Stanford Law School | Stanford Intellectual & Developmental Disabilities Law and Policy Project (SIDDLAPP)

A Fiscal Primer on California's Regional Center System

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(i) Table of Abbreviations

Acronym	Term
A&D FPL	Aged and Disabled Federal Poverty Level Medi-Cal
ABA	Applied Behavioral Analysis
ABD-MN	Aged, Blind, and Disabled Medically-Needy Medi-Cal
ABLE/CalABLE	Achieving a Better Life Experience Account
Act	Lanterman Act
ADA	Americans with Disabilities Act
ALJ	Administrative Law Judge
ARCA	Association of Regional Center Agencies
BHT	Behavioral Health Treatment
CCF	Community Care Facility (such as licensed group homes)
CDER	Client Development Evaluation Report
CHIP	Children's Health Insurance Program
CIE	Competitive, Integrated Employment
CMS	Centers for Medicare and Medicaid Services
CSSA	County Social Services Agency
DC	Developmental Center
DDS	Department of Developmental Services
DHCS	California Department of Health Care Services
DRC	Disability Rights California (formerly Protection and Advocacy, Inc.)
EPSDT	Early and Periodic Screening, Diagnosis & Treatment
FAPE	Free and Appropriate Public Education
FM	Federally-Matched
FPL	Federal Poverty Line
FSFM	Full-Scope, Federally-Matched
GF	State General Fund
HCBS	Home and Community-Based Services
HCBS Waiver	1915(c) HCBS Waiver
HO	Hearing Officer
ICF	Intermediate Care Facility (funded by CMS, ICFs for Individuals with Intellectual Disability, or ICF-IIDs, technically include CA developmental centers)
I/DD	Intellectual and developmental disabilit(ies)
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IPP	Individualized Planning Process
LOC	Level of Care

LRE	Least restrictive environment (i.e. the right to community-based treatment)
MAGI	Modified Adjusted Gross Income Medicaid
NCIS	National Core Indicators Survey
OAH	Office of Administrative Hearings
OPS	Operations
PAI	Protection and Advocacy Inc. (precursor to DRC)
PDF	Program Development Fund
POS	Purchase of Services
QAF	Quality Assurance Fees
QIDP	Qualified Intellectual Disability Professional
RC	Regional Center
SC	Service Coordinator (regional center case manager)
SCDD	California State Council on Developmental Disabilities
SGA	Substantial Gainful Activity
SNF	Skilled Nursing Facility
1915(i) SPA	1915(i) State Plan Amendment
SSA	Federal Social Security Administration
SSBG	Social Security Block Grants
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Insurance
TCM	Targeted Case Management
TMFTP	"The Money Follows the Person" (earmarked federal funding program)
WDP	250% Working Disabled Medi-Cal

(ii) Table of Regional Centers[1]

Acronym	Regional Center Full Name	Location	Consumers Served
ACRC	Alta Regional Center	Sacramento	22,700
CVRC	Central Valley Regional Center	Fresno	18,979
ELARC	Eastern LA Regional Center	Alhambra	11,480
FDLRC	Frank D. Lanterman Regional Center	Los Angeles	11,440
FNRC	Far Northern Regional Center	Redding	8,188
GGRC	Golden Gate Regional Center	San Francisco	9,642
HRC	Harbor Regional Center	Torrance	14,237
IRC	Inland Regional Center	San Bernadino	33,853
KRC	Kern Regional Center	Bakersfield	8,691
NBRC	North Bay Regional Center	Napa	9,617
NLACRC	Northern LA County Regional Center	Chatsworth	26,162
RCEB	Regional Center of the East Bay	San Leandro	20,568
RCOC	Regional Center of Orange County	Santa Ana	22,031
RCRC	Redwood Coast Regional Center	Ukiah	3,997
SARC	San Andreas Regional Center	San Jose	18,165
SCLARC	South Central LA Regional Center	Los Angeles	16,485
SDRC	San Diego Regional Center	San Diego	27,127
SG/PRC	San Gabriel/Pomona Regional Center	Pomona	14,118
TCRC	Tri-Counties Regional Center	Santa Barbara	16,265
VMRC	Valley Mountain Regional Center	Stockton	14,631
WRC	Westside Regional Center	Culver City	9,490

[1] *Regional Center Oversight Dashboard*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/RCOversight/Overview_WRC.cfm (last visited Jan. 17, 2019).

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 Act, now codified in the California Welfare and Institutions Code, 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 developmental disabilities 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 regional centers) 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 regional center 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.

This report is part of a series issued by the Stanford Intellectual and Developmental Disabilities Law and Policy Project (SIDDLAPP), at the request of Disability Rights California (DRC) and the State Council on Developmental Disabilities (SCDD), to explore steps that the state might take to protect the Lanterman Act entitlement. The research was conducted from September, 2017 through June, 2019, by a team of researchers—including Stanford law students, research

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[2] CAL. WELF. & INST. CODE § 4501 (2017).

[3] *See* GRETCHEN ENGQUIST ET. AL., CTR. HEALTH CARE STRATEGIES, SYSTEMS OF CARE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A SURVEY OF STATES (Sept. 2012) (providing survey results of different states' systems of care for individuals with I/DD, such as states with population and/or income gaps and those states administering care via the HCBS Waiver) (last visited Feb. 14, 2019), http://www.chcs.org/media/IDD_State_Priorities_and_Barriers_Snapshot_082812.pdf.

fellows, and undergraduates—under the direction of Alison Morantz, Director of SIDDLAPP and the James and Nancy Kelso Professor of Law.

Research team members used several complementary approaches to investigate each issue considered. 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 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 regional center 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: DRC, 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 purpose of this report, A Fiscal Primer on California's Regional Center System, is to provide a comprehensive overview of the laws, institutions, and demographic trends that are shaping the regional center system in California. The report begins with a general historical overview, provides a budgetary survey of the I/DD service delivery system, and then summarizes the escalating fiscal challenges that are taxing the system.

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

II. Executive Summary

California's regional center (RC) system has undergone transformative changes in the half-century since the passage of the Lanterman Act. Following the exodus of individuals with intellectual and developmental disabilities (I/DD) from state institutions, and their integration into their communities, came a dramatic proliferation in services designed to promote consumer independence. This is not to say that the system has evolved in a consistent or linear fashion. For example, although eligibility criteria were expanded in the 1970s to include more developmental disabilities, the eligibility criteria were tightened after the turn of the millennium in ways that excluded some individuals from coverage. The pace of deinstitutionalization has also fluctuated over time, in part due to focused pressure from legal advocacy organizations.

At the same time, the demographic composition of the consumer population has shifted in ways that would have been difficult to anticipate a half century ago. About 40% of today's regional center consumers are Hispanic, and almost two-thirds are under the age of 22. Once a relatively rare condition, autism has grown to comprise over a quarter of all diagnoses.

The core fiscal challenge of California' I/DD service support system has been to fund an open-ended entitlement system on a fixed budget. Despite the difficulty of anticipating the needs of the more than 325,000 consumers statewide who depend on RC support, the total budget of the Department of Developmental Services (DDS) is determined at the beginning of the fiscal year.

Although the system was initially funded with state resources, the overall share of federal Medicaid funding has increased markedly over time. If current trends persist, most Lanterman Act consumers will be eligible for two Medicaid programs designed to support individuals in the home or in community-based settings. Although advantageous from a budgetary standpoint, the state's substantial reliance on Medicaid funds makes the system vulnerable to cuts in federal aid.

A variety of fiscal and demographic trends are likely to tax the capacity of the service delivery system to adequately support consumers in the coming years. First and foremost, the percentage of California residents requiring regional center support continues to increase. The aging of the consumer and caregiver populations, and the dramatic rise in the prevalence of autism, are likely to increase costs while diminishing the capacity of family members to support relatives in their homes. The supply side of the service delivery system is also facing significant challenges. Below-market reimbursement rates, the high cost of housing, and rising labor costs are driving some providers out of the industry. Regional centers are likewise struggling to attract and retain qualified personnel due to their limited capacity to offer competitive salaries to qualified personnel. Finally, the failure of many home and community-based settings to comply with regulations issued by the Centers for Medicare and Medicaid Services could threaten the availability of federal funding over the long term. Since the state is currently experiencing a

period of relative economic prosperity, we recommend that it address these escalating challenges in a systematic fashion and thereby protect the Lanterman Act's vibrancy for generations to come.

III. Historical Overview

A. Major Statutory and Structural Reforms: 1965–2018

In 1965, prior to passage of the Lanterman Act, 12,648 Californians with I/DD resided in large state institutions.[4] Even as thousands of Californians with I/DD waited an average of two years to gain admission to these facilities,[5] newspaper and television reports nationwide exposed the deplorable conditions faced by their residents. One report, produced by three nationally-recognized experts in the field of intellectual disability, found that "[m]entally retarded patients [at Sonoma State Hospital] . . . [were] treated like, and consequently behaved like, animals in a zoo."[6] Distressed by these reports yet unable to meet their children's substantial needs at home, some parents advocated for a new option: government-funded, community-based services.

Partly as a result of these advocacy efforts, the Study Commission on Mental Retardation released a report in 1965 calling on California to accept responsibility for supporting persons with I/DD through a regional system of community services.[7] The report identified at least seven different state agencies that shared partial responsibility for the care of persons with I/DD.[8] Finding that this disjointed system placed an unsustainable burden on individuals with I/DD and their families, the report recommended that California provide services "so complete as to meet the needs of each retarded person, regardless of his age or degree of handicap, at each stage of his life development."[9] "Moreover," the report continued, "no retarded person should enter an institution who can be cared for in the community, and no one should remain in an institution who can adjust outside."[10]

Later that same year, the California Assembly, led by Assemblyman Frank Lanterman, embraced the Commission's vision through the passage of Assembly Bill 691. The bill called for the

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[4] STUDY COMMISSION ON MENTAL RETARDATION, THE UNDEVELOPED RESOURCE: A PLAN FOR THE MENTALLY RETARDED IN CALIFORNIA 28 (1965) [hereinafter THE UNDEVELOPED RESOURCE]; *See also* FRANK D. LANTERMAN REGIONAL CENTER, STRENGTHENING THE COMMITMENT . . . REINVESTING IN THE SYSTEM: A JOURNEY OF COMMUNITY PARTNERSHIP 3 (2016) [hereinafter STRENGTHENING], https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf (last visited Jan. 17, 2019) (noting that in the 1950s there were sometimes as few as five, and sometimes as many as nine, state institutions in which people with I/DD resided).

