind, we estimated that all deviations between California and the national average that were at least three percentage points in magnitude were likely to be statistically significant. Note that the distribution of California’s performance relative to the national average does not change materially even if more stringent (or less stringent) requirements for significance are imposed.

²⁶³ In addition to four metrics pertaining to service coordination and access, *see infra* note 264, California outperformed by three or more percentage points on five additional measures. *See* 2017-18 AIPS, *supra* note 56, at 53 tbl.44 (reporting that 41% of CA consumers that have a paid community job receive paid time off compared to 32% nationwide); *id.* at 73 tbl.63 (reporting that 82% of CA consumers get to go out and do the things they like to do in the community as often as they want compared to 79% nationwide); *id.* at 78 tbl.67 (reporting that 39% of CA consumers want more help to meet or keep in contact with friends compared to 42% nationwide); *id.* at 90 tbl.78 (reporting that 68% of CA consumers that attend a day program or workshop are happy with the amount of time they spend there compared to 60% nationwide); *id.* at 143 tbl.123 (reporting that 9% of CA consumers say others read their mail or e-mail without asking them compared to 12% nationwide).

²⁶⁴ *See* 2017-18 AIPS, *supra* note 56, at 107 tbl.91 (reporting that 0% of CA consumers needed additional service coordination or case management compared to 4% nationwide); *id.* at 107 tbl.91 (reporting that 1% of CA consumers needed additional respite or family support services compared to 7% nationwide); *id.* at 107 tbl.91 (reporting that 4% of CA consumers needed additional transportation services compared to 10% nationwide); *id.* at 107 tbl.91 (reporting that 6%

metrics (36% of the total),²⁶⁵ including three that relate to service coordination and access,²⁶⁶ eight relating to choice and decision making,²⁶⁷ four relating to community inclusion,²⁶⁸ and seven relating to health and wellness.²⁶⁹ For the remaining 49 metrics (54% of the total), California was within three percentage points of the national average.

of CA consumers needed additional assistance finding, maintaining, or changing jobs compared to 10% nationwide). For the purpose of this analysis, we consolidate the NCI designated categories of Service Coordination (encompassing questions relating to whether “[s]ervice coordinators are accessible, responsive, and support the person’s participation in service planning,”), *id.* at 92, and Access (encompassing questions relating to whether “[p]ublicly funded services are readily available to individuals who need and qualify for them.”), *id.* at 101.

²⁶⁵ In addition to 22 listed metrics pertaining to service coordination and access; choice and decision making, community inclusion; and health and wellness, *see infra* notes 266-269, California underperformed by three or more percentage points on eleven additional measures. *See* 2017-18 AIPS, *supra* note 56, at 48 tbl.39 (reporting that 15% of CA consumers have a paid job in the community compared to 18% nationwide); *id.* at 60 tbl.51 (reporting that 54% of CA consumers attend a day program or workshop compared to 57% nationwide); *id.* at 61 tbl.52 (reporting that 27% of CA consumers volunteer compared to 31% nationwide); *id.* at 76 tbl.65 (reporting that 73% of CA consumers have friends who are not staff or family members compared to 78% nationwide); *id.* at 77 tbl.66 (reporting that 67% of CA consumers have a best friend compared to 70% nationwide); *id.* at 89 tbl.77 (reporting that 31% of CA consumers that have a paid job in the community want to work somewhere else compared to 26% nationwide); *id.* at 91 tbl.71 (reporting that 87% of CA consumers say their services and supports help them live a good life compared to 91% nationwide); *id.* at 136 tbl.116 (reporting that 42% of CA consumers have a key to the home compared to 47% nationwide); *id.* at 138 tbl.118 (reporting that 39% of CA consumers can lock their bedroom compared to 48% nationwide); *id.* at 146 tbl.126 (reporting that 18% of CA consumers have attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to compared to 24% nationwide); *id.* at 147 tbl.127 (reporting that 28% of CA consumers have ever voted in a local, state or federal election or have chosen not to compared to 37% nationwide).

²⁶⁶ *See id.* at 94 tbl.81 (reporting that 84% of CA consumers’ case manager/service coordinator asks them what they want compared to 88% nationwide); *id.* at 95 tbl.82 (reporting that 84% of CA consumers are able to contact their case manager/service coordinator when they want to compared to 88% nationwide); *id.* at 100 tbl.87 (reporting that 76% of CA consumers were able to choose, or had some input in, the services they receive as part of their IPP compared to 79% nationwide); *see also supra* note 264 (describing our categorization of metrics as relating to service coordination and access).

²⁶⁷ 2017-18 AIPS, *supra* note 56, at 38 tbl.30 (reporting that 51% of CA consumers chose or had some input in choosing where they live *if not living in the family home* compared to 57% nationwide); *id.* at 39 tbl.31 (reporting that 37% of CA consumers chose or had some input in choosing their housemates *if not living in the family home*, or chose to live alone compared to 43% nationwide); *id.* at 40 tbl.32 (reporting that 83% of CA consumers chose or had some help in choosing their paid community job compared to 87% nationwide); *id.* at 41 tbl.33 (reporting that 47% of CA consumers chose or had some input in choosing their day program or workshop compared to 56% nationwide); *id.* at 42 tbl.34 (reporting that 59% of CA consumers chose their staff or were aware they could request to change their staff compared to 65% nationwide); *id.* at 43 tbl.35 (reporting that 82% of CA consumers decide or have help deciding their daily schedule compared to 85% nationwide); *id.* at 44 tbl.36 (reporting that 89% of CA consumers decide or have help deciding how to spend free time compared to 92% nationwide); *id.* at 45 tbl.37 (reporting that 82% of CA consumers decide or have help deciding what to buy or have set limits on what to buy with their spending money compared to 87% nationwide).

²⁶⁸ *See id.* at 65 tbl.55 (reporting that 81% of CA consumers went out on errands at least once in the past month compared to 86% nationwide); *id.* at 70 tbl.60 (reporting that 21% of CA consumers took part in a community group in the past month compared to 32% nationwide); *id.* at 71 tbl.61 (reporting that 43% of CA consumers went on vacation in the past year compared to 46% nationwide); *id.* at 72 tbl.62 (reporting that 82% of CA consumers were able to go out and do the things they like to do in the community compared to 85% nationwide).

²⁶⁹ *See id.* at 115 tbl.98 (reporting that 52% of CA consumers had an eye exam in the past year compared to 58% nationwide); *id.* at 116 tbl.99 (reporting that 50% of CA consumers had a hearing test in the past five years compared to 56% nationwide); *id.* at 117 tbl.100 (reporting that 48% of CA consumers had a Pap test in the past three years (among women 21 and older) compared to 57% nationwide); *id.* at 118 tbl.101 (reporting that 69% of CA consumers had a mammogram test in the past two years (among women age 40 and over) compared to 73% nationwide); *id.* at 119 tbl.102 (reporting that 32% of CA consumers had not had a colorectal cancer screening within the past 10 years (among people age 50 and over) compared to 16% nationwide); *id.* at 120 tbl.103 (reporting that 69% of CA consumers had a flu vaccine in the past year compared to 74% nationwide); *id.* at 132 tbl.113 (reporting that 31% of CA consumers exercise or do physical activity for arms, legs, back or chest at least once a week compared to 36% nationwide). For the purpose of this analysis we consolidate the NCI designated categories of health (encompassing questions relating to consumers’ ability to

In short, to the extent that the adequacy of current services and supports sheds light on the efficacy of systemic oversight, available data provide scant reassurance. Regardless of whether one focuses on per capita expenditures or self-reported measures of autonomy and well-being, the tepid results cast doubt on whether RC consumers are as well equipped as their counterparts in many other states to achieve their life goals. To be sure, these disparities cannot be attributed solely to deficiencies in systemic oversight. After all, it is the Legislature, not DDS, that sets DDS’s annual budget. This budget determines the maximum level of resources the system as a whole can provide, which in turn affects consumers’ autonomy and well-being in myriad ways.²⁷⁰ Yet disentangling how much of California’s lackluster performance stems from budgetary constraints, and how much can be attributed to a deficiency in systemic oversight *per se*, is no simple matter.

In light of such complexities, analyzing the *equity* of the RC system—that is, taking the level of total resources as given, and asking whether services and supports are allocated in an equitable fashion among all consumers—may be a more illuminating indicator of the adequacy of current oversight measures. Here again, available data are not reassuring.

First, many prior analyses of POS data have revealed large disparities in expenditures across different ethnic groups and regions of the state. Not only are there large differences in average expenditures *across* RCs—which are highly (negatively) correlated with the fraction of consumers in the RCs’ respective catchment areas that are Hispanic and African-American—but there are also significant demographic disparities in POS funding *within* RCs, with White children typically receiving more than their Hispanic and African-American peers.²⁷¹ These disparities were well documented by 2008²⁷² and have been confirmed repeatedly in subsequent studies,²⁷³ including a report issued a few months before the release of this report.²⁷⁴

“secure needed health services.”), *id.* at 110, and wellness (encompassing questions relating to consumers’ “are supported to maintain healthy habits.”), *id.* at 130.

²⁷⁰ See LANTERMAN PRIMER, *supra* note 5, § IV. A. (describing California’s budgeting process).

²⁷¹ PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING, *supra* note 8, at 10.

²⁷² See Charlene Harrington & Taewoon Kang, *Disparities in Service Utilization and Expenditures for Individuals with Developmental Disabilities*, 1 DISABILITY & HEALTH J. 184, 188-194 (2008) [hereinafter *Disparities in Service Utilization*]; see also CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: WITHOUT SUFFICIENT STATE FUNDING, IT CANNOT FURNISH OPTIMAL SERVICES TO DEVELOPMENTALLY DISABLED ADULTS 15 (1999), <https://www.bsa.ca.gov/pdfs/reports/99112.pdf> (last visited Jan. 16, 2019) (finding that DDS’s budget allocation methodology, which was not based on the needs of consumers within each regional center’s catchment area, was contributing to persistent geographic disparities between RCs in POS expenditures).

²⁷³ See, e.g., *Disparities in Service Utilization*, *supra* note 272, at 188-194; Charlene Harrington & Taewoon Kang, *Disparities in Service Use and Expenditures for People with Intellectual and Developmental Disabilities in California in 2005 and 2013*, 54 INTELL. & DEV. DISABILITY 1, 7-8 tbl.2 (2016); MAGER-MARDEUSZ & KOMINSKI, *supra* note 3, at 6 tbl.4 (analyzing FY 2011-12 and FY 2013-14 POS data and finding that per capita spending on White consumers in FY 2013-14 was \$17,449, compared to \$13,568 for Black consumers and \$8,083 for Latino consumers; moreover, whereas 33% of consumers were White, 49% of POS expenditures were for White consumers); PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING, *supra* note 8, at 10-12 (analyzing data for FY 2011-12 through FY 2015-16).

²⁷⁴ See PUBLIC COUNSEL, ADDRESSING FUNDING DISPARITIES, *supra* note 8 (analyzing data from FY 2011-12 through FY 2017-18).

Secondly, the survey responses from the AIPS, discussed earlier, also display significant disparities. While the data are not broken down by race or ethnicity,²⁷⁵ they do display significant heterogeneity by RC.²⁷⁶ For example, while 88% of surveyed consumers from Tri-Counties Regional Center had at least some input in their IPP, the corresponding percentages for Alta California and Inland Regional Centers were just 66%.²⁷⁷ Similarly, whereas 90% of respondents from Tri-Counties Regional Center reported that their “[c]ase manager/service coordinator asks [them] what s/he wants,” just 72% of respondents from San Diego Regional Center gave the same response.²⁷⁸

Overall, then, our survey of available data on the adequacy and equity of California’s service delivery system justifies concerns about deficiencies in systemic oversight. To be sure, robust oversight *per se* cannot solve core structural problems. Even with perfect oversight, a steep fall in legislative appropriations would compromise the RC system’s ability to deliver adequate services to all consumers. Yet the persistence of sizable service disparities, despite the extensive evidence documenting their existence, suggests that DDS is not as well equipped as it could be to ensure that RCs “provide services and supports to consumers in compliance with the principles of [the Lanterman Act].”²⁷⁹

²⁷⁵ See 2017-18 AIPS, *supra* note 56. It is worth noting that while the report made available on the DDS website does not allow readers to view the survey responses broken by race and ethnicity, this functionality is available on the independent NCI website (although the data have not yet been updated to reflect the results of the 2017-18 AIPS, the most recent AIPS conducted in California). See *NCI Charts (2016-17)*, *supra* note 60.

²⁷⁶ See 2017-18 AIPS, *supra* note 56.

²⁷⁷ *Id.* at 100 tbl.87.

²⁷⁸ *Id.* at 94 tbl.81.

²⁷⁹ CAL. WELF. & INST. CODE § 4434(a) (Deering, LEXIS through 2019 Sess.); see also CAL. WELF. & INST. CODE § 4629(b) (Deering, LEXIS through 2019 Sess.) (“[RC] contracts shall include a provision requiring each regional center to render services in accordance with applicable provision of state laws and regulations”).

VI. Suggested Reforms

As noted at the outset, the primary purpose of this report is to assess the RC system’s current levels of transparency and oversight, and propose reforms that could improve the lives of the Lanterman Act’s beneficiaries. Historically, many of the strongest calls for systemic reform have come during times of fiscal crisis.²⁸⁰ Yet when the state is in a reduced funding environment, it is difficult for state officials to vet and explore potential reforms in a thoughtful manner that incorporates as much information as possible about each reform’s likely risks and benefits. We believe that structural and systemic changes are best undertaken in times of relative fiscal stability, such as the one the state is experiencing at the time of this writing.

To encourage the State to exploit this window of opportunity, this section proposes a number of systemic reforms that are designed to improve transparency, oversight and accountability. We are not the first to propose many of these ideas, and many of them are open to critique on empirical, normative, or theoretical grounds. Importantly, our goal is not to describe (or defend) each proposal in exhaustive detail. Rather, we err on the side of over-inclusion in summarizing a wide range of potentially promising reforms that we believe warrant, at the very least, thoughtful consideration by the I/DD policy-making community.

We divide these proposals into three categories: reforms designed to enhance systemic transparency; reforms designed to strengthen consumer and family self-advocacy; and reforms designed to strengthen public oversight and accountability. These categorizations are somewhat arbitrary, since as noted previously, many transparency-enhancing reforms promote accountability (and vice versa). Indeed, two of the measures recommended to promote public accountability—publishing all CAPs, and disclosing detailed data on SIRs (special incident reports) and NCI survey responses—take the form of transparency measures. Nevertheless, the overall thrust of the first category is to increase the breadth and granularity of information provided to the public, whereas the second and third categories focus primarily on mechanisms

²⁸⁰ Over the last several decades, the State has faced two major budgetary shortfalls, first in 1996-98 and subsequently in 2011-13, as evidenced by diminished DDS spending per consumer during those periods, *see* LANTERMAN PRIMER, *supra* note 5, § IV. B. fig.6. During the first time period, there were efforts to systemically alleviate disparities in RC expenditures and improve investigations of alleged subpar care. *See, e.g.*, CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: REGIONAL CENTER BUDGETS ARE NOT BASED ON NEEDS, AND DEPARTMENTAL OVERSIGHT COULD BE IMPROVED S-3 (April 1998), <https://www.bsa.ca.gov/pdfs/reports/97024.pdf> (last visited Jan. 9, 2020) (recommending the analysis of “causes of expenditure variances and trends to determine if variances are the result of disparate treatment in purchased services... [and] to revise the budget and allocations accordingly”); *see also* CITYGATE INDEPENDENT EVALUATION, *supra* note 8, at IV-13-IV-14 (recommending protocols and practices RCs should adopt to ensure appropriate care, investigate disparities and subpar care, and remedy such conditions). During the second time period (the Great Recession), there were efforts to systemically enhance statewide quality management systems and once again alleviate disparities in RC expenditures, *see, e.g.*, ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 6 (“With the successful quality management system from the Agnews Developmental Center closure as a model, Californians now have an unparalleled opportunity to design a Consolidated Quality Management System for monitoring and improving... statewide services”); *see also* *Ensuring Fair & Equal Access to Regional Center Services for Autism Spectrum Disorder Before the Special Committee On Autism & Related Disorders*, 2012 Leg., 11 (Cal. 2012) (statement of Terri Delgadillo, Dir., Cal. Dep’t of Developmental Servs.) [hereinafter Delgadillo], <http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/Regional%20Services%20hearing%20-full%20transcript.pdf> (last visited Jan. 12, 2020) (explaining how the budget formulary based on historical expenditures, as opposed to variance in RC catchment area demographics, has driven disparities in RC funding per consumer).

to empower consumers or other stakeholders to hold individual providers, RCs, and the system as a whole accountable for their performance.

A. Reforms to Enhance Systemic Transparency

(1) Increase Compliance with Current Disclosure Requirements

As discussed in section IV, above, there is considerable room for improvement in DDS's and RCs' respective levels of compliance with existing transparency requirements. The public's limited access to mandated disclosures makes it more difficult for key stakeholders, including the Legislature, to meaningfully evaluate whether the RC system is achieving its primary statutory objectives.

Interested stakeholders and policymakers should explore ways to incentivize DDS and RCs to comply more fully with existing transparency requirements. With this objective in mind, we have launched an interactive search tool, called the "Lanternman Transparency Tracker," on the SIDLAPP website. The tool enables stakeholders to select particular reporting entities (such as DDS and/or specific RCs); select specific statutory provisions that mandate web-based disclosures; and observe at a glance whether the selected entit(ies) are complying fully, partially, or not at all with the selected provision(s). The tool is available at <https://law.stanford.edu/sidlapp/lanterman-transparency-tracker/>. As of this writing, our intent is to update it annually.

For the reasons discussed earlier,²⁸¹ the inaccessibility of most OAH decisions is an especially formidable barrier to systemic oversight and accountability. To rectify the current state of affairs, in which only about 64 percent of all decisions are publicly available,²⁸² the legislature could: (a) require DDS, or the OAH as its contractor, to post online all fair hearing decisions within 30 days of their issuance; (b) set a deadline whereby all fair hearing decisions from the past ten years must be posted; and (c) augment the OAH Search Tool's existing functionality, which only permits users to search for decisions by keyword and case number, to allow searches by RC, year of issuance, and the issue(s) at stake in the hearing.²⁸³

(2) Make All Data Available in Machine-Readable Format

The provision of information in non-machine-readable formats²⁸⁴ is a well-known and extensively documented barrier to both transparency and oversight. During the Obama Administration, the U.S. federal government introduced an Open Data Policy designed to increase transparency in the executive branch by mandating that newly generated government data be made available in machine-readable format.²⁸⁵ Following the passage of the OPEN

²⁸¹ See discussion *supra* § IV. C.

²⁸² See discussion *supra* pp. 29-31 (describing the methodology for determining the online availability of OAH fair hearing decisions).

²⁸³ See *supra* note 169 and accompanying text (describing the OAH Search Tool).

²⁸⁴ See *supra* note 57 (defining machine-readability).

²⁸⁵ Exec. Order No. 13642, 78 Fed. Reg. 28,111 (May 9, 2013); see also *About Data.gov*, DATA.GOV, <https://www.data.gov/about> (last visited Jan. 9, 2020) ("Under the terms of the 2013 Federal Open Data Policy, newly-

Government Data Act on January 14th, 2019,²⁸⁶ these provisions were permanently enshrined in federal law.²⁸⁷ As an article posted on Data.gov (the federal repository of open, machine-readable data) noted, “[t]he degree to which information is machine readable . . . is critical to meeting priorities such as open government and open data, and directly influences, and in many cases limits, the uses citizens and other interested parties can make of that information.”²⁸⁸

The latter concerns apply no less to California’s RC system than to U.S. government agencies. Yet remarkably, hardly any of the quantitative information produced by DDS and individual RCs is currently provided to the public in machine-readable format. Instead, the information is typically presented in the form of PDF summary tables, or graphical images (such as graphs and charts) for which the underlying data are not made available. The absence of readily-accessible, machine-readable data significantly diminishes the level of transparency throughout the RC system.

S.B. 81, which took effect on June 27, 2019,²⁸⁹ was the first statute requiring any Lanterman Act-related information to be provided in machine-readable format. First, the statute required the information on DDS’s Performance Dashboard to be posted in machine-readable format.²⁹⁰ Secondly, S.B. 81 amended the WIC to require RCs to publish RC-specific NCI survey results on their respective websites in machine-readable format.²⁹¹

Although the latter two provisions were an important first step, their scope is relatively narrow, and as mentioned above, the vast majority of mandated public disclosures remain in formats that are not machine-readable.²⁹² In the summer of 2019, legislation was introduced in the California

generated government data are required to be made available in open, machine-readable formats, while continuing to ensure privacy and security.”).

²⁸⁶ Foundations for Evidence-Based Policymaking Act of 2018, Pub. L. No. 115-435, tit. II, 132 Stat. 5529, 5534-5543 (2019) (enacting the OPEN Government Data Act).

²⁸⁷ Hyon Kim, *Data.gov at Ten and the OPEN Government Data Act*, DATA.GOV (May 31, 2019), <https://www.data.gov/meta/data-gov-at-ten-and-the-open-government-data-act/> (last visited Jan. 3, 2020) (“The OPEN Government Data Act makes Data.gov a requirement in statute, rather than a policy. It requires federal agencies to publish their information online as open data, using standardized, machine-readable data formats.”).

²⁸⁸ HENDLER & PARDO, *supra* note 57.

²⁸⁹ Act of Jun. 27, 2019, ch. 28, 2019 Cal. Legis. Serv. 1270 (West).

²⁹⁰ Act of Jun. 27, 2019 sec. 11, § 4572 (updating CAL. WELF. & INST. CODE § 4572 to require DDS to post the annual Performance Dashboard in machine-readable format). The Performance Dashboard is to include: quality and access measures, HCBS Waiver compliance measures, trends in integrated employment, 4731 Complaint rates, and fair hearing rates. CAL. WELF. & INST. CODE § 4572(a)-(e) (Deering, LEXIS through 2019 Sess.). Following S.B. 81, RCs are required to publish their own Performance Dashboards as well, although it is not immediately clear from the statutory language whether or not the machine-readability requirement likewise applies. Act of Jun. 27, 2019 sec. 11, § 4572 (revising CAL. WELF. & INST. CODE § 4572 to read: “The [DDS] dashboard shall be published . . . in machine-readable format. Each regional center shall publish its own dashboard”). There are nine additional RC disclosure requirements which could potentially be in machine-readable format, *see supra* Table 2; predate the passage of S.B. 81; are not components of the newly required RC Performance Dashboards; and therefore are still not required to be in machine-readable format.

²⁹¹ Act of Jun. 27, 2019 sec. 10, § 4571 (h)(1)-(2) (requiring RCs to collect and annually report, in machine-readable format, the results of the quality assurance instrument). While the statute references only reports relating to a “quality assurance instrument,” DDS and RCs have chosen to comply with this requirement by reporting the results of the NCI surveys, albeit in a non-machine-readable format. *See supra* note 34 and accompanying text (discussing the quality assurance instrument, and DDS’s choice to fulfill this requirement through the NCI Surveys).

²⁹² As of this writing, DDS provides only 11% of its numerical disclosures in machine-readable format, *supra* Table 1, while RCs provide, on average, only 1.1% of their numerical disclosures in machine-readable format, *supra* Table 2. *See supra* notes 57, 68, 73-74 and accompanying text (providing an in-depth definition for machine-readability as well as the methodology used for calculating these percentages). Providing data in machine-readable format likewise does not seem

Senate that would have required DDS to provide all of its numerical data in machine-readable format, but the measure was held in the Senate Appropriations Committee.²⁹³ Just a few weeks before the completion of this report, however, a DDS official indicated that a separate state law, primarily aimed at increasing the accessibility of public information to stakeholders with disabilities, had been interpreted by DDS to require the machine-readability of DDS data, and that the Department was working to comply with the latter provision.²⁹⁴ If DDS follows through on this pledge, the most significant remaining barrier to machine-readability would be the ubiquity of PDF and other non-machine-readable formats among the documents posted by RCs on their internet websites.

To permanently eliminate non-machine-readability as a barrier to system-wide transparency, the Legislature could require *all* quantitative information that DDS and RCs make publicly available—whether on their respective websites, upon request, or in response to CPRA requests—to be provided in machine-readable formats.

(3) Standardize Regional Centers' Web-Based Disclosures

There is remarkably little consistency in the layout, content, presentation, and location of mandated disclosures posted on different RCs' websites. Even materials that are similar in content and format are often stored in different locations under different headings. For example, Far Northern Regional Center posts information on annual independent audits on its Transparency Portal page under the heading "Annual Independent Audits,"²⁹⁵ whereas Valley Mountain Regional Center posts the same information on its Public Disclosures page under the heading "S.B. 74 and Other Disclosures."²⁹⁶ Such inconsistencies make it difficult and time-consuming for stakeholders to access vital information or make comparisons across different RCs.

Shortly before the completion of this report, modest progress was made toward increasing the consistency of RCs' mandated disclosures. In addition to the provisions noted earlier regarding

to be DDS's standard practice when responding to CPRA requests. For example, even when explicitly asked for 4731 Complaints data in Excel format, *see* Request to Inspect Public Record from Alison Morantz to Cal. Dep't of Developmental Servs. (Nov. 18, 2018), *supra* note 182, DDS initially sent the data in protected PDF format. *See* E-mail from Alexandra Sanders to Alison Morantz (Nov. 26, 2019), *supra* note 156. DDS did, however, provide the data in Excel format after an additional follow-up. *See* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158.

²⁹³ *See* S.B. 683, 2019 Leg., Reg. Sess. (Ca. 2019).

²⁹⁴ Initial meeting of DDS Disparities Data Focus Discussion Group, Dec. 19, 2019 (in which Vicky Lovell, Ph.D., Chief of DDS's Research, Audits and Evaluation Branch, distributed a document to attendees entitled "Accessibility Requirements for Posting Data to DDS' Website: Statute and Examples," listing the first requirement as "Making Data Machine-Readable," and stated that machine-readability was required by the Web Content Accessibility Guidelines (WCAG) 2.1, with which all state agencies were required to comply following the passage of A.B. 434); *see also* Act of Oct. 14, 2017, ch. 780, 2017 Cal. Legis. Serv. 5956 (codified as amended at CAL. GOV'T CODE § 11546.7 (2019)) (requiring that before July, 1 2019, and biennially thereafter, all state agencies certify that their websites are in compliance WCAG 2.0, or a subsequent version, at a minimum Level AA success criteria).

²⁹⁵ *Transparency Portal – Annual Independent Audits*, FAR NORTHERN REG'L CTR., <http://www.farnorthernrc.org/transparency-portal/> (last visited Jan. 7, 2020).

²⁹⁶ *Public Disclosures – S.B.74 and Other Disclosures*, VALLEY MOUNTAIN REG'L CTR., <https://www.vmmc.net/public-disclosures/> (last visited Jan. 7, 2020).

machine-readability, S.B. 81 required RCs to create their own Performance Dashboards²⁹⁷ (similar to the one that DDS has been required to publish since 2016),²⁹⁸ on which several indicators of the quality of community-based services are to be displayed.²⁹⁹ Although the passage of S.B. 81 is an important first step, it does not affect other transparency-related provisions related to RCs. Thus even if all RCs complied with its provisions, there would still be a great deal of inconsistency in the way that RCs present mandatory disclosures to the public.

Although legislation introduced in the summer of 2019, discussed earlier in the context of machine-readability, would also have required DDS to develop “transparency guidelines for the disclosure of all information that [RCs] are required to post on their websites,” the measure was held in the Senate Appropriations committee.³⁰⁰

To promote systemic transparency, the Legislature might consider adding language to the Lanterman Act requiring DDS to promote substantial uniformity in the content, names, headings, formatting, and locations of all web-based disclosures made by RCs. Because DDS is already authorized to adopt regulations prescribing “a uniform reporting system” whenever doing so would provide “a larger degree of uniformity and consistency” in RCs’ administrative practices,³⁰¹ such language would, in effect, simply nudge DDS to exercise power it already possesses.

(4) Improve Classifications of Ethnicity & Residence Type

DDS provides a variety of information summarizing the characteristics of the individuals served by the RC system. Since 1998, for example, it has published Fact Books on a (nearly) annual basis that “present[] pertinent data about the individuals served by the Department of Developmental Services (DDS) and include[] an overview of services and trends in California.”³⁰² For most purposes, DDS breaks down data on actual and potential RC consumers into five different categories that depend on residence type, age, and eligibility status:

1. Applicants for regional center services whose eligibility is determined through an intake and assessment process (status code 0);
2. Children under 3 years of age who qualify for Early Start services (status code 1);

²⁹⁷ Act of Jun. 27, 2019, ch. 28, sec. 11 § 4572, 2019 Cal. Legis. Serv. 1270, 1285 (West) (amending CAL. WELF. & INST. CODE § 4572 to require RCs to publish their own Performance Dashboards).

²⁹⁸ Act of Jun. 27, 2016, ch. 26, § 8, 2016 Cal. Legis. Serv. 937, 946-947 (codified as amended at CAL. WELF. & INST. CODE § 4572 (2019)) (requiring DDS to publish a Performance Dashboard).

²⁹⁹ The Performance Dashboard is to include: quality and access measures, HCBS Waiver compliance measures, trends in integrated employment, 4731 Complaint rates, and fair hearing rates. CAL. WELF. & INST. CODE § 4572(a)-(e) (Deering, LEXIS through 2019 Sess.).

³⁰⁰ See S.B. 683, 2019 Leg., Reg. Sess. (Ca. 2019).

³⁰¹ CAL. WELF. & INST. CODE § 4631(a) (Deering, LEXIS through 2019 Sess.) (“In order to provide to the greatest extent practicable a larger degree of uniformity and consistency in the services, funding, and administrative practices of regional centers throughout the state, the State Department of Developmental Services shall, in consultation with the regional centers, adopt regulations prescribing a uniform accounting system, a uniform budgeting and encumbrancing system, a systematic approach to administrative practices and procedures, and a uniform reporting system.”).

³⁰² CAL. DEP’T OF DEVELOPMENTAL SERVS., FACT BOOK: FISCAL YEAR 2017-18 2 (16th ed. 2019) [hereinafter FY 2017-18 FACTBOOK],

https://www.dds.ca.gov/wp-content/uploads/2019/11/DDS_FactBook_2019.pdf (last visited Jan. 10, 2020).

3. “Active” consumers, defined as “people with a diagnosed developmental disability served in the community rather than a developmental center” (status code 2);
4. People with I/DD served in developmental centers (status code 8); and
5. Children under three years of age with a genetic predisposition to develop I/DD who were eligible for prevention services prior to 2012 (status code P).³⁰³

Meanwhile, DDS breaks down consumers into five ethnic groups: White, Hispanic, Black/African-American, Asian, and Other.³⁰⁴ “Other” is the third-largest ethnic group (after White and Hispanic), comprising 13.2% of all consumers in January of 2018.³⁰⁵

DDS’s reliance on these two classification schemes obscures important, system-wide characteristics of RC consumers. First, the definition of “active” (status 2) consumers as “people with a diagnosed developmental disability served in the community rather than a developmental center” is highly misleading and aligns poorly with the Final Settings Rule.³⁰⁶ The problem is that the *only* groups excluded from Status 2 are individuals residing in developmental centers, and those under 3 years of age.³⁰⁷ The “active” consumer category thus includes individuals living in other environments that are extremely restrictive, such as jails, prisons, and Institutions for Mental Disease.³⁰⁸ The latter institutional settings are the very antithesis of the home- and community-based settings upon which the receipt of federal matching funds is conditioned.³⁰⁹

The second problem with DDS’s current demographic classifications is that the “Other” category is ill defined and difficult to track. The Fact Book defines this group as “[i]nclud[ing] multiple ethnicities.”³¹⁰ Yet it is unclear which particular combinations of ethnicities the category comprises (and their relative frequencies); whether the category includes individuals who belong to a single, uncommon ethnic group not listed in the table; and whether the category includes individuals who decline to state any ethnicity at all. If many consumers classified as “Other” belong to multiple ethnic/language minority groups that receive lower POS (on average) than White consumers, then the current ethnic classification scheme may *understate* the true magnitude of racial and ethnic disparities across the RC system. (For example, if a sizable share of consumers classified as “Other” are partly Hispanic and receive very low POS, the exclusion

³⁰³ *Id.* at 9. The Prevention Program (whose enrollees were designated as status code P) was ended on September 30, 2012; therefore, for the purposes of the statistics presented in the fact book (unless specifically noted otherwise) the program’s enrollees are included in the counts and percentages for Early Start Services enrollees (status code 1). *Id.* at 9.

³⁰⁴ *Id.* at 14.

³⁰⁵ *Id.* at 13 tbl.4. It is unclear whether the totals presented in the table include all consumers or only “active” consumers, although the notes seem to suggest that the only excluded group is those with is status code 0 (receiving intake and assessment).

³⁰⁶ See FEDERAL LANTERMAN FUNDING REPORT, *supra* note 5, § V. B. (noting that the Centers for Medicare and Medicaid Services has recently adopted a Final Settings Rule that will more clearly define what qualifies as a Home and Community-Based Setting).

³⁰⁷ E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep’t of Developmental Servs., to Alison Morantz, Dir. of SIDDLAPP, Stanford Law School (Sept. 12, 2018) (“With respect to the Status 2 terminology, I am told that it is an identifier of all Lanterman eligible consumers (typically above the age of 2) that do not reside in a DC. Those are the only qualifiers for Status 2.”).

³⁰⁸ See *id.*; see Letter from Stephen W. Mayberg, Dir., Cal. Dep’t of Health Servs., Mental Health Div., to Local Mental Health Dirs. et al. 2 (Feb. 1, 2010), https://www.dhcs.ca.gov/services/MH/Documents/ProviderFile/Ltr_10_02.pdf (last visited Feb. 11, 2019) (defining Institutions for Mental Disease).

³⁰⁹ See FEDERAL LANTERMAN FUNDING REPORT, *supra* note 5, § IV.

³¹⁰ FY 2017-18 FACTBOOK, *supra* note 302, at 14.

of these individuals from the “Hispanic” category could bias the comparison of White versus Hispanic consumers.)

The solutions to both of these problems are straightforward. To provide a more accurate portrait of the distribution of consumers by residence type, DDS should use a category comprising *only* consumers who are truly “served in the community,” and thus (at least potentially)³¹¹ eligible for HCBS funding. In addition, DDS should provide information separately on individuals who reside in settings that are just as (or even more) restrictive than developmental centers, such as jails, prisons, and Institutions for Mental Disease. Meanwhile, to eliminate the ambiguity surrounding the “Other” group, DDS should disaggregate this category in such a way that stakeholders can differentiate between distinct groups of multi-ethnic consumers; consumers who report uncommon races/ethnicities; and consumers who report no race/ethnicity at all.

(5) Require Regional Centers to Report Intake & Assessment Data

WIC section 4640(b) states that “[i]n order to ensure uniformity in the application of the definition of developmental disability contained [division 4.5 of the WIC], the Director of Developmental Services shall, by March 1, 1977, issue regulations that delineate, by diagnostic category and degree of disability, those persons who are eligible for services and supports by regional centers.”³¹² Yet as a practical matter, it is difficult stakeholders (or even DDS) to assess whether different RCs are, in fact, interpreting and applying the Lanterman Act’s eligibility criteria in a uniform manner. Although DDS reports annual counts of applicants for RC services who are being assessed for eligibility,³¹³ these data are not broken down by RC. It is likewise unclear how far an individual must advance in the process in order to be included in these counts. Nor is information available on how many individuals in each RC complete each stage of the intake and assessment process.