[5] THE UNDEVELOPED RESOURCE, *supra* note 4, at 28 (noting "the average waiting time for admission to state hospitals is about two years").

[6] STRENGTHENING, *supra* note 4, at 7-8 (quoting Dr. Gunnar Dybwad, Dr. Richard Koch, and Dr. Ivy Mooring).

[7] THE UNDEVELOPED RESOURCE, *supra* note 4, at 3 (calling for "Establishment of Regional Diagnostic and Counseling Centers, located no more than two hours' driving time from any California family").

[8] *Id.* at 35 (identifying State Departments of Mental Hygiene, Education, Employment, Public Health, Vocational Rehabilitation, Social Welfare, and Youth Authority).

[9] *Id.* at 1.

[10] *Id.* at 1-2.

establishment of regional centers (RCs), which would contract with the Department of Public Health to provide diagnosis, counseling, and continuing services for "mentally retarded persons and their families."[11] Shortly thereafter, the first two pilot RCs—Children's Hospital Los Angeles and San Francisco Aid for Retarded Children—began providing community-placement recommendations for individuals who had been waitlisted for admission to state institutions.

As the number of individuals residing in state institutions continued to grow, so too did interest in community-based alternatives. By 1968, 13,175 individuals with I/DD resided in state institutions, which were operating at about 2,500 residents over capacity.[12] In response to these overcrowded conditions, the Assembly commissioned a study on the status of the two pilot RCs.[13]

The resulting report, published in 1969, described the primary role of RCs as coordinating the provision of services. The first step in assisting a family was to determine whether another agency (or agencies) bore responsibility for providing needed services and supports. If all needed services were available from other agencies, the RC only assisted the family in securing these resources, and the case was classified as one of "information and inquiry."[14] If, however, the family required services or supports that other agencies could not provide, the case became "active."[15] The report noted that "information and inquiry" cases outnumbered "active" ones by a two-to-one margin.[16]

Another important source of variation among RC consumers was their receipt of purchase of services (POS) funds to cover services and supports that RC personnel were unable to provide in-house. RC clients who received POS funds cost the state an average of $2,346 per year (about $17,347 in 2018 dollars), whereas "information and inquiry" clients averaged just $874 ($6,461 in 2018 dollars).[17] Both of these figures were dwarfed, however, by the cost of state institutions

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[11] 1965 Cal. Legis. Serv. Ch. 1242 (A.B. 691) (codified at CAL. HEALTH & SAFETY CODE §§ 415–416.2 (1969)) (repealed 1969).

[12] ASSEMBLY OFFICE OF RES., CAL. LEG., A PROPOSAL TO REORGANIZE CALIFORNIA'S FRAGMENTED SYSTEM OF SERVICES FOR THE MENTALLY RETARDED E-1 (1969) [hereinafter PROPOSAL TO REORGANIZE], https://www.dds.ca.gov/Publications/HistoricPub/1969_Cal_FragmentedSvcsMR.pdf (last visited Jan. 17, 2019).

[13] CAL. DEP'T PUB. HEALTH, REGIONAL CENTERS FOR THE MENTALLY RETARDED: THE FIRST TWO YEARS 5–8 (1969), http://www.dds.ca.gov/Publications/HistoricPub/1969_RCsfortheMR_First2Yrs.pdf (last visited Jan. 17, 2019).

[14] *Id.* at 4.

[15] *Id.* at 4–5.

[16] *Id.* at 4.

[17] PROPOSAL TO REORGANIZE, *supra* note 12, at A4 (Nominal figures are given for FY 1967─68, and we calculated these annual averages by multiplying the average monthly state expenditures for FY 1967─68 by 12); *see also CPI Inflation Calculator*, U.S. BUREAU OF LABOR STATISTICS, https://fred.stlouisfed.org/series/CPIAUCSL (last visited Apr. 25, 2019) (converting January 1968 dollars to August 2018 dollars).

care, which averaged $5,037–$7,190 per year ($37,245–$53,165 in 2018 dollars).[18] The report predicted that the annual cost of care for people receiving RC services would rise by about 5% annually.[19] Based on these findings, the authors deemed the pilot RCs a success and recommended that the model be expanded into a statewide system that would provide "diagnosis, counseling, referral, purchase of services and guardianship for people with developmental disabilities"[20] through a mixture of public and private funding.[21]

In 1969, Governor Ronald Reagan signed into law Assembly Bill 225, which proclaimed, "California accepts a responsibility for its mentally retarded citizens and an obligation to them which it must discharge."[22] This landmark legislation, and its subsequent statutory amendments, are generally known as the "Lanterman Act."[23] The Act required that a system of community-based supports be developed to serve Californians with I/DD.[24] The bill also restructured the way in which services were provided. Instead of being divided among eight different state agencies, responsibility for the provision of services and supports was transferred to a network of

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[18] PROPOSAL TO REORGANIZE, *supra* note 12, at H1 (Nominal figures are given for FY 1967─68, and we calculated these annual averages by multiplying the average daily costs in FY 1967─68 of state institution care for the categories "Generally Mentally Retarded" and "Intensive Nursing – Geriatric Care" by 365, *respectively*); *see also CPI Inflation Calculator*, *supra* note 17 (converting January 1968 dollars to August 2018 dollars).

[19] PROPOSAL TO REORGANIZE, *supra* note 12, at A7.

[20] *Id.* at 14.

[21] A PROPOSAL TO REORGANIZE, *supra* note 12, at vi (The report recommended: "Families of children under the age of 18 who are receiving out-of-home services purchased by the regional center will be required to contribute to the cost of services depending upon their ability to pay, but not to exceed the cost of caring for a normal child at home. Fees shall be the same regardless of where the child receives care and shall take into consideration extraordinary family expense in the care of the child. All funds thus collected shall be used for additional services.")

[22] 1969 Cal. Legis. Serv. Ch. 1594 § 38001 (A.B. 225) (codified at CAL. WELF. & INST. § 4501 (2019)).

[23] It should be noted that there is some inconsistency regarding the use of the term "Lanterman Act." The original 1969 Act was officially titled the "Lanterman Mental Retardation Services Act of 1969," *see id.* § 38000. Some sources simply refer to the original 1969 Act as the "Lanterman Act," *see, e.g.*, OFFICE HUMAN RIGHTS & ADVOCACY. SERVS., CAL. DEP'T DEVELOPMENTAL SERVS., A CONSUMER'S GUIDE TO THE LANTERMAN ACT 3 (2001), https://www.dds.ca.gov/ConsumerCorner/docs/LA_Guide.pdf (last visited Jan. 17, 2019) (describing the original 1969 Act as the "Lanterman Act"). Other sources, however, use the term "Lanterman Act" to refer to the 1977 legislation that expanded the scope of the original legislation, *see, e.g.*, *Lanterman Developmental Disabilities Act*, WIKIPEDIA, https://en.wikipedia.org/wiki/Lanterman_Developmental_Disabilities_Act (last visited Jan. 17, 2019) (using "Lanterman Act" to refer to 1977 legislation). The popular names of each of the Act's amendments have likewise evolved over time, and as a result may be inconsistently, *see, e.g.*, *History of Regional Centers and the Lanterman Act*, ALTA CALIFORNIA REGIONAL CENTER, https://www.altaregional.org/history-regional-centers (last visited Jan. 17, 2019) (noting that the original Act passed in 1969, originally called the "Lanterman Mental Retardation Act," was renamed the "Lanterman Developmental Disabilities Services Act" in 1977). Since these semantic distinctions are relatively immaterial for our purposes, we have opted to use the term "Lanterman Act" to refer to the original Act as well as its subsequent statutory amendments.

[24] 1969 Cal. Legis. Serv. Ch. 1244 § 38100 (A.B. 225) (codified at CAL. WELF. & INST. CODE § 4620(a) (2019)) (noting the importance of "provid[ing] a link between the mentally retarded and services in the community, including state-operated services, to the end that the mentally retarded and their families may have access to the facilities best suited to them throughout the life of the retarded person").

independent, non-profit RCs. Declaring that "[t]he services provided to individuals and their families by regional centers [was] of such a special and unique nature that it [could not] be satisfactorily provided by state agencies," the Act characterized the independence of the RCs as a critical precondition for the provision of appropriate support.[25]

In 1977, the legislature passed Assembly Bill 846,[26] which made permanent the system of independent RCs and further cemented Frank Lanterman's vision of community-based services for Californians with I/DD. The legislature also amended the Lanterman Act by requiring RCs to contract with the newly-created Department of Developmental Services (DDS),[27] which was vested with "jurisdiction over the execution of the laws relating to the care, custody, and treatment of developmentally disabled persons"[28] along with the oversight of state institutions for people with I/DD, known as Developmental Centers (DCs).[29] DDS, in turn, encouraged the formation of the Association of Regional Center Agencies (ARCA), an organization that represents the RCs' interests on issues of common concern.[30] The formation of ARCA made it possible for DDS to engage with a single representative entity instead of 21 individual regional centers, although agreements between ARCA and DDS are not binding on individual RCs unless the same provisions are included in regional centers' respective contracts with DDS.[31]

The Act also created several other entities whose intended functions were designed to be independent of the RCs to provide system oversight and legal protections. The federally-funded State Council on Developmental Disabilities (SCDD), which operated on a statewide level, was charged with planning and advocating on behalf of persons with I/DD and their families.[32] A

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[25] *Id.* (codified at CAL. WELF. & INST. CODE § 4620(b) (2019)).

[26] 1977 Cal. Legis. Serv. Ch. 1252 § 550 (A.B. 846) (later known as the "Lanterman Developmental Disabilities Act" and codified at CAL. WELF. & INST. CODE § 4500 (2019)).

[27] *See id.* (codified starting at CAL. WELF. & INST. CODE § 4620 (2019)).

[28] *Id.* § 549 (codified at CAL. WELF. & INST. CODE § 4416 (2019)).

[29] *Id.* § 549 (codified at CAL. WELF. & INST. CODE §§ 4440–4440.1 (2019)). A state institution under the jurisdiction of DDS is known as a developmental center, *see* CAL. WELF. & INST. CODE § 4440.5 (2019).

[30] CAL. DEP'T FIN., FISCAL AND PROGRAM COMPLIANCE REVIEW OF DEPARTMENT OF DEVELOPMENTAL SERVICES REGIONAL CENTER OPERATIONS 93-94 (Apr. 1979), https://www.dds.ca.gov/Publications/HistoricPub/1979_FiscalPrgmComplianceReview_DDSRCOPs.pdf (last visited Feb. 14, 2019).