As a first step toward exploring whether RCs are applying eligibility criteria in a uniform manner—and consequently, whether individuals with I/DD in some regions of the state are more likely to be served by the RC system than others—the Legislature could require each RC to compile and report information how many eligibility inquiries it receives on a monthly (or annual) basis; what these individuals are told regarding the intake and assessment process; how many individuals who make inquiries are scheduled for assessments; and how many of those who undergo assessments are ultimately deemed eligible for services.

(6) Make Regional Centers Subject to the California Public Records Act

RCs are, in effect, quasi-governmental actors who carry out governmental functions with state and federal funds. Yet as private nonprofit corporations, they have traditionally been considered

³¹¹ Certification of community residence does not lead to automatic enrollment of consumers into the HCBS Waiver; rather, eligibility for the HCBS Waiver in California requires the fulfillment of several other requirements including enrollment in full-scope federally matched Medi-Cal, receipt of at least one eligible purchase of service, and fulfillment of level of care requirements, *see* FEDERAL LANTERMAN FUNDING REPORT, *supra* note 5, § IV.

³¹² CAL. WELF. & INST. CODE § 4640(b) (Deering, LEXIS through 2019 Sess.) (emphasis added).

³¹³ *See* FY 2017-18 FACTBOOK, *supra* note 302.

exempt from the California Public Records Act (CPRA), the state’s premier transparency-promoting statute. The inability of stakeholders to obtain any information from RCs that is not covered by a statutory disclosure provision is a significant barrier to systemic transparency. For example, little information is available on RCs’ operational expenditures besides the relatively scant information included on mandatory tax filings,³¹⁴ and the information on compensation levels and administrative expenses required by WIC sections 4629.5(b)(3), 4629.5(b)(13), and 4629.5(b)(15), respectively.³¹⁵

On two occasions, legal authorities have considered the argument that RCs should be treated like government agencies since they carry out governmental functions, although neither case involved CPRA. In 1991, stakeholders requested a regulatory determination from the Office of Administrative Law (OAL) that Far Northern Regional Center’s policies regarding vendorization violated administrative law. The requesters argued that as an agent of DDS, the RC should follow procedures for the adoption of administrative regulations under the Administrative Procedure Act. OAL rejected the argument on the ground that, based on the language of the Lanterman Act and its subsequent interpretation by the California Supreme Court,³¹⁶ DDS did not have a “right to control” the regional center, and therefore the RC could not be considered DDS’s agent.³¹⁷ Yet in recent years, state courts (and the California Legislature) have significantly expanded the circumstances in which private actors can be considered agents of a principal in other contexts, casting doubt on the continuing relevance of the traditional “right to control” test.³¹⁸

A federal case decided in 2008, although again not directly implicating CPRA, lends credence to the idea that RCs may be considered agencies or instrumentalities of the State. In *Knight v. Standard Insurance Company*, an employee of Far Northern Regional Center argued in U.S. district court that the RC was an “agency of instrumentality” of the State, and therefore, her long-term disability plan fell under the “governmental plan” exception to the Employee Retirement Income Security Act of 1974 [ERISA].³¹⁹ After applying a multi-factor test drawn from an Internal Revenue Service ruling, the *Knight* court held that “it is plausible that Far Northern [Regional Center] constitutes an agency or instrumentality of the state, thereby falling within the

³¹⁴ As 501(c)(3) entities, RCs are required to file with IRS basic financial information, including total revenues and expenses, funding sources categories, and personnel information. *See, e.g., Kern Regional Center*, GUIDESTAR, <https://www.guidestar.org/profile/23-7115846> (last visited Jan. 7, 2020) (providing 501(c)(3) IRS disclosures from Kern Regional Center).

³¹⁵ *See* CAL WELF. & INST. CODE § 4629.5(b)(13), (15) (Deering, LEXIS through 2019 Sess.) (requiring RCs to publish on their internet website reports pursuant to section 4639.5, which are to include complete “salary schedule[s]” and information on “all prior fiscal year expenditures . . . for administrative services”); *id.* WELF. & INST. CODE § 4629.5(b)(15) (LEXIS) (requiring RCs to disclose on their websites “[t]he salaries, wages, and employee benefits for all managerial positions for which the primary purpose is the administrative management of the regional center, including, but not limited to, directors and chief executive officers”).

³¹⁶ *See* *Ass’n for Retarded Citizens v. Cal. Dep’t of Developmental Servs.*, 38 Cal. 3d 384, 390-1 (1985); *see also* LANTERMAN ENTITLEMENT REPORT, *supra* note 5, § VI.

³¹⁷ Determination Decision, Cal. Reg. Notice Register 91. No. 27-Z 896, 899 (OAL 1991).

³¹⁸ *See* *Dynamex Operations W. v. Superior Court*, 416 P.3d 903, 916-917 (Cal. 2018) (establishing the “ABC test” which specifies that a business can only contract with a worker as an independent contractor if the work performed a) is under the worker’s control and not that of the business, b) is not part of the company’s core business, and c) is part of the worker’s independent profession). This decision has subsequently been codified into state law by the passage of California Assembly Bill 5 on September 18, 2019. Act of Sept. 18, 2019, ch. 296, 2019 Cal. Legis. Serv. 2893 (amending scattered sections of the CAL. UNEMP. INS. CODE and CAL. LAB. CODE).

³¹⁹ *Knight v. Std. Ins. Co.*, No. Civ. 07-1691, 2008 U.S. Dist. LEXIS 8742, at *15 (E.D. Cal. Feb. 5, 2008).

governmental exception to ERISA preemption,” and ordered additional discovery.³²⁰ The logic of the *Knight* opinion, in short, seemed to leave the door open for an affirmative argument to be made.

Moreover, a 2002 opinion issued by the California Attorney General, involving the applicability of CPRA to a private, nonprofit corporation formed to provide educational programming on a cable television channel, likewise suggests that RCs may be covered by CPRA.³²¹ The Attorney General opined that because the City Council delegated the authority to operate the channel to the nonprofit company, the latter’s board of directors constituted a “legislative body” of a local agency under the pertinent section of the Government Code, and the nonprofit therefore constituted a “local public agency” under CPRA.³²²

Given the dramatic expansion of circumstances in which entities who act at the behest of, and are financially dependent upon, principals are treated as agents under state law—and the potential benefits of including RCs within the ambit of CPRA—the OAL could draw on the logic of *Knight* and the 2002 Attorney General Opinion to overturn its prior determination and hold that RCs are, in fact, “local public agencies” covered by CPRA. To ensure that such an interpretation was viewed as consistent with legislative intent, CPRA could be amended to explicitly define RCs as “public agencies.”³²³

(7) Create a High-Performance I/DD Database

Tracking detailed information on each RC consumer is no simple task, in part because the manner in which DDS records data on Lanterman Act beneficiaries has evolved in piecemeal fashion since the Act’s passage. In the 1970s, the introduction of the Client Development

³²⁰ *Id.* at *15. The *Knight* court found that at least six factors analyzed supported the regional center’s status as an agency or instrumentality of the State, and thus that the argument in favor of granting the plaintiff’s claim for long-term disability benefits was sufficiently plausible to warrant further discovery. *Id.* at *15.

³²¹ 85 Op. Cal. Att’y Gen. 55, 59 (2002).

³²² *Id.* at 57-58; *see also* CAL. GOV’T CODE § 6252(d) (Deering, LEXIS through 2019 Sess.) (noting that public agency means any state or local agency); CAL. GOV’T CODE § 54952(c)-(d) (Deering, LEXIS through 2019 Sess.) (defining a legislative body as “multimember body that governs a private corporation...that is created by the elected legislative body in order to exercise authority that may lawfully be delegated by the elected governing body...[or] the lessee of any hospital...where the lessee exercises any material authority of a legislative body of a local agency delegated to it by that legislative body”).

³²³ For example, the legislature might add a provision to Cal. Government Code section 6252(d) stating, “Notwithstanding paragraph (1) or any other law, for the purposes of this chapter, a ‘public agency’ also includes a regional center pursuant to the Lanterman Developmental Disabilities Act (Division 4.5 of the California Welfare and Institutions Code, commencing with section 4500).” Such a provision could be modeled on Cal. Government Code section 6252(f)(2), which defines the term “state agency” to include the State Bar of California. GOV’T CODE § 6252(f)(2) (LEXIS). Because some of the information collected by RCs contains personally identifying information protected by the Health Insurance Portability and Accountability Act (HIPAA) and other privacy laws, *see* 42 U.S.C § 201 (West, Westlaw through Pub. L. No. 116-91), it would likely be prudent to add an additional provision aligning the scope of mandated disclosures with state and federal privacy protections. In 2010, an Assembly Bill was introduced that would have amended the definition of “local agency” under section 6252(a) to subject RCs to CPRA, but the bill did not pass. A.B. 2220, 2010 Leg., Reg. Sess. (Ca. 2010). Interestingly, the committee reports on the bill expressed concern that the bill’s passage would “open the possibility for numerous private, nonprofit agencies to be subject to [CPRA],” *see Bill Analysis from Hearing on A.B. 2220 Before Assembly Comm. On Appropriations*, 2010 Leg., Reg. Sess. (Cal. 2010) (commenting on the “disconcerting precedent” that such legislation could set); however, in reality, only a small portion of private, nonprofit agencies would even arguably qualify as “legislative bodies” under the reasoning of the 2002 Attorney General Opinion, *see supra* notes 321-322 and accompanying text.

Evaluation Report (CDER) to track data on individual consumers was a significant innovation that improved oversight and accountability.³²⁴ In the decades that followed, DDS gradually updated the CDER system by computerizing it; adding additional fields on health, intellectual disability and medication;³²⁵ and adding information on skills, challenges, and outcomes of services.³²⁶

Ultimately, DDS’s data system came to encompass three different databases, whose fields can be interlinked through the use of a unique client identifier. In addition to CDER (which in its current form also contains a few self-reported indicia of support adequacy and well-being), the system comprises a *Client Master File* with a wide range of basic information such as name, address, demographic characteristics, family history and contacts, living arrangement, and current/former RC affiliation(s); and a *Claims File* listing the service (sub-)code, service date, vendor code, and total amount billed for each claim.³²⁷

Yet in recent decades, the shortcomings of the current system—in which data are stored in three separate databases with overlapping fields,³²⁸ and lack information on many policy-relevant outcomes³²⁹—have become increasingly apparent. As early as 2001, DDS recognized that its “non-integrated [computing] systems environment results in data redundancy, data duplication and a lack of data integrity.”³³⁰ In an effort to address this problem, DDS contracted for the development of a new, integrated data storage system called the California Developmental Disabilities Information System (CADDIS), which was intended to “manage all consumer, quality assurance and fiscal data in one system, and make information for quality assurance and other reporting easily accessible.”³³¹ Yet the project was riddled with implementation problems and five years (and \$10 million) later, it was abandoned.³³²

³²⁴ ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 8.

³²⁵ *Id.* at 9.

³²⁶ *Id.* at 10.

³²⁷ See E-mail from Paul Choate, Appeals, Complaints & Projects, Cal. Dep’t of Developmental Servs., to Julia Bodson, Research Fellow, Stanford Law School (Jan. 18, 2019) (on file with authors) (providing, in the form of an excel spreadsheet attachment, descriptions of the fields used by each of the three databases). Note that the *Claims File* also includes a handful of other fields used for accounting or internal recordkeeping.

³²⁸ For example, a number of fields—such as Initial Interview Data, Case Manager Code, Living Arrangement, IPP Frequency, Ethnicity, and Legal Status—are included in both the CDER and the *Client Master File*. *Id.*

³²⁹ The *Claims File*, for example, specifies only the type and total cost of each service (along with the vendor number, date, and billing-related fields); it does not capture the price per unit or quantity (e.g., hours) received. *Id.* Thus comparing the *quantity* (as opposed to total cost) of services received among different groups of consumers requires considerable extrapolation and is likely to be measured with error, especially for services with negotiated rates. Moreover, none of the three files contain any information on other key outcome variables, such as how much support (if any) the consumer is obtaining through generic resources (including, for example, In-Home Support Services and public school districts); whether the IPP has authorized a service that the consumer is not receiving because no suitable vendor can be found; and, for consumers earning wage income, the sector and occupation in which they are employed. *Id.*

³³⁰ CAL. DEP’T OF DEVELOPMENTAL SERVS., REQUEST FOR PROPOSALS FOR THE CALIFORNIA DEVELOPMENTAL DISABILITIES INFORMATION SYSTEM (CADDIS) PROJECT I-2 (2001), <http://www.atwebo.com/RFP%20CADISS.pdf> (last visited Jan. 7, 2020).

³³¹ ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 13.

³³² LITTLE HOOVER COMMISSION, A NEW LEGACY SYSTEM: USING TECHNOLOGY TO DRIVE PERFORMANCE 3 (November 2008), <http://www.lhc.ca.gov/sites/lhc.ca.gov/files/Reports/193/Report193.pdf> (last visited Jan. 7, 2020) (noting that CADDIS project was cancelled by the State in November of 2006).

As of this writing, however, it appears that DDS is preparing to launch a new data quality initiative. In a recent Budget Change Proposal (BCP) submitted to the Legislature as part of the FY 2020-21 budget process,³³³ DDS acknowledged the limitations of the current system,³³⁴ and requested funding for the hiring of two additional full-time employees and the creation of an Enterprise Data Office (EDO).³³⁵ In the BCP, DDS justified the proposed EDO by noting the need to ensure data quality, and argued that the requested resources would allow the Department to enforce data governance standards, improve the timeliness of data publication, improve data consistency, and enhance its ability “to make data driven [] and person-centered decisions, improving consumer outcomes.”³³⁶ DDS also outlined plans for the creation of an “EDO data store,”³³⁷ which would integrate the Department’s different data sources, “enriching the data accessible for business operations.”³³⁸ The proposed data store would integrate five new data sources per year (presumably including the CDER, Client Master File, and Claims File); and the new positions hired to staff the EDO would “liaison [sic] with business program staff and organizational stakeholders to identify data needs and plan the steps necessary to address these data needs” with “[d]ata stakeholder meetings [] beginning in 2020-21.”³³⁹

Such a proposal, if enacted by the Legislature and implemented in a thoughtful and strategic fashion, could significantly help DDS advance strategic objectives, enabling RCs to collect and analyze data in a more holistic manner that could help further the goals established in each consumer’s IPP. With over a decade having now elapsed since the CADDIS debacle, DDS is also better equipped to learn from its early mistakes in upgrading its IT capabilities.³⁴⁰ Moreover, if coupled with a systematic effort to improve the accuracy and completeness of the data the system contains,³⁴¹ such an initiative could have a dramatic impact on the quality and efficiency of the service delivery system.

For example, such a system could help DDS pinpoint areas where provider shortages are particularly acute. As we discuss in a separate report,³⁴² a common complaint among

³³³ See *supra* note 9 (describing the role of Budget Change Proposals in California’s Budget Process).

³³⁴ CAL. DEP’T OF DEVELOPMENTAL SERVS., FY 2020/21 BUDGET CHANGE PROPOSAL 4 (2020) [hereinafter FY 2020-21 DDS IT DATA AND PLANNING BCP], https://esd.dof.ca.gov/Documents/bcp/2021/FY2021_ORG4300_BCP3540.pdf (last visited Jan. 14, 2020) (“Comparison of the various data sets is cumbersome, error-prone, and requires time-consuming manual workaround processes. Additionally, databases are not adequately defined which makes the creation of necessary standardized reports difficult or impossible to develop.”)

³³⁵ *Id.* at 6.

³³⁶ *Id.* at 6.

³³⁷ A data store (alternatively datastore) is a repository for storing, managing, and distributing data sets on an enterprise level. It incorporates all types of data that are produced, stored and used by an organization. See *Datastore*, TECHOPEDIA, <https://www.techopedia.com/definition/23343/datastore> (last visited Jan. 21, 2020).

³³⁸ FY 2020-21 DDS IT DATA AND PLANNING BCP, *supra* note 334, at 10.

³³⁹ *Id.* at 10-11.

³⁴⁰ See generally LITTLE HOOVER COMMISSION, *supra* note 332, at iv-v, 3 (describing several early successes in state departments that launched performance measurement programs through significant IT upgrades and relatively low failure rate for state-financed technology projects). In 2009, the State consolidated technology functions under the Office of the Chief Information Officer, which was later renamed the California Department of Technology (CDT). *About Our Organization*, CAL. DEP’T OF TECH., <https://cdt.ca.gov> (last visited Jan. 16, 2019). Part of the CDT’s mission is to form partnerships with other state entities “to deliver digital services, develop innovative and responsive solutions for business needs, and provide quality assurance for state government Information Technology (IT) projects and services.” *Id.*

³⁴¹ See CAL. DEP’T OF DEVELOPMENTAL SERVS., *supra* note 330, at I-2 to I-4 (noting that DDS cited a lack of “data integrity” as a weakness of the CDER system, a concern that was echoed by several stakeholders with whom we spoke).

³⁴² LANTERMAN PRIMER, *supra* note 5, at 47-48.

stakeholders is the scarcity of providers in some regions of the state. Yet as the LAO has explained:

It is currently difficult to quantify the full extent of any service gaps since DDS lacks a standardized method for understanding these gaps on a system-wide basis. At best, DDS may know anecdotally that certain services are hard to find or that certain providers are going out of business.³⁴³

In DDS's current database, the *Claims File* tracks individual expenditures, including the service code(s) of specific vendors. Yet from this information alone, it is impossible to know whether *no POS funds at all* were expended on a given service because the service was not required, or alternatively because no qualified provider could be found. A high-performance I/DD database could not only link services that are being provided to expenditures in the POS file, but also could identify services that have been authorized but not provided. By tracking information on unmet needs across the state and over time, DDS could target additional resources toward service types or RCs where services are being underprovided.

Another benefit of a high-performance I/DD database is that it could help DDS ensure that RCs are functioning as payers of last resort³⁴⁴ while helping the State access more federal matching funds. To further the former goal, the system could track the amount of services and supports and support each consumer is receiving through so-called “generic” resources,³⁴⁵ such as In-Home Support Services,³⁴⁶ public school districts, and private insurance. Meanwhile, as we discuss at length in a separate report, the State could potentially recoup hundreds of millions of additional federal dollars by enrolling more consumers in two HCBS programs operated by the Center for Medicare and Medicaid Services (CMS).³⁴⁷ As soon as an individual is deemed eligible for RC services, the database could prompt service coordinators to complete all of the data fields that are necessary to identify viable pathways to federal match program enrollment, such as the consumer's (potential) eligibility for Medi-Cal.³⁴⁸ A computer-generated algorithm could then lay out all of the available pathways to eligibility, including the steps that each would require. The IPP team could then determine which pathway would be the least onerous, and help the

³⁴³ See SEQUESTERING SAVINGS, *supra* note 31, at 17.

³⁴⁴ See LANTERMAN ENTITLEMENT REPORT, *supra* note 5, § V. C.

³⁴⁵ See generally CAL. WELF. & INST. CODE § 4659(f) (2017) (“In order to best utilize generic resources, federally funded programs, and private insurance programs for individuals with developmental disabilities, the department and regional centers shall engage in the following activities: (1) Within existing resources, the department shall provide training to regional centers, no less than once every two years, in the availability and requirements of generic, federally funded and private programs available to persons with developmental disabilities, including, but not limited to, eligibility requirements, the application process and covered services, and the appeal process.”).

³⁴⁶ In-Home Support Services include housecleaning, meal preparation, laundry, grocery shopping, personal care services (such as bowel and bladder care, bathing, grooming and paramedical services), accompaniment to medical appointments, and protective supervision, *In-Home Supportive Services (IHSS) Program*, CAL. DEP'T OF SOC. SERVS., <https://www.cdss.ca.gov/in-home-supportive-services> (last visited Jan. 4, 2020), and are classified as a “generic” resource. See *Claimant vs. San Andreas Reg'l Ctr.*, No. 2015030573 (Cal. OAH Sept. 11, 2015), <https://www.dgs.ca.gov/OAH/Case-Types/General-Jurisdiction/Resources/-/media/Divisions/OAH/General-Jurisdiction/DDS-Decisions/2015030573.pdf> (last visited Jan. 10, 2019) (ruling that In-Home Support Services were a generic resource that need to be exhausted before seeking alternative service provision).

³⁴⁷ FEDERAL LANTERMAN FUNDING REPORT, *supra* note 5, at 41-46.

³⁴⁸ California's In-Home Supportive Services program is partly funded with federal Medicaid funds. See CAL. DEP'T OF SOC. SERVS., *supra* note 346.

consumer to complete the remaining steps. In short, a high-performance I/DD database could promote fiscal prudence and the efficient use of the State's budgetary resources.

Yet another potential advantage is that DDS could gain more insight into the range of vendor rates and funding formulas being utilized by RCs across the state. The current system makes it extremely difficult to ascertain the quantity and net price per unit of services purchased on each consumer's behalf. As noted earlier, the *Claims File* only records the service (sub-)code, service date, vendor code, and total amount billed for each claim.³⁴⁹ Yet some service codes are attached to fixed rates, while others are negotiated by RCs or set at the vendor's "usual and customary rate."³⁵⁰ Especially for service codes that allow for some flexibility, these general principles can be applied by different RCs in different ways, using funding formulas that may involve hourly rates, fixed fees for longer durations (such as administrative or monthly fees), or some combination of the two.³⁵¹ Moreover, in unusual situations, individual RCs may grant "Director's Exceptions,"³⁵² or DDS may grant "Health and Safety Waivers,"³⁵³ to enable RCs to pay vendors more than the customary rates. DDS's *Claims File* does not capture such nuances, which dramatically limits the State's capacity to understand the myriad ways in which vendors are being compensated under different service codes. A high-performance I/DD database that included more granular fields on funding formulas, the fixed and variable costs of each service, the total units of services received by the consumer, and any special conditions (such as a Health and Safety Waiver or a Director's Exception) would give policymakers a far more comprehensive and accurate picture of how the price structure and net cost of service delivery varies across vendors, consumers, and RCs.

Relatedly, a high-performance I/DD data store could help stakeholders track in a more meaningful and precise way the magnitude of racial, ethnic and geographic disparities in service provision. To date, public attention has focused almost exclusively on disparities in purchase of services.³⁵⁴ Although such comparisons are a useful starting point, they are arguably less

³⁴⁹ See E-mail from Paul Choate to Julia Bodson (Jan. 18, 2019), *supra* note 327. The *Claims File* also contains several accounting-related and internal recordkeeping fields, such as Transaction Type, General Ledger Account, and Transaction Code. *Id.*

³⁵⁰ See *Vendorization & Rates Frequently Asked Questions*, *supra* note 226 (Under the "Reimbursement Rates FAQs" tab, in answer to Question #5, "How are rates determined?", noting that "[t]here are several different methods which are used to set reimbursement rates. . . . For example, services which are similar to services covered by MediCal are paid according to the rate schedule (Schedule of Maximum Allowances [SMA]) maintained by the California Department of Public Health. In-home respite service rates (procured through respite agencies) and community-based day program rates are set by the Rates & Fiscal Support Section. These rates are based on actual costs submitted on cost statements, within a range of lower and upper limits. New programs receive a temporary payment rate. Supported living rates are negotiated between vendors and regional centers, and transportation rates are based upon a standard rate schedule, state mileage rate, SMA, bids or negotiated contracts with regional centers. All other services are either negotiated contracts with regional centers or set at the vendor's 'usual and customary' rate").

³⁵¹ Telephone call with Douglas Pascover, Exec. Dir., Imagine Supported Living Servs. (December 25, 2019) (noting that different RCs use different funding formulas for Supported Living providers).

³⁵² *Id.* (noting that a "Director's Exception" could be used to adjust rates in unusual circumstances).

³⁵³ See *Health and Safety Waiver Process*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/health-safety-waiver-process/> (last visited Dec. 26, 2019) ("[DDS can] approve exemptions to rate freezes [on an individual basis] for the purpose of mitigating risks to consumer health and safety.").

³⁵⁴ RCs are annually required to post onto their websites data on POS disparities as well as disparity data on individuals determined to be eligible for RC services but that are not receiving POS funds. CAL. WELF. & INST. CODE § 4519.5(a)(1)-(5), (b)-(c) (Deering, LEXIS through 2019 Sess.). In addition to these requirements, RCs must also post a report on the results of annual stakeholder meetings reviewing the aforementioned POS and access disparity measures. See WELF. &

informative than comparisons of the *mix* and *quantity* of services that consumers receive. With more detailed and transparent data on purchased services, including the funding formula(s) utilized, the number of hours provided, and so forth, DDS and the Legislature could obtain a more nuanced portrait of the persistence and magnitude of systemic inequalities.

Interestingly, in a blue-ribbon panel convened a decade ago, the Service Provider Advisory Committee of Golden Gate Regional Center reached very similar conclusions regarding the advantages of a high-performance database in improving system-wide accountability. The impetus for the group's formation was the widespread concern that

[t]he quality assurance system today is inefficient at best, and at worst promotes an environment in which compromised accountability puts people with developmental disabilities at risk and ignores their rights. . . . Volumes of data are collected by multiple state agencies, federal agencies, regional centers and private certification agencies. Maintained in separate systems ranging from paper to electronic, the information is often never used. . . The disparate monitoring process, data points and information systems are resistant to consolidation and interpretation. Each data point represents expensive, marginally useful information that neither ensures nor promotes quality, compromising California's quality assurance system and wasting taxpayer money.³⁵⁵

Among the group's main findings was a recommendation that the State create a comprehensive, integrated data system to track outcomes, thereby eliminating bureaucratic redundancies and streamlining DDS's oversight functions.³⁵⁶

In short, creating a high-performance I/DD database (ideally subsumed within a comprehensive data repository, such as the data store envisioned in the Governor's Proposed Budget)³⁵⁷ would serve numerous policy goals. First, it could help to improve the equity, transparency and efficacy of the service delivery system. Secondly, it could promote budgetary frugality by enabling RCs to better assist consumers with the task of exhausting generic resources and enrolling in federally matched programs. More broadly, such a system would improve systemic accountability by helping the Legislature identify and address areas in which the system is falling short.

INST. 4519.5(f)(1) (LEXIS). Links to these data and reports can be found on the DDS website. *Purchase of Service Data*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/purchase-of-service-data/> (last visited Jan. 3, 2020); *Purchase of Service Annual Reports*, CAL. DEP'T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/rc/disparities/data/purchase-of-service-annual-reports/> (last visited Jan. 3, 2020).

³⁵⁵ ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 4-5.

³⁵⁶ *Id.* at 6, 27.

³⁵⁷ See discussion *supra* notes 334-339 (describing the FY 2020-21 BCP submitted by DDS for the purpose of investing in an enterprise data store).

B. Reforms to Strengthen Accountability Through Individual Self-Advocacy

(1) *Permit Complaints Regarding Intakes & Assessments*

In theory, all RCs apply identical standards in assessing whether an individual with I/DD is eligible for services under the Lanterman Act,³⁵⁸ and all applicants are protected by the same procedural safeguards during the intake and assessment process.³⁵⁹ For example, when an individual with I/DD or his/her family members reach out to a RC for assistance, the RC is required to schedule an intake appointment within 15 working days, and to complete formal assessments (if it decides one is warranted) within 120 days.³⁶⁰

Yet in practice, it is unclear whether sufficient safeguards are in place to ensure that RCs are held accountable for carrying out all of these responsibilities in a timely and diligent manner. If a RC deems an individual with I/DD ineligible for services under the Lanterman Act, this determination can be challenged through the OAH fair hearing process.³⁶¹ However, the fair hearing process cannot be used to challenge situations in which the RC, rather than deeming an individual ineligible for services, imposes lengthy delays or makes no determination at all, causing a *de facto* denial or diminution of services. Although procedural violations during the intake and assessment process cannot be challenged through the OAH fair hearing process, they are at least arguably covered by the 4731 Complaint process, whereby consumers can file complaints if their rights have been “abused, punitively withheld, or improperly or unreasonably denied by a regional center, developmental center, or service provider.”³⁶²

However, several stakeholders with whom we spoke reported that some RCs have taken the position that individuals in this position cannot file complaints because, by definition, they do not yet qualify as “consumers” under the Act.³⁶³ If this interpretation of the Lanterman Act

³⁵⁸ See FEDERAL LANTERMAN FUNDING REPORT, *supra* note 5, § V. A.

³⁵⁹ See CAL. WELF. & INST. CODE §§ 4642-4644 (Deering, LEXIS through 2019 Sess.) (guaranteeing intake and assessment for “[a]ny person believed to have a developmental disability, and any person believed to have a high risk of parenting a developmentally disabled infant”).

³⁶⁰ WELF. & INST. § 4642(a)(2) (LEXIS).

³⁶¹ CAL. WELF. & INST. CODE § 4710.5(a) (Deering, LEXIS through 2019 Sess.); *see also supra* note 205 (discussing the differences between the 4731 Complaint and OAH fair hearing processes).

³⁶² CAL. WELF. & INST. CODE § 4731(a) (Deering, LEXIS through 2019 Sess.) (describing the purpose of section 4731 Complaints); *see also* discussion *supra* § IV. C. 3. (Summary Data on Consumer Complaints). Consumers appear to have made very limited use of this mechanism, with only five of the 256 WIC section 4731 Complaints referred to DDS from July 1st, 2011 to December 26, 2019 potentially referencing violations in the initial intake and assessment process, *see* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158 (providing, in excel format, all 4731 Complaints referred to DDS in the specified period). It was unclear, however, whether all five of these complaints referred specifically to assessments at the intake stage of the process because, as previously noted, the 4731 Complaint data sent to us by DDS was vague and lacked important detail, *see* discussion *supra* pp. 33-36. In any event, of these five cases, DDS categorized one as “outside the scope of [section] 4731” and three as “no violation.” In the fifth case, no finding at all was listed in the spreadsheet.

³⁶³ Section 4731 gives consumers the right to file a complaint with the RC and/or DDS when they believe “any right to which a consumer is entitled has been abused, punitively withheld, or improperly or unreasonably denied.” CAL. WELF. & INST. CODE § 4731(a) (Deering, LEXIS through 2019 Sess.); *see also* discussion *supra* § IV. C. 3. (Summary Data on Consumer Complaints).

prevails, RCs may not be held accountable for violating the rights of individuals with I/DD and their families during the intake and assessment process.

To enhance accountability and equity, the Legislature could amend the Lanterman Act to specify that individuals who are receiving intake and assessment services from their RCs have the right to file 4731 Complaints against their RC if they believe their rights have been violated.

(2) Send Written Notice of All Service Changes & Deter Case Deactivation

Under the Lanterman Act, RCs must provide written notice if a decision to reduce, terminate, or change services set forth in a consumer's IPP is made without the "mutual consent" of the service recipient or his/her authorized representative.³⁶⁴ Yet determining whether "consent" has taken place is often complex and subjective. Even a consumer who appears to give "consent" may not fully understand the nature of what was consented to. RCs' capacity to withhold written notice in cases of (apparent) consent may deter some consumers from enforcing their rights, particularly those from underserved communities or for whom English is a second language.

A related barrier to consumer self-advocacy is that in some RCs, several stakeholders reported, service coordinators close or "deactivate" cases that remain inactive for prolonged periods of time without providing any notice to affected consumers or their families. For example, a consumer who ages out of school district services in early adulthood may be told that her file with the RC is no longer active. Consumers in this position may be required to complete extensive paperwork to "reopen" or "reactivate" their cases, which can impose a significant time cost and delay the provision of needed services and supports. There is no basis in the Lanterman Act for demoting, let alone deactivating, consumers whose needs are fully met by public school systems or other generic resources for a discrete period of time. Although there is nothing inherently problematic about RCs differentiating between consumers who do and do not receive POS for internal recordkeeping purposes, forcing a consumer to shoulder an extra paperwork burden after a prolonged period of inactivity arguably constitutes a civil rights violation.

To address these concerns, the Legislature could: (1) amend WIC section 4710 to remove the provision that permits the agency to forgo issuing a notice if the consumer or his or her representative purportedly has consented to the agency action,³⁶⁵ and (2) require DDS to investigate how often RCs are unlawfully "deactivating" cases after periods of inactivity, and take affirmative steps to eliminate this practice.

(3) Allow Consumers to Request Independent Evaluations

When parents disagree with an evaluation of their child conducted by a public school district, they have a right under the Individuals with Disabilities in Education Act (IDEA) to request an

³⁶⁴ CAL. WELF. & INST. CODE § 4710(a)-(b) (Deering, LEXIS through 2019 Sess.).

³⁶⁵ In the summer of 2019, legislation was introduced in the California State Assembly that would have implemented the first of these recommendations, but the measure did not pass. A.B. 1643, 2019 Leg., Reg Sess. (Ca. 2019) (requiring affected service agencies to provide written notice to the consumer irrespective of whether the consumer or his or her representative had mutually consented to the agency action).

Independent Educational Evaluation (IEE) “by a qualified examiner who is not employed by the public agency responsible for the education of the child in question.”³⁶⁶ The school district is legally required to consider the results of the IEE in determining which educational services to provide.³⁶⁷ If parents request that an IEE be conducted at public expense, the school district must either cover the cost or timely request a due process hearing to challenge its necessity.³⁶⁸

The rationale for authorizing an independent evaluation (IE) at public expense is arguably just as strong for RC consumers as it is for parents of special education students. In *Schaffer v. Weast*, the United States Supreme Court found that school districts have a “‘natural advantage’ in information and expertise,” and therefore, IEEs ensure that students and parents “are not left to challenge the government without a realistic opportunity to access the necessary evidence, or without an expert with the firepower to match the opposition.”³⁶⁹ RC consumers are likewise disadvantaged in disputes where they typically have limited information and expertise. Just like a school district in the context of the IDEA, a RC’s “failure to receive and consider [a consumer’s] information, including evaluations they may obtain, directly denies [consumers] the pivotal role they should enjoy in the development of their [IPPs].”³⁷⁰ Requiring RCs to fund and consider IEs would help “ensure[] that a program is individualized and provide[] a check on the judgments being made by [RC] officials regarding the [consumer].”³⁷¹

While there are differences between evaluation processes specified in the IDEA and the Lanterman Act, these distinctions, if anything, tend to strengthen the rationale for allowing IEs in the latter context. First, unlike school districts, RCs may hire outside vendors to conduct evaluations on their behalf.³⁷² Yet many of these vendors are likely to have well-established relationships with RCs, giving them strong incentives to render determinations that further RCs’ institutional interests. Secondly, whereas school districts must evaluate special education students in all areas of suspected disability at least once every three years,³⁷³ RCs are only required to conduct assessments for purposes of determining eligibility³⁷⁴ and if a consumer is at risk of being institutionalized.³⁷⁵ Given the extremely high stakes of the latter two decisions—

³⁶⁶ 34 C.F.R. § 300.502(a)(1),(a)(3)(i) (2019), WL 34 C.F.R. § 300.502(a)(1), (a)(3)(i).

³⁶⁷ 34 C.F.R. § 300.503(c) (2019), WL 34 C.F.R. § 300.503(c) (“If the parent obtains an independent educational evaluation at private expense, the results...*must* be considered by the public agency in any decision made with respect to the provision of a [free appropriate public education] to the child.”) (emphasis added).

³⁶⁸ 34 C.F.R. § 300.502(b)(2) (specifying conditions under which parents can obtain an IEE at public expense if they disagree with an evaluation obtained by a public school); *see also* Pajaro Valley United Sch. Dist. v. J.S., 2006 U.S. Dist. LEXIS 90840 (N.D. Cal. 2006) (ruling that a school district’s failure to request a due process hearing in a timely manner can result in waiver of right to challenge parents’ request for an IEE).

³⁶⁹ *Schaffer v. Weast*, 546 U.S. 49, 60-61 (2005).