[31] *Id.* at 94.

[32] Developmental Disabilities Services and Facilities Construction Amendments, Pub. L. No. 91–517, § 134, 84 Stat. 1316, 1319–21 (1970). The California State Council on Developmental Disabilities (SCDD) was established to "engage in advocacy, capacity building, and systemic change activities that are consistent with the policy contained in federal law and contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system that includes the provision of needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families," *see* CAL. WELF. & INST. CODE § 4520(c) (2017); *see also* 42 U.S.C. § 15021 (2019); *see also* 42 U.S.C. § 15025 (2019). SCDD's main responsibility is to prepare and implement a State Plan at least every five years, and

network of 13 Area Boards on Developmental Disabilities,[33] and the overarching Organization of Area Boards, were tasked with planning, monitoring, and advocating for consumers.[34] Finally, in accordance with new federal mandates authorized by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), California created a new, independent entity called Protection & Advocacy, Inc. (PAI) whose mandate was to provide legal support to underserved populations with I/DD and to work at the state level to protect and empower consumers.[35] Independent of service-providing agencies such as DDS and RCs, PAI was intended not only to provide legal support to individuals with I/DD, but also to provide self-advocacy training and technical assistance.[36] Shortly after its creation in 1978, the organization began bringing individual and class action lawsuits on behalf of Californians with I/DD.

By 1979, then, the basic contours of the current I/DD service delivery system were already in place. For the next 35 years, DDS funded the 21 independent RCs and ran the Developmental Centers (DCs), while SCDD, Area Boards, and PAI performed a variety of complementary functions related to advocacy, monitoring and oversight.[37]

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to review and revise the State Plan on an annual basis, *see* CAL. WELF. & INST. CODE § 4561 (2017); *see also* 42 U.S.C. § 15024–25 (2018). The State Plan specifically includes priorities "for [new] program and facility development" and "priority recommendations for program termination, modification or reduction," *see* AG Opinion, No. 81–706, 64 Ops. Cal. Atty. Gen. 912 (Dec. 30, 1981); *see also* CAL. WELF. & INST. CODE § 4677 (2017); *see also* AG Opinion, No. 87–503, 70 Ops. Cal. Atty. Gen. 241-243 (Oct. 1, 1987) (holding that any allocations from the State's General Fund, which is collected from parental fees and is intended to implement new programs and services, must be consistent with the priorities identified in the Council's State Plan); *see also* AG Opinion, No. 81–706, at 915 (holding if DDS makes allocations from the fund that are inconsistent with the Council's state plan, the Council can "insure [sic] that its statutory duties are fulfilled" by filing a writ of mandate to enjoin DDS); *see also* CAL. WELF. & INST. CODE § 4540 (2017) (with limited exceptions, SCDD may not "engage in the administration of the day–to–day operation of service programs identified in the state plan, nor in the financial management and accounting of funds").

[33] Law of Oct. 1, 1977, CAL. WELF. & INST. CODE § 4570-4579 (2017), 1977 Cal. Laws ch. 1252, 4 (repealed 2002).

[34] *See* ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, MONITORING AND REVIEW TECHNICAL ASSISTANCE REVIEW SYSTEMS REPORT 7 (January 14─17, 2013) [hereinafter MONITORING AND REVIEW TECHNICAL ASSISTANCE REVIEW SYSTEMS REPORT], http://thearcca.org/policy/CA_DDC_2013_MTARS_REPORT_FINAL.pdf (last visited Jan. 17, 2019) (noting that Lanterman Act "established local Area Boards on developmental disabilities to conduct the local advocacy, capacity building and systems change activities…").

[35] *The Developmental Disabilities Assistance and Bill of Rights Act of 2000,* ADMIN. CMTY. LIVING, https://www.acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000 (last visited Jan. 17, 2019) (describing DD Act's creation of State Protection and Advocacy Systems).

[36] *State Protection & Advocacy Systems,* ADMIN. CMTY. LIVING, https://www.acl.gov/node/70 (last visited Jan. 17, 2019) (describing in greater detail the creation of State Protection and Advocacy Systems).

[37] CAL. DEP'T FINANCE, FISCAL AND PROGRAM COMPLIANCE REVIEW OF DEPARTMENT OF DEVELOPMENTAL SERVICES REGIONAL CENTER OPERATIONS iii (1979), http://www.dds.ca.gov/Publications/HistoricPub/1979_FiscalPrgmComplianceReview_DDSRCOPs.pdf (last visited Jan. 17, 2019); *see also* CAL. WELF. & INST. CODE § 4416 (2017) ("Unless otherwise indicated in this code, the State Department of Developmental Services has jurisdiction over the execution of the laws relating to the care, custody, and treatment of developmentally disabled persons, as provided in this code. As used in this division,

Around the turn of the millennium, this structure was modified in several ways. Most importantly, the state's longstanding practice of funding Area Boards with a federal grant provided by the Administration on Intellectual and Developmental Disabilities (AIDD) for SCDD functions was not allowed under the grant's purpose. As a part of a series of reviews and site visits between 1994 and 2014, AIDD determined that funding both SCDD and Area Boards with these federal funds violated the federal DD statute and required the state to make changes or risk losing funding.[38] The process culminated in 2014 with legislative changes that replaced the relatively autonomous 13 Area Boards with 13 Regional Advisory Committees that advise SCDD.[39] One of these Regional Advisory Committees subsequently closed in response to budgetary pressure.[40] SCDD, its Regional Advisory Committees, and its associated Regional Offices are funded through an AIDD grant.[41] Meanwhile, through a variety of state and federal

'establishment' and 'institutions' include every hospital, sanitarium, boarding home, or other place receiving or caring for developmentally disabled persons."); *see also* CAL. WELF. & INST. CODE § 4440 (2017) ("The department has jurisdiction over the following institutions: Fairview State Hospital, Frank D. Lanterman State Hospital, Porterville State Hospital, Sonoma State Hospital."); *see also* CAL. WELF. & INST. CODE § 4449 (2017) ("The State Department of Developmental Services has general control and direction of the property and concerns of each state hospital specified in Section 4440. The department shall: (a) Take care of the interests of the hospital, and see that its purpose and its bylaws, rules, and regulations are carried into effect, according to law; (b) Establish such bylaws, rules, and regulations as it deems necessary and expedient for regulating the duties of officers and employees of the hospital, and for its internal government, discipline, and management; (c) Maintain an effective inspection of the hospital").

[38] MONITORING AND REVIEW TECHNICAL ASSISTANCE REVIEW SYSTEMS REPORT, *supra* note 34, at 9-10 (summarizing a series of reviews and assessments concluding that the Council's structure and activities violated various provisions of the Lanterman Act and the Developmental Disabilities Assistance and Bill of Rights Act).

[39] In 2014, Area Boards were eliminated and reconstituted as State Council Regional Advisory Committees, tasked with advising the SCDD Regional Offices in their efforts to connect consumers with services and supports, systematically improve the quality of available services and supports in their region, and encourage the inclusion of people with I/DD in their communities, *see* CAL. WELF. & INST. CODE § 4544 (2017); *see also Regional Offices on Developmental Disabilities*, ST. COUNCIL DEVELOPMENTAL DISABILITIES, https://scdd.ca.gov/regionaloffices (last visited Jan. 23, 2019); *see also* ST. COUNCIL DEVELOPMENTAL DISABILITIES, REGIONAL ADVISORY COMMITTEE MINUTES 3-4 (Apr. 13, 2016) [hereinafter REGIONAL ADVISORY COMMITTEE MINUTES], https://scdd.ca.gov/wp-content/uploads/sites/33/2018/02/2016.RO8_.RAC_.6.8.pdf (last visited Jan. 23, 2019) (noting that the Regional Office Manager "discussed the findings of the Deficit Committee including the closure of the Regional Center Coast Office").

[40] *See* REGIONAL ADVISORY COMMITTEE MINUTES, *supra* note 39, at 4.

[41] *See What is the State Council on Developmental Disabilities?*, CAL. ST. COUNCIL DEVELOPMENTAL DISABILITIES, https://scdd.ca.gov/about/ (last visited Mar. 25, 2019).

grants,[42] PAI progressively expanded the scope of its activities and broadened the populations it served.[43] In 2008, it also changed its name to Disability Rights California (DRC).[44]

Despite these structural modifications, the system currently in place still largely resembles the one that was established in the late 1960s and '70s. To this day, DDS and the 21 independent RCs that it oversees are primarily responsible for effectuating the provisions of the Lanterman Act, with SCDD and DRC continuing to play important ancillary roles.

B. The Changing Pace of Deinstitutionalization

In the 1950s and '60s, lifelong institutionalization of individuals with I/DD was the norm in California and other U.S. states.[45] As community-based services and supports grew throughout the 1970s, however, reliance on DCs progressively declined. In 1971, DeWitt State Hospital became the first California state institution serving people with I/DD to close its doors.[46] Modesto and Mendocino State Hospitals followed suit later that year.[47] By 1993, only 6,093 individuals lived in DCs, compared to the 13,175 that had resided in them twenty-five years earlier.[48]

The main impetus for this dramatic shift in residential living patterns was class action litigation. In 1990, thirteen DC residents filed a class action, *Coffelt v. Department of Developmental Services*, against DDS and four RCs.[49] The plaintiffs argued that the slow pace of deinstitutionalization effectively deprived them of their right to live in community-based

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[42] *List of Funding Grants and Contracts*, DISABILITY RIGHTS CAL., https://www.disabilityrightsca.org/pod/list-of-funding-grants-and-contracts (last visited Jan. 17, 2019).

[43] *Our History: Disability Rights California Through the Years 1978 —2017*, DISABILITY RIGHTS CAL., https://www.disabilityrightsca.org/who-we-are/our-history (last visited Jan. 17, 2019).

[44] Emails sent to representatives from PAI/DRC in September 2008 were sent to PAI email addresses, *see* E-mail from Karen Ullman, Public Counsel, to Katie Hornberger, Prot. & Advocacy, Inc. (Sept. 19, 2008, 17:47 PT) (on file with authors) (where Katie Hornberger had a "pai-ca.org" email address on September 19, 2008). However, by October 2008, a month later, emails from the same representatives from PAI/DRC were received from DRC email addresses, *see* E-mail from Katie Hornberger, Disability Rights California, to Karen Ullman, Public Counsel (Oct. 24, 2008, 13:55 PT) (on file with authors) (where Katie Hornberger had a "disabilityrightsca.org" email address on October 24, 2008). Therefore, at some point between September 19, 2008 and October 24, 2008, PAI's name was officially changed to DRC.

[45] FRANK D. LANTERMAN REG'L CTR., REAFFIRMING THE COMMITMENT: REALIZING THE VISION: HISTORY OF THE REGIONAL CENTERS IN CALIFORNIA 2 (2006), https://mn.gov/mnddc/parallels2/pdf/00s/00/00-lanterman-ca.pdf (last visited Jan. 17, 2019).

[46] STRENGTHENING, *supra* note 4, at 9.

[47] *Id.*

[48] CAL. DEP'T DEVELOPMENTAL SERVS.., CONSUMER FACT BOOK: 1ST ED. 13 (1998), http://www.dds.ca.gov/FactsStats/docs/factBook_1st.pdf (last visited Jan. 17, 2019); A PROPOSAL TO REORGANIZE, *supra* note 12, at E-1.

[49] Settlement Agreement at C-2, Coffelt v. Dep't Developmental Servs. (1994) (No. 916401).

settings.[50] As part of a settlement agreement reached in 1994, the state agreed to reduce the DC population by more than one third.[51] This shift was accomplished through the Community Living Options Initiative, which mandated the movement of 2,000 people from DCs to the community over five years; a moratorium on future admissions to DCs except in the most difficult circumstances; and the closure of the Stockton and Camarillo DCs.[52] Stockton shut its doors in 1996, followed by Camarillo DC in 1997.[53] From 1995 to 2005, the number of Californians residing in DCs declined by about 40%.[54]

After the turn of the millennium, however, progress temporarily slowed. From 2000 to 2005, the DC population declined by only about 131 persons per year.[55] This slowing trend was likely caused in part by the expiration of the *Coffelt* Settlement Agreement in 1998.[56] The release of the "Strauss Report" in 1996, which found a higher mortality rate among consumers living in the community than among consumers living in DCs, may also have played a role.[57] Although the Strauss Report's validity was subsequently contested, its release prompted a delay in the planned closure of the Agnews DC in 1997, as well as statewide hearings on the quality of community-based supports and services.[58] A subsequent bill transferred responsibility for quality of life assessments from RCs to Area Boards,[59] and shifted responsibility for the provision of clients' rights advocacy services to PAI (now DRC).[60]

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[50] *Id.* at 3 (noting parties agreeing to increase the availability of quality, stable, normalized, integrated community living arrangements).

[51] *Id.*

[52] *Id.* at 4.

[53] *See* STRENGTHENING, *supra* note 4, at 23.

[54] CAL. DEP'T DEVELOPMENTAL SERVS., CONSUMER FACT BOOK: 4TH ED. 3 (2000), http://www.dds.ca.gov/FactsStats/docs/factBook_4th.pdf (last visited Jan. 17, 2019).

[55] CAL. DEP'T DEVELOPMENTAL SERVS., CONSUMER FACT BOOK: 9TH ED. 5 (2007), http://www.dds.ca.gov/FactsStats/docs/factBook_9th.pdf (last visited Jan. 17, 2019) (noting in 1995, 4,937 consumers resided in DCs, whereas in 2005, 3,054 consumers resides in DCs).

[56] Settlement Agreement, *supra* note 49, at 13 (specifying the number of DC resident who would be transitioned the community each year between 1993 and 1998).

[57] Strauss et. al., *Predictors of Mortality in Children with Severe Mental Retardation: The Effect of Placement*, 86 Am. J. Pub. Health 1422, 1426–27 (1996); *but see* CAL. DEP'T DEVELOPMENTAL SERVS., INDEPENDENT EVALUATION OF THE DEPARTMENT OF DEVELOPMENTAL SERVICES' COMMUNITY PLACEMENT PRACTICES: FINAL TECHNICAL REPORT V-10, V-20-23 (1998) [hereinafter FINAL TECHNICAL REPORT] (finding that people moving into the community had a better quality of life and lower mortality rates than people living in DCs).

[58] *See* FINAL TECHNICAL REPORT, *supra* note 57, at I-11.

[59] *See* 1997 Cal. Leg. Serv. Ch. 294 § 35 (S.B. 391) (codified at CAL. WELF. & INST. CODE § 4596.5 (2002)) (repealed 2002).

[60] *See id.* § 34 (codified at CAL. WELF. & INST. CODE § 4433 (2019)) (Every state that receives federal money to operate a State Council on Developmental Disabilities is required to concurrently have in effect a system "to protect the legal and human rights of individuals with developmental disabilities"); *see also* 28 U.S.C. §15041 (2018)

In response to the slowed rates of community placement, fifteen DC residents filed a second class action in 2002 called *Capitol People First v. Department of Developmental Services*.[61] In 2009, the plaintiffs agreed to settle the case on the condition that DDS and RCs would systematically "discuss with [each consumer and his/her family] whether a Community Living Option would meet the [consumer's] needs, preferences and life choices" and whether the consumer could take advantage of a Community Placement Plan designed to ease his/her transition to the community.[62] Perhaps most critically, even during a time of severe budgetary shortfalls, the settlement required DDS to guarantee funding for Community Placement Plans (CPPs).[63] The CPPs enabled RCs to enhance community service delivery systems, and reduce their reliance on DCs and other highly restrictive residential placements, despite the ill effects of the Great Recession.

The *Capitol People First* settlement helped bring about a new wave of DC closures. In 2009, Agnews DC closed its doors.[64] In 2012, the legislature placed even stricter limits on new DC admissions, authorizing DCs to accept only individuals in acute crisis or those involved in the criminal justice system.[65] In 2014, all of the residents of Lanterman DC were successfully transitioned into community-based placements.[66] In 2015, the legislature mandated the closure of the three remaining DCs—Sonoma, Fairview, and Porterville's non-secure treatment facility—by 2021.[67]

(Protection and Advocacy Systems, among other programs, have the authority "pursue legal, administrative, and other appropriate remedies or approaches" to protect the rights of state residents with I/DD); *see also Id.* § 15041(a)(2)(A) (there are currently 57 Protection and Advocacy Systems in the United States and its territories, and each is independent of service-providing agencies in their states); *see also State Protection & Advocacy Systems*, ADMIN. CMT'Y LIVING, https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems (last visited Jan. 17, 2019) (In California, Disability Rights California (formerly Protection and Advocacy, Inc.) has the contract to operate the state's protection and advocacy system); *see also id.* (noting DRC is independent of DDS as a Protection and Advocacy System).

[61] Capitol People First v. Cal. Dep't of Developmental Servs., 155 Cal. App. 4th 676 (Cal. Ct. App. 2007).

[62] [Proposed] Settlement Agreement, Capitol People First v. Dep't Of Developmental Services at 12-17, 155 Cal. App. 4th. 676 (2009) (No. 2002-038715), 2003 WL 25315367.

[63] *Id.* at 12-15.

[64] *Agnews Developmental Center*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/Agnews/ (last visited Jan. 17, 2019).

[65] *See* 2012 Cal. Legis. Serv. Ch. 25 § 7 (A.B. 1472) (codified at CAL. WELF. & INST. CODE § 4507 (2019)).

[66] *Lanterman Developmental Center*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/Lanterman/ (last visited Jan. 17, 2019).

[67] *See* 2015 Cal. Legis. Serv. Ch. 23 § 6 (S.B. 82) (codified at CAL. WELF. & INST. CODE § 4474.11(a) (2019)); *see also Developmental Center Closures*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/DevCtrs/DCClosures.cfm (last visited Jan. 17, 2019).

C. The Development of Early Intervention Services

In 1993, the legislature passed the California Early Intervention Services Act (CEISA) to expand services and supports to children under three years of age.[68] The legislature reasoned that "there [was] a need to provide appropriate early intervention services individually designed for infants and toddlers from birth to two years of age, inclusive, who have disabilities or are at risk of having disabilities, to enhance their development and to minimize the potential for developmental delays."[69] DDS and the California Department of Education (CDE) are responsible for providing services to children with a significant delay in at least one area of development, an established "high probability" of a developmental delay, or a "high risk" of a developmental disability.[70] Though the third (high risk) eligibility pathway was eliminated during the Great Recession,[71] it was reinstated as of January 1, 2015.[72]

CEISA encompasses three early intervention programs. First, through the Early Start program, RCs hire independent clinicians to provide early intervention services to approximately 33,500 (82%) of the state's infants and toddlers with developmental disabilities.[73] Secondly, through the Legacy Program, schools provide early intervention services for approximately 5,000 (12%) of infants and toddlers with special needs (including developmental disabilities).[74] The third program, which is also school-based, provides early intervention services to approximately 1,500

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[68] CEISA was passed in compliance with Part C (Supports to Improve Results for Children with Disabilities) of the Individuals with Disabilities Education Act (IDEA). Under the IDEA, "Each State that receives funds under this chapter shall…ensure that any State rules, regulations, and policies relating to this chapter conform to the purposes of this chapter," *see* 20 U.S.C. § 1407 (2019). As a result, CEISA "shall remain in effect only until the state terminates its participation in Part C of the federal Individuals with Disabilities Education Act," *see* CAL. GOV. CODE § 95003 (2019).

[69] 1993 Cal. Legis. Serv. Ch. 945 § 2 (S.B. 1085) (codified at CAL. GOV. CODE §§ 95001– 95029.5 (2019)).

[70] 1993 Cal. Legis. Serv. Ch. 945 § 2 (S.B. 1085) (codified at CAL. GOV. CODE § 95014(a) (2019)) (child is eligible if (s)he displays (1) a "significant difference between the expected level of development for their age and their current level of functioning" in at least one of five areas of development (cognitive, physical and motor, communication, social or emotional development, or adaptive), (2) an established "high probability" of a developmental delay based on known etiology or conditions with established harmful developmental consequences, or (3) a "high risk" of having substantial developmental disability due to a "combination of biomedical risk factors").

[71] 1993 Cal. Legis. Serv. Ch. 945 § 2 (S.B. 1085) (codified at CAL. GOV. CODE § 95014(a) (2019)); *see also* 2009 Cal. Legis. Serv. 4th Ex. Sess. Ch. 9 § 2 (A.B. 9) (codified at CAL. GOV. CODE § 95014(a) (2019)) (tightening eligibility standards by requiring that toddlers 24-36 months of age must have one area of 50% delay or greater or two or more areas of 33% delay or greater each; further requiring than children fewer than 24 months of age were held to the original standard of one area of 33% delay or greater).