³⁷⁰ *Cnty. Consol. Sch. Dist. No. 180*, 27 IDELR 1004, 1006 (Ill. 1998).

³⁷¹ *Id.*

³⁷² CAL. WELF. & INST. CODE § 4648(a)(3) (Deering, LEXIS through 2019 Sess.) (“A regional center may, pursuant to vendorization or a contract, purchase services or supports for a consumer from an individual or agency that the regional center... determines will best accomplish all or part of that consumer’s program plan.”).

³⁷³ 20 U.S.C. § 1414(a)(2) (West, Westlaw through Pub. L. No. 116-91); 34 C.F.R. § 300.303, 34 C.F.R. § 300.303.

³⁷⁴ CAL. WELF. & INST. CODE § 4643(a) (Deering, LEXIS through 2019 Sess.) (requiring that RCs conduct assessments if needed to make an eligibility determination); CAL. WELF. & INST. CODE § 4643.5(b) (Deering, LEXIS through 2019 Sess.) (requiring that the RCs conduct a comprehensive reassessment of eligibility, and determine that the initial eligibility assessment was “clearly erroneous,” in order to remove a consumer’s eligibility).

³⁷⁵ CAL. WELF. & INST. CODE § 4648(a)(9)(C)(vi) (Deering, LEXIS through 2019 Sess.) (requiring that RCs complete comprehensive assessments of consumers placed in institutions for mental disease); CAL. WELF. & INST. CODE §§

which determine an individual’s ability to access state services and to live in the community—the rationale for allowing consumers to request IEs at public expense seems particularly compelling.³⁷⁶

To deter consumers and families from filing frivolous requests, RCs (like public school districts under the IDEA)³⁷⁷ could be granted a limited right to request administrative hearings to challenge the necessity of conducting an IE; any RCs that prevailed in such hearings would not be required to pay for the IE (or to reimburse the consumer’s legal costs).³⁷⁸ Yet if RCs failed to carry this burden, attorneys’ fees would be available to prevailing consumers, so that RCs could not deter consumers from requesting IEs by routinely challenging them through the fair hearing process and forcing consumers to bear their own legal costs.

(4) Enable Prevailing Consumers to Recover Litigation Costs

Given the centrality of the fair hearing process in enabling consumers to enforce their rights under the Lanterman Act, ensuring access to justice is critical. Yet as discussed earlier, only about 8% of the 1,400 requests for fair hearing filed each year result in a full hearing and at least a partial victory for the claimant; almost three-quarters of all requests are withdrawn or administratively closed.³⁷⁹ From the data collected by DDS, there is no way to know how many requests for fair hearing do not advance to the hearing stage because they are resolved informally in claimants’ favor, and how many are withdrawn or closed simply because claimants cannot find (or afford) legal representation.³⁸⁰

In evaluating these statistics, however, it is important to bear in mind that prevailing claimants in OAH hearings cannot recover any attorney’s fees, and only in exceptional circumstances can claimants recover their litigation costs following a successful appeal to superior court.³⁸¹ As a

4418.25(c), 4418.7 (Deering, LEXIS through 2019 Sess.) (requiring comprehensive assessments of consumers placed in developmental centers).

³⁷⁶ In 2017, the California legislature enacted A.B. 126, repealing WIC section 4686.5, Act of Jul. 10, 2017, ch. 65, §1, 2017 Cal. Legis. Serv. 1756, 1757-58 (repealing CAL. WELF. & INST. CODE § 4686.5 effective Jan. 1, 2018), which had previously limited in-home respite to 90 hours per consumer per quarter, and out-of-home respite to 21 days per fiscal year. CAL. WELF. & INST. CODE §4686.5 (West 2017) (repealed 2018). Nevertheless, many RCs continue to use evaluation tools and assessments to limit respite services. *See, e.g.*, GOLDEN GATE REG’L CTR., FAMILY RESPITE NEEDS ASSESSMENT GUIDELINES (2019), http://www.ggrc.org/storage/documents/Services/Family_Respites_Guidelines_1-19.pdf (last visited Jan. 17, 2019) (outlining the assessment performed by the RC to determine respite hours); HARBOR REG’L CTR., RESPITE PACKET, http://www.harborrc.org/files/uploads/Respites_Session_1_Packet_Presentation.pdf (last visited Jan. 17, 2020) (describing how respite hours are determined in a section entitled “Determining Respite Hours”). Given the importance of respite services in enabling families to support children in the family home, the tools and assessments used to determine respite eligibility and hours might also be treated as “evaluations,” conferring on parents the request IEs.

³⁷⁷ *See supra* note 368 and accompanying text (specifying that school districts have a limited right to challenge the necessity of an IEE in the IDEA context).

³⁷⁸ *Schaffer v. Weast*, 546 U.S. 49, 62 (2005).

³⁷⁹ *Supra* § V. A. (presenting data on OAH fair hearing outcomes).

³⁸⁰ *See discussion supra* p. 31 (discussing the limitations of the OAH fair hearings data currently provided).

³⁸¹ *See* DISABILITY RIGHTS CAL., RIGHTS UNDER THE LANTERMAN ACT: DISAGREEMENTS WITH REGIONAL CENTERS AND DEVELOPMENTAL CENTERS 12-25, <https://www.disabilityrightscal.org/system/files/file-attachments/506301Ch12.pdf> (last visited Jan. 16, 2019) (noting that although “no one has ever asked the court to award lawyer’s fees for an appeal of an administrative hearing in a regional center matter,” DRC believes that such fees may be recoverable if the case implicates rights under the Medi-Cal waiver; alleges a violation of federal due process rights by a state actor; or is brought to force a RC to comply with a prior fair hearing decision); *see also* CAL. CIV. PROC. CODE § 1021.5 (Deering, LEXIS through 2019 Sess.) (providing that attorneys’ fees may be recovered if a “significant benefit” is conferred on the general public, the

result, some families may decline to bring cases to fair hearing simply because they feel ill-prepared to represent themselves and cannot afford lawyers; even those families with the financial means to hire a private attorney may have difficulty finding one who is qualified.³⁸²

The inability of most consumers to recoup their litigation fees, even if they successfully appeal an adverse fair hearing decision to state court, sets the Lanterman Act apart from most federal and state laws designed to protect individual civil rights. Both of the preeminent federal civil rights laws that affect the rights of individuals with I/DD, the Americans with Disabilities Act (ADA) and the IDEA, contain cost-shifting provisions that allow plaintiffs to recover attorneys' fees in their initial administrative hearings and in any subsequent appeals.³⁸³ Such provisions are not limited to the disability rights arena; U.S. Congress has created approximately two hundred exceptions to the "American rule" (whereby each litigant bears his/her own attorney's fees and costs) in a wide variety of civil rights, environmental protection, and consumer protection contexts where policymakers' aim is to "help to equalize contests between private individual plaintiffs and corporate or government defendants."³⁸⁴ Under most cost-shifting statutes, a federal court may order the losing party, if it is a corporation or (quasi-)governmental entity, to pay the prevailing party's attorneys' fees and costs.³⁸⁵ Although in theory the prospect of recovering litigation costs could encourage frivolous litigation, this concern is mitigated by the fact that fees are *only* recoverable if the plaintiff wins her case, giving private attorneys little incentive to accept marginal cases.³⁸⁶

"necessity and financial burden of private enforcement" makes the award appropriate, and it is "in the interest of justice" that the fees not be paid out of the recovery); *Samantha C. v. State Dep't of Developmental Servs.*, 142 Cal. Rptr. 3d 625, 632 (Cal. Ct. App. May, 24, 2012) (awarding attorneys' fees under the Private Attorneys General Act because "the erroneous statutory interpretation that had led to HRC's denial of benefits [to claimant]...had also been applied to all other applicants who had sought benefits on similar grounds in the past and that, but for [the claimant's] action and our ruling, HRC's erroneous interpretation would have continued to be applied to those who would do so in the future").

³⁸² The concern is that few private attorneys will develop expertise in the fair hearing process simply in order to represent those few clients who can pay out of pocket. In areas of law that include the possibility of large monetary awards, lawyers may offer clients a so-called "contingency fee" arrangement, whereby instead of charging an hourly fee, the attorney takes a fixed percentage of any monetary recovery (and receives no compensation at all if the plaintiff loses). See David Root, *Attorney Fee-Shifting in America: Comparing, Contrasting, and Combining the "American Rule" and "English Rule,"* 15 Ind. Int'l & Comp. L. Rev. 583, 593-96. Yet since most disputes under the Lanterman Act involve the prospective provision of services rather than monetary damages, private attorneys with expertise in the area presumably would be unlikely to accept a contingency fee arrangement.

³⁸³ 20 U.S.C. § 1415(i)(3)(b) (West, Westlaw through Pub. L. No. 116-91) (The IDEA, describing that "[i]n any action or proceeding brought under this section, the court, in its discretion, may award reasonable attorneys' fees as part of the costs."); see also HENRY COHEN, LEG. ATT'Y, AM. LAW. DIV., CONG. RES. SERV., AWARDS OF ATTORNEYS' FEES BY FEDERAL COURTS AND FEDERAL AGENCIES 33 (2008), <https://fas.org/sgp/crs/misc/94-970.pdf> (last visited Jan. 7, 2020) (explaining that because "[a]dministrative proceedings are mandatory under the EHA, and [because] the legislative history makes clear that courts may award fees incurred at the administrative and the judicial levels," parties are entitled to recover fees "when [they] prevail[] at the administrative level and bring[] a court action solely to recover fees"); 42 U.S.C. § 12205 (West, Westlaw through Pub. L. No. 116-91) (describing as part of the ADA that "[i]n any action or administrative proceeding commenced pursuant to this Act, the court or agency, in its discretion, may allow the prevailing party, other than the United States, a reasonable attorney's fee, including litigation expenses, and costs, and the United States shall be liable for the foregoing the same as a private individual.").

³⁸⁴ COHEN, *supra* note 383, at ii.

³⁸⁵ See generally *id.* at 25-39 (summarizing federal civil rights statutes with cost-shifting provisions and noting that where the government prevails, the losing private party is not required to reimburse the government for its attorney's fees and costs).

³⁸⁶ See Root, *supra* note 382, at 596 (noting that in the analogous context of contingency fee arrangements, some commentators find the concern about creating a high frequency of frivolous litigation to be without merit).

Attorneys' fee awards are likewise the norm under California laws designed to protect the rights of social service recipients. For example, the WIC provides that consumers of public social services, such as Medi-Cal, "shall be entitled to reasonable attorney's fees and costs" if they successfully appeal administrative hearing decisions³⁸⁷ to superior court.³⁸⁸

The Legislature has explicitly acknowledged that RC consumers, like vulnerable claimants in other arenas, may have difficulty enforcing their rights. The Lanterman Act notes that "[p]ersons with developmental disabilities are vulnerable to abuse, neglect, and deprivations of their rights,"³⁸⁹ and for that very reason, DDS allocates funding to the Office of Clients' Rights Advocates (OCRA), a division of DRC, to train a cadre of attorneys to help consumers across the state access a broad range of programs and institutions that require legal advocacy.³⁹⁰ The difficulty, however, is that since each RC is assigned only one CRA, it is impractical for CRAs to provide more than consultation and advice to most consumers. Only rarely do CRAs provide full representation in fair hearings or subsequent appeals.³⁹¹ The number of consumers in need of direct representation significantly exceeds the capacity of the CRAs to provide it, and this shortfall has escalated in recent years.³⁹²

³⁸⁷ CAL. WELF. & INST. CODE §§ 10950-10967 (Deering, LEXIS through 2019 Sess.) (establishing the fair hearing procedure for social services provided pursuant to WIC division 9 ("Public Social Services")).

³⁸⁸ The WIC includes a provision allowing social services recipients or applicants to appeal an adverse fair hearing decision to a superior court and, if successful, recover attorney's fees. CAL. WELF. & INST. CODE § 10962 (Deering, LEXIS through 2019 Sess.). This cost-shifting provision is in the sole chapter covering fair hearings and decision appeals in WIC division 9, which governs services administered by the California Departments of Social Services and Health Care Services, such as Medi-Cal services, CalWORKs services, and electronic benefits transfers. CAL. WELF. & INST. CODE §§ 10000 - 18999.98 (Deering, LEXIS through 2019 Sess.); *see also* JEN FLORY ET AL., WESTERN CTR. ON LAW & POVERTY, GETTING AND KEEPING HEALTH COVERAGE FOR LOW-INCOME CALIFORNIANS: A GUIDE FOR ADVOCATES 270-280 (2016) (explaining the fair hearing process and possibility of recovering attorney fees); *Conlan v. Bonta*, 125 Cal. Rptr. 2d 788, 102 Cal. App. 4th (2002) (affirming that Medi-Cal beneficiaries have the right to recover reimbursement from the department administering services); *State Hearing Requests*, CAL. DEP'T OF SOC. SERVS, <https://www.cdss.ca.gov/hearing-requests> (last visited Jan. 17, 2019) (listing the services about which a recipient of applicant can request a fair hearing); CAL. WELF. & INST. CODE §§ 10054-10055 (Deering, LEXIS through 2019 Sess.) (defining "Department" and "Director" in WIC division 9 to mean the State Department of Social Services and the director of that department, respectively, both of which are used throughout the division's chapter on the fair hearing process).

³⁸⁹ CAL. WELF. & INST. CODE § 4433(a)(2) (Deering, LEXIS through 2019 Sess.).

³⁹⁰ The Office of Clients Rights Advocates (OCRA), with which DDS contracts to serve this function, is a division of DRC. *See* WELF. & INST. § 4433(b)(1) (LEXIS); *Office of Clients' Rights Advocacy (OCRA)*, DISABILITY RIGHTS CAL., <https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra>, (last visited Jan. 10, 2020). OCRA is required to provide clients' rights advocacy services, including assistance with pursuing administrative and legal remedies; investigate complaints about licensed health and community care facilities; coordinate the provision of clients' rights advocacy services; and provide self-advocacy trainings for consumers and their families. WELF. & INST. § 4433(d) (LEXIS). In FY 2018-19, OCRA fulfilled these statutory requirements by providing biannual self-advocacy training, DISABILITY RIGHTS CAL., OFFICE OF CLIENTS RIGHTS, OCRA ANNUAL REPORT 20 (2018) [hereinafter OCRA ANNUAL REPORT], <https://www.disabilityrightsca.org/system/files/file-attachments/DirectorsReportJuly2018-June2019.pdf> (last visited Jan. 14, 2020), as well as direct representation for issues relating to public benefits, RC services, community placement, special education, and housing, *id.* at 5. Additionally, the SCDD may, "[w]henver the advocacy efforts of a regional center to secure or protect the civil, legal, or service rights of any of its consumers prove ineffective," provide advocacy assistance to a person with I/DD, or his/her parents, legal guardian, or other representative, *see* CAL. WELF. & INST. CODE § 4648(b)(2) (Deering, LEXIS through 2019 Sess.).

³⁹¹ *See* DISABILITY RIGHTS CAL., *supra* note 381, at 12-11 (noting that CRAs can only take on a limited number of cases for direct representation); *see also* OCRA ANNUAL REPORT, *supra* note 390, at 13 (noting that in FY 2018-19 all but 32 of 10,032 (99%) consumer issues were resolved informally, without using hearings or court).

³⁹² In its most recent annual report, OCRA noted that the demand for a higher level of service provision, including direct representation, continues to increase, and that a greater number of cases "require direct representation or limited scope

In light of these trends, the Lanterman Act’s anomalous failure to award litigation costs to prevailing plaintiffs very likely impedes the capacity of some RC consumers to obtain adequate services and supports. Amending the Act to enable victorious plaintiffs to recover their attorneys’ fees and costs in OAH hearings and subsequent appeals—as is the norm in most state and federal policy domains that implicate civil rights or the provision of social services—would advance several important public policy goals. First, these reforms would help enrich public law defining the scope of the Lanterman Act entitlement, because more consumers would pursue claims that would result in precedential decisions.³⁹³ Secondly, such provisions could help catalyze the growth of a private bar of Lanterman Act attorneys who could complement the work of the CRAs, thereby helping to preserve the core of the Lanterman Act entitlement.³⁹⁴ Finally, a cost-shifting provision would make the fair hearing and appeals process more accessible to underrepresented consumers from marginalized communities, helping to alleviate system-wide disparities.

C. Reforms to Strengthen Public Oversight & Accountability

(1) Protect Regional Center Board Members from Retaliation

RCs’ boards of directors play critical roles in ensuring that RCs are responsive to the needs of the communities they serve. Their independence and willingness to speak freely, without fear of reprisal, is a critical precondition to their ability to carry out their oversight role effectively. Yet some of the stakeholders with whom we spoke suggested that board members who are also RC consumers or family members may hesitate to criticize RC executives for fear that their services will be reduced.

In 1999, DDS distributed a policy explicitly prohibiting RCs and their staff from “engag[ing] in any behavior that could be considered to be a ‘reprisal’ against any consumer, family member, advocate or others for making a complaint against the regional center or a service provider.”³⁹⁵ Yet on its face, this policy pertains only to 4731 Complaints;³⁹⁶ it does not make any reference to statements RC board members make in carrying out their duties.

To strengthen the critical role of RC board members in ensuring that RCs are accountable to their local communities, it would be helpful for DDS to distribute an anti-retaliation policy pertaining

representation, and fewer cases [can] be handled with information or advice.” OCRA ANNUAL REPORT, *supra* note 390, at 28.

³⁹³ LANTERMAN ENTITLEMENT REPORT, *supra* note 5, at 6 (noting the limited case law available to define the scope of the Lanterman Act).

³⁹⁴ Another virtue of fostering a robust private bar is that it could help level the playing field at fair hearings, since plaintiffs’ attorneys who specialize in this area could amass knowledge and experience on par with officials representing RCs’ interests. In the current system, consumers are effectively “one-shot” players who are, for that reason, likely to be at a structural disadvantage. *Cf.* Blomgren Amsler, *supra* note 212 (describing evidence of repeat player bias in context of arbitration).