[72] 2014 Cal. Legis. Serv. Ch. 761 § 2 (A.B. 1089) (codified at CAL. GOV. CODE § 95014(a) (2019)).

[73] MAC TAYLOR, CAL. LEG. ANALYST'S OFFICE, EVALUATING CALIFORNIA'S SYSTEM FOR SERVING INFANTS AND TODDLERS WITH SPECIAL NEEDS 3 (2018), https://lao.ca.gov/reports/2018/3728/serving-toddlers-with-special-needs-010418.pdf (last visited Jan. 17, 2019).

[74] *Id.* at 3-4.

infants and toddlers with Hearing, Visual, and Orthopedic Impairments.[75] In a 2018 report, the Legislative Analyst's Office suggested that the bifurcation of early intervention services between DDS and CDE generates significant service delays that could be ameliorated by housing all such services under DDS.[76]

D. Changes Over Time in Lanterman Act Eligibility Criteria

The scope of the Lanterman Act has also evolved markedly since its initial passage. The original Act covered persons who were "mentally retarded,"[77] a poorly defined classification. In 1973, the Act was amended to cover cerebral palsy, epilepsy, autism, and other conditions closely related to I/DD.[78] In 1975, eligibility was expanded further to include autism and "handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but . . . not . . . other handicapping conditions that are solely physical in nature."[79]

After the turn of the millennium, however, the trend of expanding coverage came to a halt and the eligibility criteria to receive Lanterman Act benefits were significantly tightened.[80] According to the eligibility guidelines first articulated in a 1973 addition to the Health and Safety Code, a developmental disability must have "originate[d] before an individual attains age 18, continues, or can be expected to continue indefinitely, and constitutes a substantial handicap for such individual."[81] Under revised guidelines introduced in 2003,[82] the developmental disability must also be substantially disabling, defined as causing "significant functional limitations in three or more of the following areas of major life activity: … self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; [and] economic self-

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[75] *Id.* While the school-based HVO Program serves 1,500 infants and toddlers with HVO impairments, an additional 1,000 infants and toddlers with HVO impairments are served under the Legacy Program. In total, 2,500 infants and toddlers with HVO impairments are served in school settings between the second and third CEISA early intervention programs.

[76] *Id.* at 2.

[77] 1969 Legis. Serv. Ch. 1594 § 38000 (A.B. 225) (codified at CAL. HEALTH & SAFETY CODE § 415 (1969)).

[78] 1973 Cal. Legis. Serv. Ch. 546 § 16 (A.B. 846) (codified at CAL. HEALTH & SAFETY CODE § 38003 (1976)) (repealed 1976).

[79] 1975 Cal. Legis. Serv. Ch. 984 § 16 (S.B. 363) (codified at CAL. WELF. & INST. CODE § 4512(a) (2019)).

[80] 2003 Cal. Legis. Serv. Ch. 230 § 46 (A.B. 1762) (codified at CAL. WELF. & INST. CODE § 4512 (2019)).

[81] 1973 Cal. Legis. Serv. Ch. 546 § 16 (A.B. 846) (codified at CAL. WELF. & INST. CODE § 4512 (2019)). It is worth noting that in recent years, legislators have introduced legislation in an effort to broaden the definition of a developmental disability to mean "a disability that originates before an individual attains 22 years of age," as opposed to originating before an individual attains 18 years of age, *see* S.B. 283, 2017 Leg., Reg. Sess. (Cal. 2017); *see also* A.B. 536, Reg. Sess., 2019-20 Sess. (Cal. 2019). As of this writing, however, none of these bills has passed.

[82] 2003 Cal. Legis. Serv. Ch. 230 § 46 (A.B. 1762) (codified at CAL. WELF. & INST. CODE § 4512 (2019)).

sufficiency.[83] Therefore, consumers who established eligibility under the Lanterman Act prior to 2003 had their eligibility re-determined under the new, tightened standard.

E. Growth of Services that Promote Consumer Independence

The menu of services and supports available to individuals with I/DD has evolved over time in ways that are intended to expand individual choice, integration, and independence. This shift reflects an increased focus on home- and community-based living, self-determination, and competitive integrated employment. Three state legislative enactments have been particularly consequential in bringing about these changes.

First, in 1992, Senate Bill 1383 updated the Act's purpose to endorse, "to the maximum extent possible, treatment, services, and supports . . . provided in natural community settings."[84] The bill also amended the Act to fund a new service delivery model, "supported living," which provides "opportunities for adults with developmental disabilities, regardless of degree of disability, to live in homes that they own or lease with support available as often and for as long as it is needed."[85]

Secondly, in 2013, the legislature passed a statewide Self-Determination Program.[86] The law built on a small-scale pilot, state-funded program that had been implemented successfully in five RCs in the early 2000s.[87] Based on five core principles—freedom to control personal choices; authority over personal budgetary expenditures; entitlement to the support required for community living; responsibility for personal choices; and confirmation of autonomous decision making—the Self-Determination Program "giv[es] participants (or their parents or legal representatives) a specific budget to purchase the services and supports that they need to make

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[83] CAL. WELF. & INST. CODE § 4512(l)(1) (2019).

[84] 1992 Cal. Legis. Serv. Ch. 1011 § 3 (S.B. 1383) (codified at CAL. WELF. & INST. CODE § 4502(b) (2019)).

[85] *Id.* § 24 (codified at CAL. WELF. & INST. CODE § 4689 (2019)) (The Amendment further explained:

> The range of supported living services and supports available include, but are not limited to, assessment of consumer needs; assistance in finding, modifying and maintaining a home; facilitating circles of support to encourage the development of unpaid and natural supports in the community; advocacy and self-advocacy facilitation; development of employment goals; social, behavioral, and daily living skills training and support; development and provision of 24-hour emergency response systems; securing and maintaining adaptive equipment and supplies; recruiting, training, and hiring individuals to provide personal care and other assistance, including in-home supportive services workers, paid neighbors, and paid roommates; providing respite and emergency relief for personal care attendants; and facilitating community participation).

[86] *See* 2013 Cal. Legis. Serv. Ch. 683 § 2 (S.B. 468) (codified at CAL. WELF. & INST. CODE § 4685.8 (2019)).

[87] JAMES W. CONROY ET. AL., THE CENTER FOR OUTCOME ANALYSIS, INDEPENDENT EVALUATION OF CALIFORNIA'S SELF-DETERMINATION PILOT PROJECTS: SECOND YEAR INTERIM FINDINGS i (2001), http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/sdcar2.pdf (last visited Jan. 17, 2019).

their person-centered plan work better for them."[88] Importantly, the program permits participants to "choose their services and pick which providers deliver those services" as long as they stay within their respective annual budgets.[89] Before statewide implementation could begin, however, DDS had to seek approval from the Centers for Medicare and Medicaid Services (CMS) so that participants who opted to participate would remain eligible for Medicaid funds. DDS submitted a formal waiver request to CMS in March of 2018, and CMS granted its approval on June 6, 2018.[90]

The Self-Determination Program is unfolding in two phases: an initial, three-year phase-in period in which 2,500 participants, randomly selected from among those that expressed interest, are being offered an opportunity to participate; and a subsequent full implementation phase in which any RC consumer will be permitted to join.[91] The initial selections were made on October 1, 2018, and the initial group of 2,500 were notified of their eligibility shortly thereafter.[92] As of this writing, DDS is still preparing to schedule the "informational meetings" (participant orientations) that are a prerequisite to entering the program.[93]

Finally, in 2013, the legislature also enacted the Employment First Policy, designed to grant all disabled Californians, "regardless of the severity of their disabilities," the opportunity for integrated, competitive employment."[94] The new policy established that the "highest priority" of state developmental services was to provide consumers with I/DD the option of regular jobs with regular pay,[95] underscoring the state's goal of integrating residents with I/DD into community life.[96]

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[88] *See California's Self-Determination Program*, CAL. DEPT' DEVELOPMENTAL SERVS., https://www.dds.ca.gov/SDP/sdpInformation.cfm (last visited Jan. 17, 2019).

[89] *Id*.

[90] *Self-Determination Program – Implementation Updates*, CAL. DEPT' DEVELOPMENTAL SERVS. [hereinafter *Self-Determination Program – Implementation Updates*], https://www.dds.ca.gov/SDP/SDPUpdates.cfm (last visited Jan. 17, 2019).

[91] *Self-Determination Program Enrollment*, CAL. DEPT' DEVELOPMENTAL SERVS. [hereinafter *Self-Determination Program Enrollment*], https://www.dds.ca.gov/SDP/sdpEnrollment.cfm (last visited Jan. 23, 2019).

[92] *Self-Determination Program – Implementation Updates*, *supra* note 90.

[93] *Self-Determination Program Enrollment*, *supra* note 91.

[94] CAL. WELF. & INST. CODE §§ 4869(a)(1) (2017).

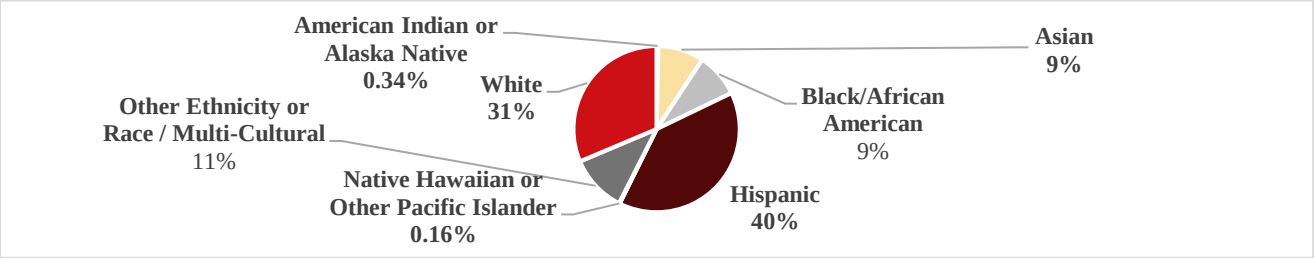
[95] *Id*.

[96] California's Employment First Policy was adopted several months before President Obama signed into law The Workforce Innovation and Opportunity Act (WIOA), which institutes a federal program designed in part to "increase access to high-quality workforce services for people with disabilities and prepare them for integrated, competitive employment," *see* CAL. ST. COUNCIL DEVELOPMENTAL DISABILITIES, EMPLOYMENT FIRST COMMITTEE: ANNUAL REPORT 6 (2014), https://www.dfeh.ca.gov/wp-content/uploads/sites/33/2016/10/HQ-EF-committee-report-annual-2014.pdf (last visited Apr. 3, 2019). WIOA requires states with "vocational rehabilitation agencies [to] set aside at least 15% of their funds to provide transition services for people with disabilities" and to "develop

F. A Demographic Snapshot of Today's Regional Center Consumers

California's I/DD system serves a highly diverse clientele. Gender is a particularly salient source of variation: only 36% of RC consumers are female.[97] The system also exhibits considerable racial and ethnic diversity. As is illustrated in Figure 1, below, about 40% of all consumers are Hispanic. Whites, at 31%, are the second largest category. Asians and African-Americans respectively comprise about 9% of all consumers. Several other ethnicities (American Indian, Alaska Native, Native Hawaiian and Pacific Islander) jointly make up less than 1%. Surprisingly, the "Other" category – including consumers who are multicultural or belong to another ethnicity/race – is the third largest category overall, comprising 11% of all consumers.

Figure 1: Consumers Receiving Regional Center Services by Race/Ethnicity, 2016–17[98]



As is shown in Figure 2, below, the consumer population as a whole is slightly skewed toward the bottom of the age distribution. School-age consumers (aged 3-21) and adults (aged 22 and above) each comprise about 44% of the total population, with the remaining 12% consisting of very young children (aged 0-2) who quality for early intervention services.

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and submit a four year strategy – in the form of a single unified strategic plan for core programs – for preparing an educated and skilled workforce and meeting the workforce needs of employers," *see id*. at 3, 6. Although California's Employment First Policy does not explicitly mention WIOA, both pieces of legislation aim to prepare individuals with I/DD for integrated, competitive employment.

[97] *See* CAL. DEP'T DEVELOPMENTAL SERVS., FACT BOOK: 14TH ED. 12 (2017) [hereinafter 14TH DDS FACT BOOK], http://www.dds.ca.gov/FactsStats/docs/factBook_14th.pdf (last visited Jan. 17, 2019).

[98] *See Regional Center Purchase of Service Data*, CAL. DEP'T DEVELOPMENTAL SERVS. [hereinafter *Regional Center Purchase of Service Data*], https://www.dds.ca.gov/RC/POSData.cfm (last visited Oct. 1, 2018) (The figures presented here were obtained from reported Regional Center POS Data, posted by DDS pursuant to WELF. & INST. CODE § 4519.5. To access the underlying data, visit https://www.dds.ca.gov/RC/POSData.cfm and select the name of a specific RC from the left column). *But see* 14TH DDS FACT BOOK, *supra* note 97, at 11 (the numbers we calculate through DDS's website are different than the system-wide numbers provided in the 14TH DDS FACT BOOK, which is not specific to POS data).

Figure 2: Consumer Population by Age Group, 2016[99]

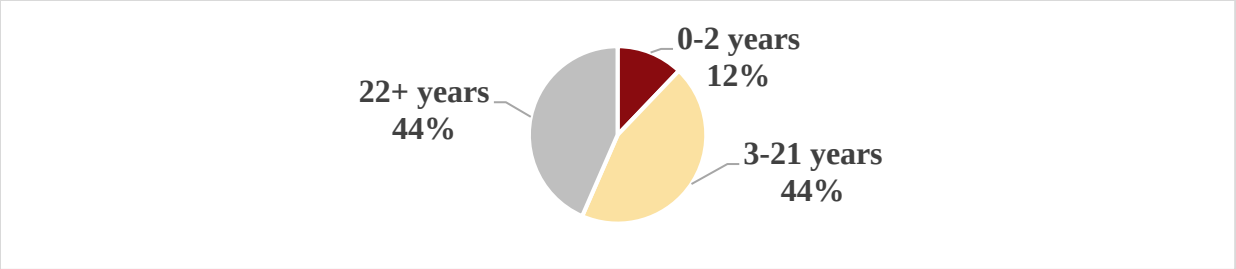

Figure 3, below, displays variation by (unduplicated) disability category. At 33%, intellectual disability is the single largest diagnostic category. Autism comprises another 23%. Epilepsy, cerebral palsy, and Category 5 jointly make up another 9%. A remarkably large fraction of consumers who receive services (35%) are diagnosed with "other" disabilities.

Figure 3: Consumer Population by Unduplicated Disability Category, 2016–17[100]

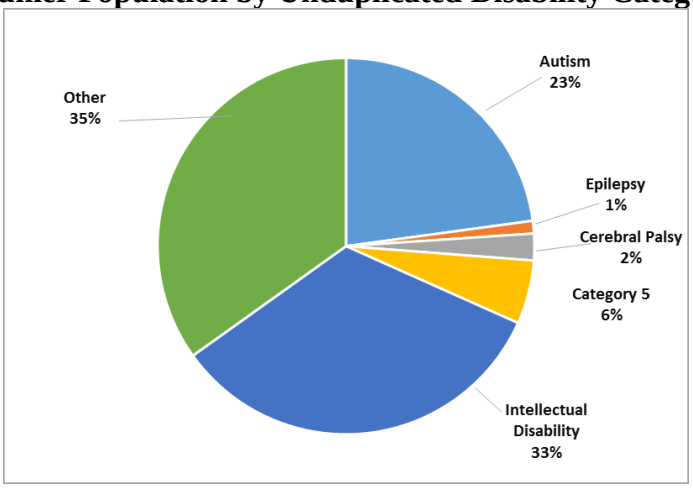

Figure 4, below, displays the distribution of consumers who receive services by residence type. An overwhelming majority (82%) live in their own or their parents' home. The second-largest group, comprising 8% of the total, receives independent or supported living services. Another 7% reside in group homes and other community care facilities. Most of the remaining 3% live in intermediate care and skilled nursing facilities; only a tiny percentage (one tenth of 1%) still reside in DCs.[101]

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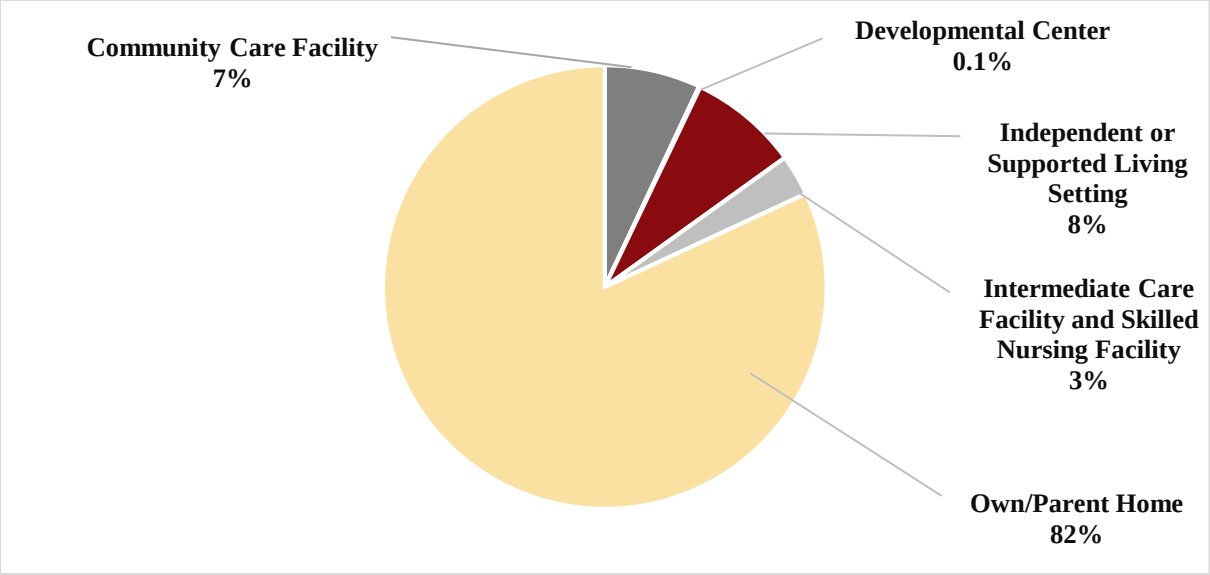
[99] *See* 14TH DDS FACT BOOK, *supra* note 97, at 10.

[100] *Id.* at 20-25 (we recorded the "Number of Consumers (Jan. 2016)" for each condition, found on pages 20-24. We did not include "Unspecified" as an intellectual disability. Based on the percentage of consumers who have *only* each of the six conditions (page 25), we calculated that number of unduplicated consumers with each condition).

[101] From the perspective of CMS, DCs are technically considered Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), a classification that also includes smaller ICFs operated by nonprofit and for-profit agencies. For these purposes, however, we distinguish DCs from other types of ICF- IIDs.

Figure 4: Consumer Population by Residence, 2016–17[102]



Finally, we note that the characteristics of the consumers receiving services vary markedly across RCs, reflecting the demographic diversity of their respective catchment areas. For example, while Hispanic consumers make up about 70% of consumers served by Eastern Los Angeles Regional Center, they make up only about 10% of consumers in Far Northern Regional Center. Similarly, only about 35% of consumers in two regional centers (Lanterman and North Los Angeles County) are adults, whereas this percentage is closer to 45% in two other RCs (Golden Gate and Far Northern). The mix of residence types, which could stem partly from variations in cultural norms and preferences, also exhibits considerable variation across regions. While the percentage of consumers living at home in Eastern Los Angeles Regional Center is about 90%, this figure in Far Northern and Redwood Coast Regional Centers is only about 70%. Disability categories exhibit similar trends, with the percentage of consumers diagnosed with autism ranging from less than 20% in Central Valley Regional Center to nearly 40% in Lanterman Regional Center.[103]

[102] *Regional Center Purchase of Service Data*, *supra* note 98.

[103] *Id.*

IV. A Budgetary Survey of the I/DD Service Delivery System

To present a well-rounded budgetary portrait of California's I/DD system, we examine the system from four different angles. First, we summarize the unique budgeting process whereby the state allocates funds to DDS, which in turn dispenses those funds to the 21 RCs. Second, we chart statewide expenditures over time and compare the level of I/DD funding in California to that of other U.S. states. Third, we identify major expenditure categories. Finally, we distinguish between state and federal funding sources, making note of the main costs funded by each category.