³⁹⁵ CMTY. SERVS. DIV., CAL. DEP’T OF DEVELOPMENTAL SERVS., PSB-99-5, DEPARTMENT OF DEVELOPMENTAL SERVICES’ POLICY ON REPRISALS (1999).

³⁹⁶ *See* discussion *supra* § IV. C. 3. (describing the section 4731 Complaint process).

to RC board members with language similar to that used in 1999 to protect 4731 Complainants. For example, the policy could prohibit RCs or their staff from engaging in any behavior that could be considered a “reprisal” for any statements made, opinions expressed, or actions taken by consumers, families, advocates or others in the scope of, or in furtherance of, their duties as RC board members.

(2) Publish Corrective Action Plans Online

Under the Lanterman Act and related laws, a Corrective Action Plan (CAP) can be issued in three different contexts to address significant problems with service delivery or violations of consumer rights. First, under WIC section 4635(b)(2), if a RC fails to fulfill its contractual obligations and DDS’s “efforts to resolve the problem are unsuccessful,” the Department can issue a “letter of noncompliance . . . [that] shall state the noncompliant activities and establish a specific timeline for the development and implementation of a corrective action plan,” which DDS is required to approve and monitor.³⁹⁷ Secondly, although not explicitly required by statute, DDS routinely issues CAPs to RCs or vendors against whom civil rights complaints are filed pursuant to WIC section 4731, if those complaints are deemed meritorious.³⁹⁸ Finally, a RC can issue a CAP to a facility that displays “substantial inadequacies” in service delivery.³⁹⁹ If the inadequacies are not corrected within the timeframe specified in the CAP, the RC may apply a variety of sanctions.⁴⁰⁰

Yet these three types of CAPs are not available easily, if at all, to the public. In the first of these scenarios, WIC section 4365(b)(2) requires DDS to provide any Letters of Noncompliance issued to RCs to the public upon request, but does not require the disclosure of the CAPs themselves.⁴⁰¹ For the second type of CAP, DDS makes publicly available a list of each civil rights complaint referred to DDS under section 4731, including whether a CAP was issued and when it was completed, but does not disclose the contents of the CAP itself.⁴⁰² Until recently, no disclosure provisions at all applied to third type of CAP, issued by RCs to deficient vendors. However, with the passage of S.B. 81, effective June 27, 2019, the WIC now requires that these CAPs be provided to DDS, which in turn is obliged to provide them to DRC and to “consult with regional centers and [DRC] . . . on the process for increasing consumer and family access to the

³⁹⁷ CAL. WELF. & INST. CODE § 4635(b)(2) (Deering, LEXIS through 2019 Sess.).

³⁹⁸ Telephone Call with Tom Blythe, *supra* note 188 (Dec. 23, 2019) (clarifying that while not statutorily required, it is DDS policy to issue a CAP after a violation is found in response to a 4731 Complaint); *see also supra* IV. C. 3 (discussing 4731 Complaints and the associated CAPs when violations are found).

³⁹⁹ CAL. CODE. REGS. tit. 17, §§ 54522, 56056 (2019).

⁴⁰⁰ CAL. CODE. REGS. tit. 17, § 56057 (2019).

⁴⁰¹ *See* WELF. & INST. CODE § 4635(b)(2) (LEXIS) (specifying that Letters of Noncompliance shall be made available to the public upon request, while only requiring that CAPs be submitted to the SCDD); *see also* E-mail from Tom Blythe to Alison Morantz (Jan. 15, 2019), *supra* note 189 (noting that CAPs would only be provided by DDS pursuant to Section 4635(b)(2) if they were described in detail in the Letter of Noncompliance, or appended to it as an attachment).

⁴⁰² *See* CAL. WELF. & INST. CODE § 4731(d) (Deering, LEXIS through 2019 Sess.) (requiring DDS to provide to the public upon request “the number of complaints filed, by each regional center and state developmental center catchment area, the subject matter of each complaint, and a summary of each decision”). The CAPs themselves, however, are not made available to those who request data under this provision. *See* E-mail from Alexandra Sanders to Alison Morantz (Dec. 26, 2019), *supra* note 158 (responding to a CPRA request for data on 4731 Complaints with an Excel spreadsheet of complaints received by each RC and including fields for the date the CAP was issued if a violation was found, as well as the date the CAP was completed; but not providing any access to the CAP itself).

information contained in [these] corrective action plans and sanctions.”⁴⁰³ Yet the latter requirements do not go into effect until July 1, 2020, and there is still no provision requiring that the CAPs be disclosed to the public.⁴⁰⁴

The inability of stakeholders to obtain and analyze CAPs makes it difficult to identify and track the prevalence of shortfalls in service delivery and civil rights violations, along with the steps being taken to correct them. Requiring DDS and RCs to publish copies of all three types of CAPs on their respective websites, in a redacted form that protects the privacy of the affected individuals, would encourage more robust public oversight and accountability.

(3) *Publish Microdata on the NCI Survey & Special Incident Reports*

Two types of data that DDS collects contain valuable information on the health, safety and welfare of RC consumers: (a) the NCI survey data, discussed earlier, which contains detailed information on consumer outcomes and satisfaction levels;⁴⁰⁵ and (b) Special Incident Reports (SIRs), which RCs are required to report to DDS within two days of a consumer’s disappearance, criminal victimization, serious injury or accident, unexpected hospitalization, or apparent abuse or neglect.⁴⁰⁶

As of this writing, neither of these datasets is disclosed to the public in the format that would be most useful in enhancing system-wide oversight and accountability. The NCI data are published online in pdf format as a series of tables listing the average responses to each survey question by RC, alongside state and national averages. The data are not disaggregated by other categories, such as age or race/ethnicity.⁴⁰⁷ Meanwhile, to the best of our knowledge, DDS publishes no detailed data at all on the frequency or distribution of SIRs at the RC level.⁴⁰⁸

To improve local and system-wide accountability, the Legislature could require DDS to make microdata (information collected at the level of individual respondents) from the NCI surveys and SIRs publicly available.⁴⁰⁹ If the form in which these data are received by DDS contains personal identifying information, they will need to be de-identified (stripped of all personal

⁴⁰³ Act of Jun. 27, 2019, ch. 28, § 20, 2019 Cal. Legis. Serv. 1270, 1293 (West) (codified as amended at CAL. WELF. & INST. CODE § 4640.9 (2019)).

⁴⁰⁴ CAL. WELF. & INST. CODE § 4640.6 (Deering, LEXIS through 2019 Sess.) (establishing that starting July 1, 2020, RCs must provide DDS with copies of CAPs that they issue to vendors).

⁴⁰⁵ See discussion *supra* § IV. B. 1. (NCI Survey Data).

⁴⁰⁶ See *supra* note 14 and accompanying text.

⁴⁰⁷ 2017-18 AIPS, *supra* note 56.

⁴⁰⁸ DDS submits a report to the legislature each year with high-level summary statistics on SIRs, such as the number reported for all individuals served by DDS, totals of each type of SIR, and comparisons to the mortality rates of other states. See *Risk Management and Mitigation*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/transparency/risk-management-mitigation/> (last visited Jan. 4, 2020) (providing annual reports to the legislature under “Report to the Legislature”); see also, e.g., CAL. DEP’T OF DEVELOPMENTAL SERVS., 2015-16 YEAR IN REVIEW: RISK MANAGEMENT AND MITIGATION (Sept. 2016), https://www3.dds.ca.gov/riskManagement/docs/riskManagement2015_16.pdf (last visited Jan. 4, 2020).

⁴⁰⁹ It is worth noting that the independent NCI website has already taken an intermediate step towards accomplishing this goal. While microdata is still unavailable, users of their website tool can subset responses to NCI survey questions by characteristics including race, gender, age, psychiatric diagnosis, ASD diagnoses, and preferred means of communication. See NCI Charts (2016-17), *supra* note 60.

identifying information) and anonymized (so the identity of individuals cannot be readily determined) before being made public. Fortunately, the procedures for rendering data suitable for public dissemination are well understood; many other surveys and regulatory datasets with information on individual events and outcomes are disclosed to the public in a fashion that promotes accountability while protecting individual privacy.⁴¹⁰

In FY 2016–17, DDS received an additional \$1.2 million in appropriations to fund the creation of a Program and Fiscal Research (PFR) Unit to “play a helpful role in responding to legislative and other requests for information.”⁴¹¹ The Legislative Analyst Office noted that the new unit “[p]resents an [o]ppportunity for [s]trategic [d]ecision-[m]aking,” and advised the Legislature to “set more specific research goals for the unit that serve to encourage data-driven decision-making.”⁴¹²

DDS’s new PFR Unit would be ideally equipped to take the lead on making the NCI and SIR data more useful to stakeholders. Drawing on the experiences of other agencies that report data on individual outcomes to the public, the Unit could devise and implement a new procedure to make both of these important datasets available to the public in a machine-readable format that protects individual privacy.

⁴¹⁰ Numerous other public agencies post individual- and establishment-level datasets related to fatalities, accidents/injuries, regulatory violations, and various economic indicators. The Mine Safety and Health Administration (MSHA) publicly posts anonymized individual-level data on each fatality that occurs at a mine. These data are reported in every mine in every year and include information about the employer, employee work history, and mine risks. *See, e.g., Fatality Reports*, U.S. DEP’T OF LABOR, MINE SAFETY & HEALTH ADMIN., <https://www.msha.gov/data-reports/fatality-reports/search> (last visited Jan. 4, 2020). MSHA and the Occupational Safety and Health Administration (OSHA) publicly report establishment-level data on accidents and injuries that occur at the workplace, *see, e.g., Mining Industry Accident, Injuries, Employment, and Production Data: Accident/Injury Self-Extracting Files*, U.S. DEP’T OF LABOR, MINE SAFETY & HEALTH ADMIN., <https://arlweb.msha.gov/STATS/PART50/P50Y2K/AITABLE.HTM> (last visited Jan. 17, 2020); *Establishment Specific Injury & Illness Data (OSHA Data Initiative)*, U.S. DEP’T OF LABOR, OCCUP. SAFETY & HEALTH ADMIN., https://www.osha.gov/pls/odi/establishment_search.html (last visited Jan. 4, 2020), and the Centers for Medicare and Medicaid (CMS) collect self-reported data from long-term care facilities on numerous variables, including staffing, number of facility deaths, and methods to control behavior. These data are self-reported via CMS’s CASPER reporting system, and researchers hoping to use these facility-level datasets may submit a request to CMS to access the data using the ASPEN Web Application, *see* CTRS. FOR MEDICARE & MEDICAID SERVS., QIES NATIONAL DATA ACCESS REQUEST: INSTRUCTIONS, https://qtso.cms.gov/system/files/2018-03/Data_Access_Request_General_Inst_20170922_0.pdf (last visited Jan. 7, 2020). Finally, economists often rely on data made publicly available by the Bureau of Labor Statistics (BLS), including the Current Population Survey (CPS) and the National Longitudinal Survey (NLS). First, the CPS is a “monthly survey of U.S. households” providing “a wide range of information about employment, unemployment, hours of work, earnings, and people not in the labor force,” at the household level. *See Labor Force Statistics from the Current Population Survey: Overview*, BUREAU OF LABOR STATISTICS, https://www.bls.gov/cps/cps_over.htm (last visited Jan. 7, 2020); *see also CPS Databases*, BUREAU OF LABOR STATISTICS, <https://www.bls.gov/cps/data.htm> (last visited Jan. 7, 2020). Second, the NLS includes “nationally representative surveys that follow the same sample of individuals from specific birth cohorts over time. The surveys collect [anonymized individual-level] data on labor market activity, schooling, fertility, program participation, health, and much . . . more,” *see National Longitudinal Surveys*, BUREAU OF LABOR STATISTICS, <https://www.nlsinfo.org/> (last visited Jan. 7, 2020).

⁴¹¹ MAC TAYLOR, LEG. ANALYST’S OFFICE, THE 2017-18 BUDGET: ANALYSIS OF THE DEPARTMENT OF DEVELOPMENTAL SERVICES BUDGET 4 (Feb. 24, 2017), <http://www.lao.ca.gov/reports/2017/3581/DDS-Budget-022417.pdf> (last visited Jan. 7, 2020).

⁴¹² *Id.* at 4, 20.

(4) Incentivize Regional Centers to Improve Person-Centered Outcomes

In 1997, the Legislature declared its intent “that the Department of Developmental Services, through appropriate and regular monitoring activities, ensure that RCs meet their statutory, regulatory and contractual obligations in providing services to persons with developmental disabilities.”⁴¹³ The Legislature further required DDS to “include annual performance objectives that shall...[b]e specific, measurable, and designed to do all of the following: (A) Assist consumers to achieve life quality outcomes. (B) Achieve meaningful progress above the current baselines. (C) Develop services and supports identified as necessary to meet identified needs.”⁴¹⁴

Several years later, as part of its Service Delivery Reform effort, DDS renewed its efforts to make the RC system more focused on the outcomes experienced by consumers and their families.⁴¹⁵ In 2002–03, DDS and six RCs tracked objective measures of consumer independence, productivity and wages.⁴¹⁶ Implementation of the Bay Area Quality Management System pilot, which encompassed several RCs in the San Francisco Bay Area, likewise emphasized the importance of tracking individual outcomes, including consumer satisfaction with services and supports.⁴¹⁷

In 2009, the Legislature built on these efforts by requiring DDS to “identify a valid and reliable quality assurance instrument that includes assessments of consumer and family satisfaction, provision of services, and personal outcomes.”⁴¹⁸ It was in response to this legislative directive that DDS began compiling aggregate responses to the NCI survey.⁴¹⁹ Following the passage of S.B. 81, each RC is now required to publish results from the NCI survey on its website in machine-readable format,⁴²⁰ so that stakeholders can compare self-reported indicia of consumer satisfaction and well-being among RCs, and between California and other states.

Another outcome measure that has received considerable attention, discussed earlier,⁴²¹ is the variation across RCs and racial/ethnic groups in average POS. Here again, the Legislature has required DDS and RCs to post relevant data on their respective websites so that stakeholders can quantify and track these disparities over time.⁴²²

Yet to date, DDS has not provided RCs with any tangible (i.e., non-reputational) incentives to demonstrate progress on any of these fronts. To promote greater accountability, DDS could develop more concrete ways to reward or penalize RCs based on their success in meeting the

⁴¹³ Act of Sept. 21, 1997, ch. 414, sec. 5, § 4500.5, 1997 Cal. Legis. Serv. 2578, 2761-2762.

⁴¹⁴ Act of Sept. 21, 1997 sec. 15, § 4629.

⁴¹⁵ ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 12.

⁴¹⁶ *Id.* at 14.

⁴¹⁷ *Id.* at 15–16.

⁴¹⁸ Act of Jul. 28, 2009, § 9, 2009 Cal. Legis. Serv. 5144, 5155-56 (codified as amended at CAL WELF. & INST. CODE § 4571(b) (2019)).

⁴¹⁹ See discussion *supra* § IV. B. 1. (NCI Survey Data).

⁴²⁰ See *supra* note 120 and accompanying text.

⁴²¹ See discussion *supra* § V. C. (Assessing the Adequacy of Current Oversight Measures).

⁴²² CAL. WELF. & INST. CODE § 4519.5(a)(1)-(5), (b) (Deering, LEXIS through 2019 Sess.) (requiring the demographic breakdown of POS expenditures, as well as the demographic breakdown of individuals determined to be eligible for RC services but that are not receiving purchase of service funds).

needs of consumers in their respective catchment areas. The data on NCI outcomes and POS disparities could be used for this purpose, either alone or in combination with other outcome measures, such as those proposed recently by the National Quality Forum in a major report on quality measurement in Medicaid-funded programs.⁴²³ Utilizing a clearly defined set of person-centered outcomes, and creating explicit performance incentives, could pave the way for a more efficient and responsive service delivery system.

We are not the first to reach this conclusion. The Service Provider Advisory Committee of Golden Gate Regional Center, discussed earlier,⁴²⁴ likewise emphasized the importance of using “quality standards” to hold the system accountable for individual outcomes such as community inclusion, empowerment, choice, and health and safety.⁴²⁵

The State recently signaled a willingness to tie RCs’ respective compensation levels to their performance on specified outcome measures. The Governor’s FY 2020-21 Budget proposes the allocation of \$78 million to establish a Performance Incentive Program that would “align with each RC performance contract” and “require [each] RC to meet an advanced tier of performance measures and outcomes to receive incentive payments.”⁴²⁶ The stated goals of the program are: “(1) focusing on a quality system that values personal outcome goals for people, such as an improved life and meaningful activities; (2) developing service options to better meet the needs of individuals and families in a person-centered way; (3) promoting the most integrated community settings; and (3) increasing the number of individuals who are competitively employed.”⁴²⁷ DDS, “in collaboration with the DS [Developmental Services] Task Force and other stakeholders,” is charged with “mak[ing] recommendations on how to reform the financing and streamlining of the developmental services delivery system to improve the quality of services delivered,” which in turn necessitates “establishing a system that prioritizes outcomes, innovation and value, which is driven by a funding structure that provides transparency, oversight, and accountability.”⁴²⁸

Although the Governor’s Budget Summary describes the Performance Incentive Program in substantially similar terms, it adds two additional nuances. First, it is worded in a way that suggests even more clearly that the incentive payments are intended to augment, rather than replace, each RC’s conventional budgetary allocation.⁴²⁹ Secondly, in addition to the four specific goals listed above, it describes the program’s aim as “increas[ing] the quality of services and addressing disparities while improving data collection to demonstrate value.”⁴³⁰ The

⁴²³ See NATIONAL QUALITY FORUM, QUALITY IN HOME AND COMMUNITY-BASED SERVICES TO SUPPORT COMMUNITY LIVING: ADDRESSING GAPS IN PERFORMANCE MEASUREMENT (Sept. 2016), <https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=83433> (last visited Jan. 7, 2020).