A. California's Budgeting Process[104]

As the California Department of Finance has acknowledged, "the budget process for California defies a simple concise definition. It is a process rather than a product."[105] Some familiarity with the budgeting process, however, brings to light important features of the multi-billion-dollar system that funds services and supports for individuals with I/DD. The process unfolds in the following basic sequence:

- ***By August 1st of each year***: Each RC submits a proposed budget plan to DDS and SCDD.[106] The plan includes estimates of the number of persons with I/DD to be served, the amount of services to be provided, the cost of each service, and a breakdown of revenue sources.[107]

- ***By (approximately) mid-September*:** DDS aggregates these individual RC budgets, combines them with its own budget (including the cost of DCs), and submits its budget proposal to the Department of Finance for the Governor's review.

- ***By January 10th***: The Governor compiles an initial comprehensive budget and submits it to the legislature.

- ***Beginning in (typically) late February***: The legislature holds hearings and considers input from DDS, the Department of Finance, departmental staff, the Legislative Analyst's Office, and other stakeholders on various budgetary items, including those pertaining to the I/DD system.

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[104] *California's Budget Process*, CAL. DEP'T FIN., http://www.dof.ca.gov/budget/Budget_Process/index.html (last visited Jan. 17, 2019).

[105] *Id.*

[106] CAL. WELF. & INST. CODE § 4776 (2017).

[107] *Id.* § 4776.

- ***By May 14th***: As part of the May Revision (often colloquially called the "May Revise"), the Department of Finance submits a revised budget to the legislature on the Governor's behalf.

- ***Beginning in mid-May***: Both houses of the legislature work toward a final resolution of the budget. If all contested issues cannot be resolved by the Budget Conference Committee, top state leadership (the Governor, Speaker of Assembly, Senate President pro Tempore, and Minority Leaders of both houses) may intervene to help broker a resolution and promote the bill's passage.

- ***By June 15th***: A final budget package is passed by a simple majority of both houses, and is sent to the Governor together with any "trailer bills" whose passage is required to accomplish particular budgetary objectives.

- ***After submission of final budget package to Governor:*** The Governor may exercise a line-item veto before signing the Budget Act into law.

- ***July 1st:*** The new fiscal year begins.

- ***August 1st***: DDS allocates funds to all 21 Regional Centers.[108]

- ***From August 2nd through end of fiscal year:*** RCs use their allocated funds for operational expenses and for the purchase of services (POS) for consumers in their catchment areas. Additional appropriations may be requested from DDS. Any funds not used by the end of the budget year are returned to DDS.

Several aspects of the budgetary process merit special attention. First and foremost, although the Lanterman Act is framed as an open-ended entitlement, the total budget allocated to DDS is fixed before the start of each fiscal year, and the amount of funds available to each RC is likewise decided (and dispensed) on August 1st. While in special circumstances DDS may request additional appropriations, for the most part, the system rests of the ability of DDS to make accurate forecasts regarding the future needs of RC consumers and the cost of the services and supports they require.

Second, the process itself is relatively opaque, with a great deal depending on the legislature's capacity to obtain accurate information (prior to or during the May Revision) regarding the growth of the I/DD population, the equity and cost-effectiveness of existing programs, areas of unmet need, and future cost trends.

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[108] *Id.* §§ 4780–80.5, 4778.

Third, although the legislature need not pass each item of the Governor's requested budget at the requested level of funding (if at all), the Governor's power to exercise the line-item veto also gives the executive branch considerable power over the funding of the I/DD system.

B. Trends over Time in Expenditures

There are far more California residents with I/DD requiring support today than there were around the time of the original Lanterman Act's passage. During the 1975–76 fiscal year (FY), the RC system served only 33,833 clients.[109] By 1985, it served 78,312;[110] by 1995, 129,230.[111] By 2017, the population served by the state's 21 regional centers had grown to 314,638.[112] The expansion in Lanterman Act beneficiaries has been significant in percentage terms as well: from 2008–2018, the average annual growth rate of total consumers served by the RC system was 3.7 percent, while the average annual growth rate of the state's population was just 0.8 percent per year.[113] Average caseloads have likewise increased dramatically. Although Frank Lanterman intended each RC's catchment area to encompass one million California residents,[114] the average number of residents per catchment area has grown to approximately 1.9 million, almost double Lanterman's vision.[115] As is illustrated in Figure 5, below, DDS's total budget has likewise increased steadily. In FY 1980–81, DDS spent $1.90 billion (inflation adjusted), a figure that rose by about 2.5% annually in subsequent years and reached $7.74 billion by FY 2018–19.[116]

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[109] STRENGTHENING, *supra* note 4, at 11

[110] *Id.* at 17.

[111] *Id.* at 21.

[112] CAL. DEP'T DEVELOPMENTAL SERVS., 15TH DDS FACT BOOK 8 (2018), *https://www.dds.ca.gov/FactsStats/docs/factBook_15th.pdf* (last visited Jan. 17, 2019).

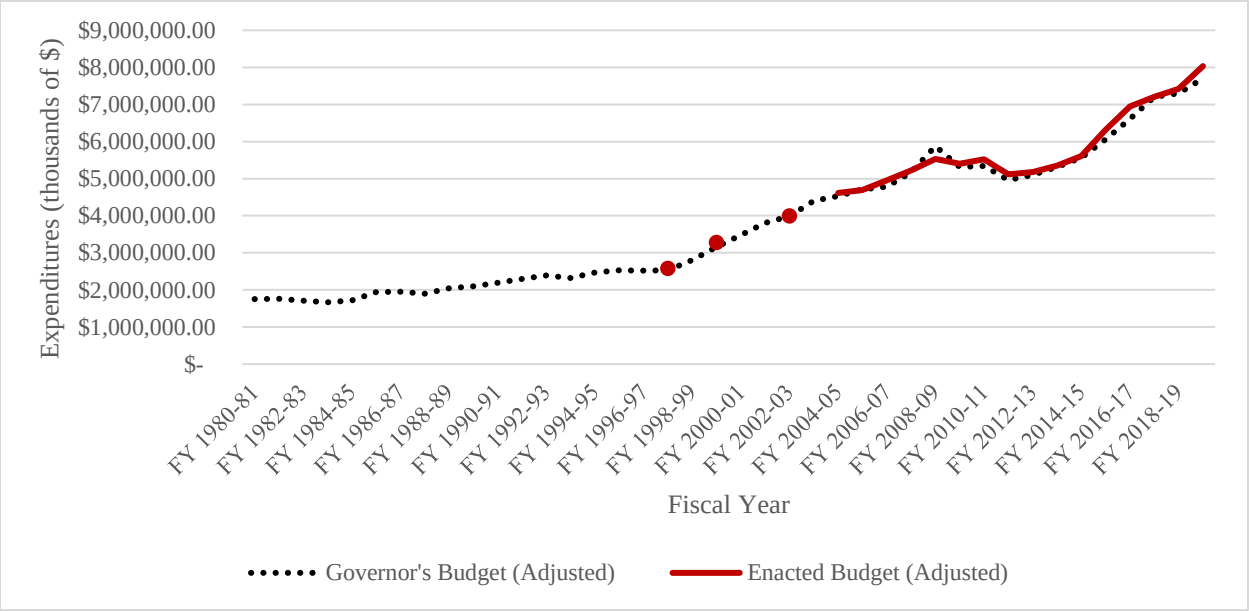
[113] Budget Request from Cal. Dep't of Developmental Servs. to Cal Dep't of Fin. 4 (Jan. 10, 2019) [hereinafter BUDGET CHANGE PROPOSAL], https://esd.dof.ca.gov/Documents/bcp/1920/FY1920_ORG4300_BCP2742.pdf (last visited Feb. 7, 2019).

[114] STRENGTHENING, *supra* note 4, at 8.

[115] *See QuickFacts: California*, U.S. CENSUS BUREAU (July 1, 2017) , https://www.census.gov/quickfacts/CA (last visited Jan. 17, 2019) (estimated California's current population at 39,536,653, and we divide this number by 21—for the 21 regional centers—to roughly estimate each center's catchment area).

[116] *Id*.

Figure 5: DDS Inflation-Adjusted Expenditures, FY 1980–81 to FY 2018–19[117]



[117] The trend lines estimate DDS's total expenditures for each fiscal year (in thousands of dollars) based on the state's Enacted Budget and the Governor's Budget. Although the figure confirms the close comparability of the two sets of budgetary estimates, the Enacted Budget is a more accurate estimate of DDS's expenditures than the Governor's Budget insofar as the Governor's Budget is merely the governor's preferred budget, whereas the Enacted Budget must be passed by the legislature and (finally) by the governor. The Governor's Budget figures from FY 1980–81 through FY 2019–20 were obtained from hard copies in Stanford's Green Library, *see Historical Budget Data*, STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW & PUB. POLICY PROJECT, https://law.stanford.edu/siddlapp/historical-budget-data/ (last visited June 28, 2019) (providing scanned copies of Governor's Budgets from FY 1980–81 to FY–2019–20). Enacted Budgets were more difficult to find. Although we located copies for fical years since FY 2004-05, they were only available sporadically for prior years. For FY 1997–98, *see Fiscal Year 1998-99 Proposed Budget: Funding Summary*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/fundfcht.htm [https://web.archive.org/web/19990127204406/http:/www.dds.ca.gov:80/fundfcht.htm] (last archived on Jan. 27, 1999) (last visited Apr. 27, 2019) (using "Estimated 1997–98" numbers). For FY 1999–00, *see* CAL. DEP'T DEVELOPMENTAL SERVS., FISCAL YEAR 1999–00 ENACTED BUDGET (June 29, 1999), http://www.dds.ca.gov/9900highlights.pdf [https://web.archive.org/web/20000115060829/http:/www.dds.ca.gov:80/9900highlights.pdf] (last visited Apr. 27, 2019) (using "FY 1999–00 Enacted" numbers). For FY 2002–03, *see* CAL. DEP'T DEVELOPMENTAL SERVS., BUDGET ACT FISCAL YEAR 2002–03: EXECUTIVE SUMMARY 4 (Sept. 5, 2002), http://www.dds.ca.gov/budget/pdf/0203_BudgetHighlights.pdf [https://web.archive.org/web/20030417021927/http:/www.dds.ca.gov:80/budget/pdf/0203_BudgetHighlights.pdf] (last visited Apr. 27, 2019) (using "Budget Act" numbers). For FY 2004–05, *see* CAL. DEP'T DEVELOPMENTAL SERVS., 2004-05 BUDGET ACT HIGHLIGHTS 2 (July 31, 2004), http://www.dds.ca.gov/Budget/pdf/0405_BudgetHighlights.pdf [https://web.archive.org/web/20041012011544/http:/www.dds.ca.gov/Budget/pdf/0405_BudgetHighlights.pdf] (last visited Apr. 27, 2019) (using "2004–05 Budget Act" numbers). For FY 2005–06, *see* CAL. DEP'T DEVELOPMENTAL SERVS., 2005-06 BUDGET ACT HIGHLIGHTS 2 (July 11, 2005), http://www.dds.ca.gov/budget/pdf/0506EnactedHighlights.pdf [https://web.archive.org/web/20060622172350/http:/www.dds.ca.gov:80/budget/pdf/0506EnactedHighlights.pdf] (last visited Apr. 27, 2019) (using "2005–06 Enacted Budget" numbers). For FY 2006–07, *see* CAL. DEP'T DEVELOPMENTAL SERVS., 2006-07 BUDGET ACT HIGHLIGHTS 2 (June 30, 2006), http://www.dds.ca.gov/budget/pdf/0607EnactedHighlights.pdf [https://web.archive.org/web/20060819095748/http:/www.dds.ca.gov:80/budget/pdf/0607EnactedHighlights.pdf]