⁴²⁴ See ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8; see also discussion *supra* p. 66.

⁴²⁵ See ACHIEVING COMPREHENSIVE EFFICIENCY, *supra* note 8, at 27.

⁴²⁶ FY 2020-21 GOVERNOR’S BUDGET, *supra* note 252, at K-27.

⁴²⁷ *Id.* at K-27.

⁴²⁸ *Id.* at K-27.

⁴²⁹ GAVIN NEWSOM, GOVERNOR OF CAL., GOVERNOR’S BUDGET SUMMARY 2020-21 42 (2020), <http://www.ebudget.ca.gov/FullBudgetSummary.pdf> (last visited Jan. 22, 2020) (specifying that RCs “must meet an advanced tier of performance measures to receive *additional* payments”) (emphasis added).

⁴³⁰ *Id.* at 42. Interestingly, the Governor’s Budget does not make specific reference to the importance of addressing disparities or improving data collection. Rather, it includes an extra section called “Assumptions,” which states in much more broadly that “[t]he Department, in collaboration with the DS Task Force and other stakeholders, will make recommendations on how to reform the financing and streamlining of the developmental services delivery system to

Governor’s Budget, in contrast, does not make specific reference to the importance of reducing racial/ethnic disparities or improving data collection.

As of this writing, the details of the proposed Performance Incentive Program are still unclear. Yet in any program of this type, the use of monetary incentives—even if they are framed as “bonus” payments that enlarge rather than redistribute the budgetary pie—creates a risk of unintended consequences. The danger is that the program could magnify pre-existing ethnic/racial and geographic disparities by advantaging consumers who reside in high-performing RCs, and further disadvantaging those who reside in RCs that lag behind. The challenge, then, is to strongly incentivize RCs to advance key policy objectives, but in ways that do not inadvertently magnify gaps in service provision.

One possibility worth considering is to rely on relative rather than absolute performance benchmarks, so that RCs would be rewarded for exceeding their own performance in prior years. In addition to lessening the risk of magnifying geographic disparities, such an approach would mitigate concerns that differing demographic characteristics among consumers in different catchment areas could make it easier for some RCs than others to attain a given set of benchmarks. In addition, DDS could ensure that a sizable fraction of the bonus payments are used not to augment RC’s operational budgets or increase the salaries of their top executives, but rather to provide incentives to the employees who most directly influence outcomes in discrete policy domains. For example, to improve outcomes related to the quality of service coordination and access (which a number of NCI survey questions are designed to measure),⁴³¹ RCs could provide service coordinators with bonuses based on the average satisfaction levels of those they serve. To improve average rates of competitive integrated employment, incentive payments could be targeted not just at service coordinators, but also at any individual staff members who are specifically tasked with improving labor market outcomes. To complement the use of monetary bonuses, DDS could provide special public recognition or commendation to the executive management teams of RCs that meet or exceed specified targets.⁴³² DDS might even

improve the quality of services delivered. This requires establishing a system that prioritizes outcomes, innovation, and value, which is driven by a funding structure that provides transparency, oversight, and accountability.” See FY 2020-21 GOVERNOR’S BUDGET, *supra* note 252, at K-27.

⁴³¹ See *supra* notes 264, 266 and accompanying text (describing the NCI questions related to service coordination and access on which California respectively outperformed and underperformed national benchmarks).

⁴³² Even relatively small monetary bonuses might provide a meaningful incentive to service coordinators and other non-managerial RC staff who subsist on relatively modest salaries. However, small financial rewards may be less likely to change the behavior of RC Executive Directors, most of whom are highly-paid professionals. A review of the RCs’ most recent available 990 Tax Filings on Guidestar (<https://www.guidestar.org/Home.aspx>) reveals that, across all RCs, the median total compensation for Executive Directors is \$271,388. There are, however, some outliers. For example, the 2017 Form 990 for Redwood Coast Regional Center indicates that the RC’s executive director earned \$136,353 in total compensation, see U.S. DEP’T OF THE TREAS., INTERNAL REVENUE SERV., RETURN OF ORGANIZATION EXEMPT FROM INCOME TAX – REDWOOD COAST DEVELOPMENTAL SERVICES CORPORATION 7 (2018), https://pdf.guidestar.org/PDF_Images/2018/942/897/2018-942897317-1054b877-9.pdf (last visited Jan. 13, 2020), whereas the 2016 Form 990 for North Los Angeles County Regional Center reported that the RC’s executive director earned \$361,707 in total compensation, see U.S. DEP’T OF THE TREAS., INTERNAL REVENUE SERV., RETURN OF ORGANIZATION EXEMPT FROM INCOME TAX – NORTH LOS ANGELES COUNTY REGIONAL CENTER (2017), https://pdf.guidestar.org/PDF_Images/2017/237/351/2017-237351340-0f09756c-9.pdf (last visited Jan. 13, 2020). For RC executive directors and other top managers, receiving formal public recognition for outstanding performance, which would likely confer significant reputational benefits, could be a strong motivator.

encourage private-sector involvement in finding creative ways to reward RCs and their staff for demonstrating significant progress.⁴³³

To be sure, any such program would raise a number of practical challenges. For example, since some RCs' staff are unionized and others are not,⁴³⁴ providing monetary inducements to non-managerial employees could require union collaboration. Additionally, defining a set of systemic outcome measures that are meaningful and person-centered, yet also readily quantifiable, is no simple task. Even if stakeholders can agree on a set of suitable metrics, it may be difficult to ensure that RCs report them accurately to DDS. If RC staff know that their compensation depends in part on trends in these reported outcomes, they may be incentivized to magnify favorable data points and mitigate negative ones. Over time, even subtle shifts in reporting practices could bias the data upon which DDS relies.

In short, giving RC personnel stronger incentives to enhance the safety, autonomy, inclusion and well-being of consumers in their respective catchment areas merits serious consideration. Yet doing so in a way that prevents unintended consequences would require careful preparation and monitoring.

(5) Require Independent Evaluation of Pilot Programs

In 2016, the Legislature provided DDS with \$11 million to “assist regional centers (RCs) in the implementation of strategies to reduce disparities in regional centers’ purchase of services (POS)” (Disparities Funding).⁴³⁵ Although the statute initially required RCs to meet with community stakeholders to discuss strategies to address disparities, and to submit reform proposals to DDS for review,⁴³⁶ the law was amended in 2017 “to allow community-based organizations (CBO[s]) to apply for and receive funding to address disparities and/or equitable

⁴³³ The Regional Center Conflict of Interest Standards and Procedures state that a RC employee, contractor, agent or consultant “shall not make, participate in making, or in any way attempt to use his or her position to influence a regional center decision in which he or she knows or has reason to know that he or she, or his or her family member, has a financial interest. . . . [which] includes . . . personal finances of two hundred fifty dollars (\$250) or more.” CAL. CODE REGS. tit. 17, § 54522 (2019); *see also* CAL. GOV’T CODE § 87103(e) (defining “financial interest” for public officials as any “gift or gifts aggregating two hundred fifty dollar (\$250) or more in value”). Since the goal of a performance bonus would *not* be to create a conflict between the interests of RC employees and the interests of the consumers they serve, but rather to better align these two sets of interests, the conflict of interest policy likely would not apply. Nevertheless, since any bonus linked to decisions affecting RC consumers would at least arguably fall within its scope, before encouraging any private-sector entities to award performance bonuses to staff of high-performing RCs, the legislature could expressly exempt any such program from the scope of CAL. CODE REGS. tit. 17, section 54522.

⁴³⁴ *See* Jim Miller, *Union Begins Organizing at Inland Regional Center*, PRESS-ENTER. (May 6, 2012), <https://www.pe.com/2012/05/06/union-begins-organizing-at-inland-regional-center/> (last visited Jan. 22, 2020) (noting that “[a]bout half of the state’s regional centers are unionized”); *see also* *Who is SEIU*, SEIU DEVELOPMENTAL DISABILITIES COUNCIL, <http://seiudd.org/seiu/> (last visited Jan. 22, 2020) (listing ten RCs—Alta RC, Far Northern RC, North Bay RC, RC of the East Bay, Valley Mountain RC, San Andreas RC, Kern RC, Tri-Counties RC, North L.A. County RC, and Harbor RC—whose workers participate in the Service Employees International Union’s CA Developmental Disabilities Council); *Fourteen-Month Struggle Brings First UE Contract at Lanterman*, UEUNION.ORG (Jul. 8, 2019), <https://www.ueunion.org/ue-news/2019/first-union-contract-at-lanterman-regional-center-california> (last visited Jan. 22, 2020) (noting the ratification of a United Electrical, Radio and Machine Workers of America [UE] contract for workers at Lanterman RC).

⁴³⁵ *Disparity Funds Program: Grant Structure*, *supra* note 230 (outlining the structure of the Disparities Funding); *see also* Act of Mar. 1, 2016, ch. 3, sec. 1, § 4519.5, 2016 Cal. Legis. Serv. 6038, 6040-6041 (allocating funding to RCs for the purpose of reducing disparities).

⁴³⁶ *Disparity Funds Program: Grant Structure*, *supra* note 230 (providing background about the Disparities Funding).

access to services.”⁴³⁷ The grant program has been renewed annually, with the most recent request for proposals occurring in August of 2019.⁴³⁸

Publicly available materials repeatedly reference the importance of measuring the effectiveness of these programs. For example, the scoring criteria used to select projects include “how the project will be evaluated to show its effectiveness”; DDS is required to “evaluate status reports to ensure . . . sufficient data is [sic] being collected to measure the project's effectiveness”; and grantees are required to “submit a comprehensive evaluation report that details the effectiveness of the project in reducing disparities in POS expenditures.”⁴³⁹

It is far from clear, however, that DDS will be able to credibly determine which, if any, funded projects are effective in reducing racial and ethnic disparities. Although the DDS website indicates that the proposal review committee includes “staff” from DDS, the Department of Rehabilitation, and DRC,⁴⁴⁰ it is unclear how many of the individuals involved in the selection process have training or expertise in policy analytic techniques. Disparities Funding recipients, most of whom are CBOs, often lack the resources to conduct (or outsource) rigorous program evaluations that meet social scientific standards of internal validity.⁴⁴¹ As of this writing, there is no information on DDS’s website regarding the success, or lack thereof, of the pilot projects implemented by Disparities Funding recipients.⁴⁴²

However well-intentioned the efforts of Disparities Funding grantees and RC staff, measurable progress is unlikely to occur unless the State can reliably identify which pilot projects are successful in reducing service gaps, so these programs can be replicated across the state. Yet the root causes of racial and ethnic POS disparities, like so many other challenges facing the RC system, are complex and multifaceted. If grantees primarily target resources at those individuals who are most eager for help, the results of any informal evaluation are likely to be biased.⁴⁴³

⁴³⁷ CAL. DEP’T OF DEVELOPMENTAL SERVS., CALL FOR APPLICATIONS: NOTICE TO PROSPECTIVE PROPOSER(S) (Aug. 17, 2018), <https://www3.dds.ca.gov/rc/Disparities/1819CallforApplications.pdf> (last visited Jan. 4, 2020) (describing program criteria for 2018-19 funding cycle).

⁴³⁸ CAL. DEP’T OF DEVELOPMENTAL SERVS., CALL FOR DISPARITY FUNDS PROGRAM APPLICATIONS NOTICE TO PROSPECTIVE APPLICANTS (Aug. 1, 2019), <https://www3.dds.ca.gov/rc/Disparities/1920DDSDisparityFundsProgramCFAUpdated.pdf> (last visited Jan. 4, 2020).

⁴³⁹ *Efforts to Reduce Purchase of Service Disparities*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www3.dds.ca.gov/rc/disparities.cfm> (last visited Jan. 5, 2020) (describing the evaluation criteria in “Structure for the Disparity Funds Program” under subsection “Project Evaluation”).

⁴⁴⁰ *See id.*

⁴⁴¹ “Internal validity” refers to whether results obtained in a research setting provide compelling evidence of a cause-and-effect relationship within the particular context examined. A given research finding is deemed internally valid if an observed change in the outcome of interest, such as POS disparities, can be attributed in a statistically credible fashion to a change in the treatment of interest, such as a project being piloted in a particular community. Importantly, the mere fact that a cause-and-effect relationship exists in a particular setting does *not* imply that the same relationship applies universally. *See* Marilyn B. Brewer, *Research Design and Issues of Validity*, in HANDBOOK OF RESEARCH METHODS IN SOCIAL AND PERSONALITY PSYCHOLOGY 3, 4 (Harry T. Reis & Charles M. Judd ed., 2000).

⁴⁴² As of January 4th, 2020, DDS’s (redesigned) website included a link on the *Disparity Funds Program* webpage entitled “Project Measures & Evaluations,” but the webpage was listed as under construction, and no content was displayed. As of this writing, however, the *Project Measures and Evaluations* link has been removed, and the *Disparity Funds Program* webpage lacks any evaluative information. *See Disparity Funds Program*, CAL. DEP’T OF DEVELOPMENTAL SERVS., <https://www3.dds.ca.gov/rc/disparities/disparity-funds-program/> (last visited Jan. 22, 2019).

⁴⁴³ The concern, often referred to as “selection bias,” is that individuals who volunteer to participate in a particular pilot project may differ from those who do not in ways that would bias a comparison of outcomes between the two groups. For example, if most participants belong to two-parent families and most non-participants belong to single-parent families,

The State could address this concern in several ways. First, the Legislature could specify that recipients of Disparities Funding or other pilot grants must include a plan for *objective* program evaluation conducted by *independent* evaluators with appropriate social scientific training. The independence of program evaluators is especially critical; if the CBO personnel implementing the pilot program are the very ones who survey participants on how much they benefitted from it, the results may be biased. Additionally, DDS could invite outside experts, including university faculty, to assist in the selection, design and evaluation of Disparities Funding grants and other state-funded pilot programs. Even federal agencies that employ many scientists with Ph.D.'s in relevant fields recruit outside experts to assist, *pro bono*, with the selection of federal grants,⁴⁴⁴ as do many federal agencies seeking to study the effectiveness of service delivery, or to measure the impact of new regulatory initiatives.⁴⁴⁵ Given that California has far more institutions of higher learning than any other U.S. state,⁴⁴⁶ reaching out to university faculty with relevant expertise could be a particularly cost-effective strategy.

(6) Revisit DDS's Budget Allocation Methodology

As noted repeatedly in this report, there are large disparities in expenditures between different RCs as well as across different racial/ethnic groups.⁴⁴⁷ For example, White children typically

then participants may be more successful over time in increasing their POS simply because their relatives are less time-constrained, even if the program itself has no effect. This concern is especially salient in situations where participants and non-participants differ in ways that are difficult to measure, such as their aptitude for and experience with self-advocacy. Although selection bias can cause agencies to waste resources on ineffective programs, it can be overcome through the use of social scientific research methods.

⁴⁴⁴ See *Merit Review*, NAT'L SCI. FOUND., https://www.nsf.gov/bfa/dias/policy/merit_review/ (last visited Jan. 7, 2020) (noting under "5: Peer Review" that "[e]xternal reviewers' analyses and evaluation of the proposal provide information to the NSF Program Officer in making a recommendation regarding the proposal"); see also *Peer Review*, NAT'L INSTS. OF HEALTH, <https://grants.nih.gov/grants/peer-review.htm> (last visited Jan. 10, 2020) ("The first level of review is carried out by a Scientific Review Group (SRG) composed primarily of non-federal scientists who have expertise in relevant scientific disciplines and current research areas.").

⁴⁴⁵ For example, the Chief Evaluation Office of the U.S. Department of Labor has frequently convened technical working groups, in which outside experts are invited to assist the Department with program implementation and evaluation. See, e.g., SUSAN HOUSEMAN ET AL., WESTAT, DEMONSTRATION AND EVALUATION OF THE SHORT-TIME COMPENSATION PROGRAM IN IOWA AND OREGON iii (2017), <https://www.dol.gov/sites/dolgov/files/OASP/legacy/files/STC-in-Iowa-and-Oregon-Final-Report.pdf> (last visited Jan. 8, 2020) (acknowledging, in a report prepared on behalf of the U.S. Department of Labor's Chief Evaluation Office, the use of a technical working group in completing the analysis); see also U.S. DEP'T OF LABOR, CHIEF EVALUATION OFFICE, PILOT SURVEYS OF EMPLOYEE VOICE IN THE COAL MINING INDUSTRY (Jan. 19, 2012), <https://arlweb.msha.gov/REGS/FEDREG/InformationCollection/1219-0149.pdf> (last visited Feb. 13, 2019) ("Consultations on research design, data collection, approaches, and survey instrument design are part of the design phase of the study of voice in mining workplaces. The consultations are aimed at ensuring the technical soundness of the study methods and verifying the importance, relevance, and accessibility of the information sought in the study. To those ends, experts from a technical working group (TWG) were consulted."); News Release, U.S. Dep't of Labor, Occ. Health & Safety Admin., U.S. Labor Department and Federal Communications Commission announce working group to prevent fatalities in telecommunications industry (Oct. 14, 2014), <https://www.osha.gov/news/newsreleases/national/10142014> (last visited Feb. 13, 2019) ("[The] working group [will] collaborate in the development and implementation of recommended safety practices for the growing telecommunications industry.").

⁴⁴⁶ See *Colleges and Universities in the United States of America (U.S.A.) by State/Possession*, UNIVSEARCH, <http://www.univsearch.com/state.php> (last visited Feb. 13, 2019) (noting that California has 1,246 public and private higher education institutions, nearly twice the number of the next highest state, New York, which has 632).

⁴⁴⁷ See discussion *supra* § V. C. (Assessing the Adequacy of Current Oversight Measures).

receive more than their Hispanic and African-American counterparts, a disparity which exists both statewide and within individual RCs.⁴⁴⁸

In 1999, the California State Auditor issued a report stating that DDS’s budget allocation methodology—which was not based on the needs of consumers within each RC’s catchment area, but on the amount that each RC had spent in the prior year—was contributing to systemic disparities in POS expenditures.⁴⁴⁹ This situation had arisen, in part, because prior spending cuts fell disproportionately on consumers from marginalized communities, who were less well equipped to maintain the level of resources specified in their IPPs.⁴⁵⁰ To mitigate these concerns about the budget allocation methodology, the State Auditor recommended that the State instead develop a “master plan based on a matrix of services” estimating the maximum service level (and cost) for each disability and severity level, which could then be “used as a guide in determining services in individual cases and in estimating each regional center’s annual budget.”⁴⁵¹ In 2012, former DDS director Terri Delgadillo acknowledged that the existing allocation method was problematic from an equity standpoint, and expressed an intent to move toward a client-needs-based methodology over the long term.⁴⁵² Since then, however, DDS has neither made any significant changes to its budget allocation methodology, nor expressed any intention to do so.⁴⁵³

In 2017, Public Counsel’s Children’s Rights Project issued a report summarizing this history, delineating the magnitude of regional and ethnic/racial disparities, and arguing anew that the budget allocation methodology used by DDS was contributing to the problem.⁴⁵⁴ The client-needs-based model endorsed by the State Auditor (and Public Counsel) is one potential way to address this problem. Devising a matrix of disabilities, severity levels, and projected costs could help ameliorate disparities in funding between (and within) RCs.

Yet if rigidly interpreted, such a formulaic approach to RC budget allocation could constrain RCs’ capacity to tailor services and supports to the needs and aspirations of each individual. Under the Lanterman Act, the fact that two consumers receive the same “disability” and “severity” ratings in a formulaic matrix does *not* necessarily imply that they are entitled to

⁴⁴⁸ PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING, *supra* note 8, at 10-11.

⁴⁴⁹ CAL. STATE AUDITOR, *supra* note 272, at 15; *see also id.* at 13-14 (finding that DDS failed to ensure that RCs were properly staffed and that their clients had equal access to case managers).

⁴⁵⁰ *See id.* at 1 (finding that the budget and allocation process used by DDS to fund RCs failed to ensure that clients throughout the state had equal access to needed services, due in large part to the \$106 million in budget cuts imposed between fiscal years 1991-92 and 1994-95). In the late 1990s, the Legislature commissioned Citygate Associates to conduct a follow-up study to determine the level of operations expenses that would enable RCs to meet their state and federal mandates. The resulting report, released in 1999, concluded that the RC system was dramatically underfunded, to the point that a 24% increase in operations funding would be required for RCs to meet their baseline statutory obligations, *see* CITYGATE INDEPENDENT EVALUATION, *supra* note 8, at V-1 (analyzing RCs’ operations budgets and concluding that to meet all of their statutory responsibilities, operations budgets needed to be increased by 24% above the proposed May 1999 Revision).

⁴⁵¹ PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING, *supra* note 8, at 5.

⁴⁵² *See* Delgadillo, *supra* note 280, at 11 (explaining that in purchasing services historically, “[DDS] had allocated money to purchase services, was based on what the regional center, each individual, had spent the prior year,” and that DDS had been made aware of disparities in RC funding and was in “discussions with the regional centers to develop a new funding formula... driven by client characteristics”).

⁴⁵³ *See* PUBLIC COUNSEL, ADDRESSING FUNDING DISPARITIES, *supra* note 8, at 5-6; PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING, *supra* note 8, at 6.

⁴⁵⁴ PUBLIC COUNSEL, ADDRESSING FUNDING DISPARITIES, *supra* note 8, at 1-2.

receive equal amounts of funding. Such a formulaic approach, often known as “capitation,” is not uncommon in other sectors of the health care industry,⁴⁵⁵ and many of the most common critiques of the approach in those settings apply with equal force to the I/DD service delivery system. In time, capitated systems can devolve into “a form of health care rationing by which the overall level of care may be reduced” in the name of cost saving.⁴⁵⁶ High-needs consumers whose disabilities are not fully captured by their official diagnoses can be placed at a particularly severe disadvantage. Thus, at least in a rigidly formulaic form, a client-needs-based system could undermine the principle of needs-based individualization at the core of the Lanterman Act.⁴⁵⁷

In short, DDS’s current budget allocation methodology very likely is contributing to the persistent disparities across RCs and ethnic/racial groups in POS expenditures. It is worth reconsidering the wisdom of this approach. Yet shifting to a rigid client-needs-based model could threaten the heart of the Lanterman Act entitlement. We suggest that DDS or the SCDD, either independently or at the Legislature’s behest, convene a technical working group to explore alternatives to the current budget allocation methodology. The group’s mission should be to identify solutions that could strike an appropriate balance between reducing system-wide disparities and preserving the principle of needs-based individualization.

(7) Create an Independent Oversight Entity

Many large, complex administrative bureaucracies struggle to hold themselves accountable for the quality and timeliness of their performance. For this reason, many federal and state agencies have created offices with independent oversight authority, whose mission is to evaluate the impact of discrete policy initiatives and/or to identify systemic barriers to effective administration.⁴⁵⁸

For example, California’s correctional system is overseen by an inspector general who acts “as the eyes and ears of the public in overseeing the State’s prisons and correctional programs.”⁴⁵⁹ The office of the inspector general performs this function by conducting medical inspections;

⁴⁵⁵ See Trisha Torrey, *How Healthcare Capitation Payment Systems Work*, VERYWELL HEALTH (Dec. 10, 2019), <https://www.verywellhealth.com/capitation-the-definition-of-capitation-2615119> (last visited Jan. 8, 2020).

⁴⁵⁶ *Id.*

⁴⁵⁷ LANTERMAN ENTITLEMENT REPORT, *supra* note 5, § IV. (The Principle of Needs-Based Individualization).

⁴⁵⁸ See *Inspectors General Directory*, COUNCIL OF THE INSPECTORS GEN. ON INTEGRITY & EFFICIENCY, <https://ignet.gov/content/inspectors-general-directory> (last visited Jan. 8, 2020) (providing contact information for the federal government’s 71 agency inspectors general, including those for the National Labor Relations Board and the Departments of Health and Human Services, Housing and Urban Development, Labor, and Education); see also *Directory of State and Local Inspector General Agencies*, ASS’N OF INSPECTORS GEN., <https://inspectorsgeneral.org/useful-links/directory-of-state-and-local-government-oversight-agencies/> (last visited Jan. 8, 2020) (providing, by state, contact information for state and local inspectors general (IG), including California’s OIG (which oversees the correctional system) and the OIG for California Highway Patrol; New York’s State Inspector General, Office of Welfare IG, State Unified Court System IG, State Workers Compensation Board Fraud IG, and Port Authority IG; Illinois’ State Auditor, Department of Health and Family Services IG, Department of Human Services IG, Legislative IG, Department of Children & Family Services IG, Secretary of State IG, and Executive IG; Maryland’s Department of Health and Mental Hygiene IG and Department of Public Safety and Correctional Services IG; Florida’s Agency of Health Care Administration IG and Department of Health IG; and Texas’ Health & Human Services Commission IG, Department of Criminal Justice IG, and Department of Public Safety IG).

⁴⁵⁹ *Office of the Inspector General*, CA.GOV, <https://www.ca.gov/agency/?item=office-of-the-inspector-general> (last visited Jan. 4, 2020).

carrying out critical incident, employee discipline, and use of force monitoring; reviewing complaints filed against the Department of Corrections and Rehabilitation; serving as chair of the California Rehabilitation Oversight Board, and conducting select reviews at the request of the Governor, Assembly, or Senate.⁴⁶⁰

In 2017, the Legislature approved a law that created a new Inspector General for Transportation, who is charged with ensuring that “[t]he [D]epartment [of Transportation], and external entities that receive state and federal transportation funds from the department, are spending those funds efficiently, effectively, economically, and in compliance with applicable state and federal requirements.”⁴⁶¹

The case for an inspector general (or similar entity responsible for independent system monitoring) is particularly compelling in the case of DDS, since DDS does not dispense any benefits or administer any programs directly to the public, but relies on a network of 21 private nonprofit agencies to do so on its behalf. Although the State has created two other entities with pervasive oversight authority, the State Controller⁴⁶² and the State Auditor,⁴⁶³ they have devoted

⁴⁶⁰ OFFICE OF THE INSPECTOR GEN., WHAT WE DO (2019), https://www.oig.ca.gov/wp-content/uploads/2019/05/What_We_Do.pdf (last visited Jan. 17, 2020).

⁴⁶¹ Road Repair and Accountability Act of 2017, Ch. 5, § 5, 2017 Cal. Legis. Serv. 30, 37-38 (codified as amended at CAL. GOV'T CODE § 14460 (2019)); *see also* Patrick McGreevy, *Caltrans investigations find waste and wrongdoing in state transportation programs*, LOS ANGELES TIMES (Dec. 6, 2019), <https://www.latimes.com/california/story/2019-12-06/waste-fraud-audit-california-transportation-spending> (last visited Jan. 24, 2020) (describing more than \$13 million in “disallowed” expenditures uncovered by auditors hired by new inspector general).

⁴⁶² *See State Controller's Function*, CAL. STATE CONTROLLER'S OFFICE, https://sco.ca.gov/eo_about_func.html (last visited Jan. 8, 2020) (noting the State Controller's is “responsible for accountability and disbursement of the state's financial resources”); *see also* CAL. GOV'T CODE §§ 12410, 12411 (Deering, LEXIS through 2019 Sess.) (noting that the State Controller “shall superintend the fiscal concerns of the state... shall audit all claims against the state, and may audit the disbursement of any state money, for correctness, legality, and for sufficient provision of law for payment” and also “shall suggest plans for the improvement and management of revenues”).

⁴⁶³ *Mission and Philosophy*, CAL. STATE AUDITOR, <https://www.auditor.ca.gov/aboutus/mission> (last visited Jan. 8, 2020) (“The California State Auditor promotes the efficient and effective management of public funds and programs by providing to citizens and the State independent, objective, accurate, and timely evaluations of state and local governments’ activities.”); *see also* CAL. GOV'T CODE § 10501 (Deering, LEXIS through 2019 Sess.). (noting the role of the Auditor General is to “ascertain facts, review reports and take action thereon...concerning the revenues and expenditures of the State, its departments, subdivisions, and agencies”).

little attention to DDS and the RC system.⁴⁶⁴ This situation is likely to persist given both offices' limited mandates and bandwidths.⁴⁶⁵

In early 2019, a bill was introduced in the California Assembly that would have created an independent oversight entity, such as an Inspector General, to oversee the RC system.⁴⁶⁶ Despite being amended to require only that DDS convene a working group to examine topics related to oversight and accountability in the developmental services system, the measure did not pass.⁴⁶⁷

To enhance the level of statewide oversight and accountability, the Legislature could establish an Inspector General or similar independent entity to “act as the eyes and ears of the public” through ongoing monitoring and evaluation of DDS and the RC system. If sufficiently well-resourced and mission driven, an Inspector General could help ensure that any proposed reforms to the IDD system are implemented in a way that conserves taxpayer dollars while effectively meeting the needs of individuals with IDD and their families.

⁴⁶⁴ Over the past two decades, the State Controller and State Auditor have paid limited attention to DDS. In this period, the Controller conducted one large audit in 2016. CAL. STATE CONTROLLER, DEPARTMENT OF DEVELOPMENTAL SERVICES: ACCOUNTING AND ADMINISTRATIVE CONTROLS REVIEW (2016), https://www.sco.ca.gov/Files-AUD/11_2016saa_dds_account.pdf (last visited Jan. 8, 2020) (reviewing the period July 1, 2011 through June 30, 2015). Also in this period, the State Auditor released seven reports specifically focused on DDS. *See* CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: REGIONAL CENTER BUDGETS ARE NOT BASED ON NEEDS, AND DEPARTMENTAL OVERSIGHT COULD BE IMPROVED (1998), <https://www.auditor.ca.gov/pdfs/reports/97024.pdf> (last visited Jan. 8, 2020); CAL. STATE AUDITOR, *supra* note 272; CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: A MORE UNIFORM AND TRANSPARENT PROCUREMENT AND RATE-SETTING PROCESS WOULD IMPROVE THE COST-EFFECTIVENESS OF REGIONAL CENTERS (2010), <https://www.bsa.ca.gov/pdfs/reports/2009-118.pdf> (last visited Jan. 8, 2020); CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: POOR-QUALITY INVESTIGATIONS, OUTDATED POLICIES, LEADERSHIP AND STAFFING PROBLEMS, AND UNTIMELY LICENSING REVIEWS PUT RESIDENTS AT RISK (2013), <https://www.bsa.ca.gov/pdfs/reports/2012-107.pdf> (last visited Jan. 8, 2020); CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: ITS PROCESS FOR ASSESSING FEES PAID BY PARENTS OF CHILDREN LIVING IN RESIDENTIAL FACILITIES IS WOEFULLY INEFFICIENT AND INCONSISTENT (2015), <https://www.bsa.ca.gov/pdfs/reports/2014-118.pdf> (last visited Jan. 8, 2020); CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: IT CAN DO MORE TO ENSURE THAT REGIONAL CENTERS COMPLY WITH THE LEGISLATURE'S COST-CONTAINMENT MEASURES UNDER THE LANTERMAN ACT (2015), <https://www.bsa.ca.gov/pdfs/reports/2015-501.pdf> (last visited Jan. 8, 2020); CAL. STATE AUDITOR, DEPARTMENT OF DEVELOPMENTAL SERVICES: IT CANNOT VERIFY THAT VENDOR RATES FOR IN-HOME RESPITE SERVICES ARE APPROPRIATE AND THAT REGIONAL CENTERS AND VENDORS MEET APPLICABLE REQUIREMENTS (2016), <https://www.bsa.ca.gov/pdfs/reports/2016-108.pdf> (last visited Jan. 8, 2020).

⁴⁶⁵ *See supra* note 464 and accompanying text (noting that over the last 20 years the State Auditor has released only seven audit reports on DDS and the State Controller has only released one audit report on DDS). This low audit rate is especially striking when compared to the number of audits conducted annually by department-specific Inspectors General in other policy arenas. *See, e.g., Audit and Other Reports*, U.S. DEP'T OF LABOR, https://www.oig.dol.gov/cgi-bin/oa_rpts-v4.cgi?s=&y=2019&a=all (last visited Jan. 8) (listing the Office of Inspector General in the Department of Labor's audit reports from last year, totaling 25 distinct audit reports in 2019).

⁴⁶⁶ *See* A.B. 812, 2019 Leg., Reg. Sess. (as introduced by Cal. Assembly Member Frazier, Feb. 20, 2019).

⁴⁶⁷ *See* A.B. 812, 2019 Leg., Reg. Sess. (as amended in Cal Assembly, Apr. 25, 2019).

VII. Conclusion

The unique design of California’s RC system—whereby DDS authorizes 21 private, nonprofit corporations across the state to dispense state services and supports to more than 330,000 individuals with I/DD—poses unique administrative challenges. Even in the best of circumstances, the complexity of the service delivery system makes it difficult for the State to maintain system-wide transparency and accountability. Yet if history is any guide, the State will one day be forced to carry out the provisions of the Lanterman Act in a reduced funding environment. When that day comes, policy makers will be poorly equipped to respond unless they can discern clearly how resources are being distributed across different programs, and how each program is advancing individual and systemic goals. With these realities in mind, we first assessed current levels of system-wide transparency and accountability, then suggested ways in which the State’s performance on both these dimensions could be improved.

Our research brought to light significant shortfalls in current levels of systemic transparency. Although we did not examine in detail DDS’s reporting obligations to other (quasi)government entities, our investigation of public disclosure provisions revealed numerous deficiencies. Many RCs have failed to comply with statutory directives to provide up-to-date information on public-facing websites. DDS is also not fully compliant with its reporting obligations, particularly those pertaining to the public disclosure of administrative hearing decisions.

Our research likewise suggests that there is considerable room for improvement in system-wide oversight and accountability. To date, DDS has deployed few “intermediate” oversight mechanisms that transcend mere soft persuasion (such as education and training), yet do not involve the use of CAPs. Since RCs’ respective levels of financial support are not tied to their success in improving person-centered outcomes, it is not surprising that overall levels of consumer satisfaction are unimpressive by national standards, and that the State has not managed to eliminate persistent funding disparities across different RCs and racial/ethnic groups.

We propose a number of reforms to improve systemic transparency. Many of these would require relatively modest changes to the status quo. For example, we recommend that the Legislature more rigorously enforce current reporting requirements, especially those pertaining to the posting of administrative hearing decisions; require mandatory public disclosures to be provided in machine-readable format; standardize the location, format and content of RCs’ web-based disclosures; improve the methods used to classify consumers by their ethnicity and whether they reside in the community; require RCs to report intake and assessment data; and make RCs subject to the California Public Records Act. To bring about more systemic and far-reaching changes, we suggest that the State revisit its prior (unsuccessful) efforts to build an integrated, high-performance I/DD database.

To strengthen system-wide accountability, we propose two types of reforms. First, we propose a number of measures to strengthen the capacity of consumers and families to enforce their rights to adequate services and supports. These proposals include explicitly allowing individuals who receive intake and assessment services to file complaints; invariably requiring RCs to notify consumers in writing if there is any change to services listed in their IPPs; deterring RCs from “deactivating” consumers who do not receive RC services for prolonged periods of time; and

allowing consumers to request independent evaluations, and to recover litigation costs if they prevail in disputes with RCs. Secondly, with the goal of strengthening public oversight, we suggest that the Legislature explicitly protect RC board members from retaliation; require DDS and RCs to publish all CAPs online; require RCs to collect and report granular data on special incident reports and NCI survey responses; give RCs stronger incentives to reach person-centered performance targets; require independent evaluations of pilot projects designed to further key policy goals; revisit DDS's budget allocation methodology; and create an inspector general or other independent entity to monitor the entire RC system.

Taking measures to improve the transparency and accountability of the RC system now—before another fiscal crisis necessitates significant spending cuts—is one of the most prudent steps the State can take to safeguard the Lanterman Act's historic legacy.

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