The most significant financial threat to the system to date occurred during the Great Recession. From 2008 to 2013, DDS underwent a series of annual budget cuts totaling approximately $984 million ($344 million in FY 2009–10, $251 million in FY 2010–11, $340 million in FY 2011–12, and $100 million in FY 2012–13).[118] Since 2013, the state's overall fiscal health has improved. DDS's total budget likewise has resumed its upward climb and, by 2014, surpassed its pre-recessionary peak. In 2016, DDS also received a one-time $287 million budget allocation over and above its general allocation.[119] Yet not all of the belt-tightening measures enacted during the Great Recession have been reversed. For example, cuts to camping, social recreation, non-medical therapies, and educational programs that were implemented in 2009 remain in place.[120] Although various stakeholders lobbied to restore some of these programs in the FY

(last visited Apr. 27, 2019) (using "2006–07 Enacted Budget" numbers). For FY 2007–08 and FY 2008–09, *see Historical Budget Documents*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/Budget/BudgetHistorical.cfm (last visited Apr. 27, 2019) (selecting "Budget Act Highlights (PDF)" for the relevant fiscal year and using "Enacted Budget" numbers). For FY 2009–10, *see* CAL. DEP'T DEVELOPMENTAL SERVS., 2009-10 MAY REVISION 1, https://www.dds.ca.gov/Budget/Docs/0910_DDSHighlights.pdf (last visited Apr. 27, 2019) (using "2009-10 May Revision" numbers). For FY 2010–11 through FY 2016–17, *see Budget Information*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/Budget/Home.cfm (last visited Apr. 27, 2019) (selecting "DDS Highlights" under "May Revision" for each fiscal year and using numbers from the "Funding Summary" table for the given fiscal year). For FY 2017–18 and FY 2018–19, *see Budget Information*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/Budget/Home.cfm (last visited Apr. 27, 2019) (selecting "Final Enacted Budget" under "May Revision" and using "Budget Act" numbers in the "Program Highlights" table). To adjust all figures for inflation, we used the Bureau of Labor Statistics' CPI Inflation calculator, *see CPI Inflation Calculator*, *supra* note 17 (for any given fiscal year, we converted the value for December of the initial calendar year—e.g., December 2015 for FY 2015–16—into December 2018 dollars). For ease of reference, see *Historical Budget Data*, STANFORD INTELLECTUAL AND DEVELOPMENTAL DISABILITIES LAW & PUB. POLICY PROJECT, https://law.stanford.edu/siddlapp/historical-budget-data/ (last visited June 28, 2019), for scanned copies of all Governor's and Enacted Budgets displayed in the figure are available on the SIDDLAPP website.

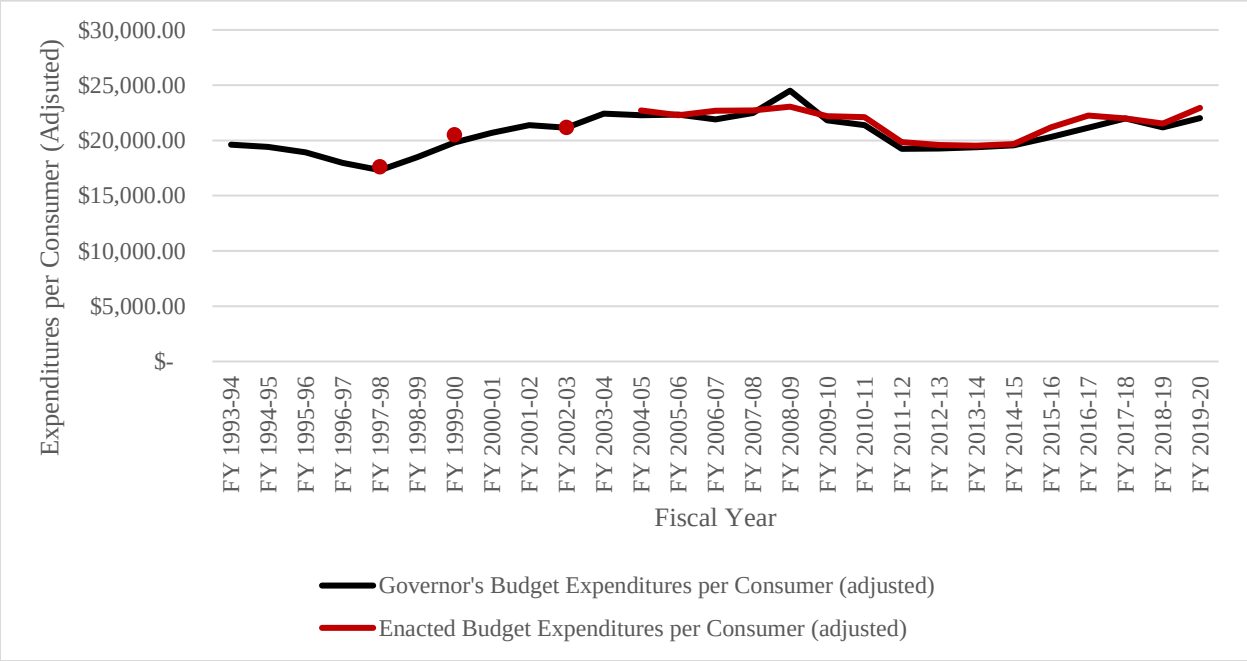
[118] STRENGTHENING, *supra* note 4, at 32-34.

[119] 2016 Cal. Legis. Serv. 2nd Ex. Sess. Ch. 3 § 15 (A.B. 1) (appropriating $287 million to the DDS General Fund); *see also id.* § 3 (codified at CAL. WELF. & INST. CODE § 4639.5(c) (2019)) (allocating funds to increase salaries for RC OPS' staffs' salaries); *see also id.* § 7 (codified at CAL. WELF. & INST. CODE § 4690.5) (increasing family-member provided respite services by 5%)); *see also id.* § 7 (codified at CAL. WELF. & INST. CODE § 4691.6(k)-(l) (2019)) (increasing the in-home respite services agency schedule rate and the independent living service rate by 5%)); *see also id.* § 8 (codified at CAL. WELF. & INST. CODE § 4690.1(a)-(b) (2019) (increasing the transportation service rate by 5%)); *see also id.* § 11 (codified at CAL. WELF. & INST. CODE § 4860(a) (2019)) (increasing the hourly rate for supported employment services); 2014 Cal. Legis. Serv. Ch. 409 § 43 (A. B. 1595) (codified CAL. WELF. & INST. CODE § 4640.6(j) (2019)) (reinstituting service coordinator-to-consumer ratio requirements for non-HCBS Waiver consumers)); 2012 Cal. Legis. Serv. Ch. 1472 § 16 (A.B. 1472) (codified at CAL. WELF. & INST. CODE § 4791 (2019)) (lifting provider rate cuts and reinstating required submission of reports by community-based day programs, in-home respite agencies, and residential service providers as of July 1, 2013); 2017 Cal. Legis. Serv. Ch. 65 § 1 (A.B. 126) (codified at CAL. WELF. & INST. CODE § 4686.5 (2019), since repealed by trailer bill) (delaying repeal of restrictions on respite care until January 1, 2018); 2017 Cal. Legis. Serv. Ch. 18 § 20 (A.B. 107) (repealed CAL. WELF. & INST. CODE § 4686.5 (2019)).

[120] CAL. WELF. & INST. CODE § 4648.5 (2017) (noting "effective July 1, 2009, a regional centers' authority to purchase the following services shall be suspended pending implementation of the Individual Choice Budget and certification by the Director of Developmental Services … (1) Camping services and associated travel expenses. (2) Social recreation activities, except for those activities vendored as community-based day programs").

2018–19 state budget,[121] these efforts proved unsuccessful.[122] Figure 6, below, displays average real spending per consumer from CY 1993 through CY 2018. Although spending per consumer has been on an upward trajectory since 2013, it has not yet attained its pre-recessionary peak (in 2007) of $22,456.63 because much of the increase in total expenditures has been offset by the concomitant growth in the consumer population.

Figure 6: Inflation Adjusted Expenditures Per Consumer, FY 1993–94 to FY 2018–19[123]



[121] *Health and Human Services: Hearing Before Cal. Assemb. Budget Subcomm. No. 1*, 2018 Leg., 2018 Reg. Sess. 45-6 (Cal. 2018) (subcommittee hearing agenda, including description of Issue 8: Advocacy Proposal on Restoration of Social Recreation and Camp Services). See CAL. DEP'T DEVELOPMENTAL SERVS., SUMMARY OF BUDGET REDUCTIONS (July 2009), https://www.dds.ca.gov/Director/docs/2009BudgetReductionsSummary.pdf (last visited Feb. 14, 2019), for a summary of budget cuts.

[122] *2018–19 May Revise Budget Issues Affecting People with Disabilities*, DISABILITY RIGHTS CAL. (May 14, 2018), https://www.disabilityrightsca.org/legislation/2018-19-may-revise-budget-issues-affecting-people-with-disabilities (last visited Jan. 23, 2019) (noting "Unfortunately, the Governor … did not fund social recreation and camping, all of which are important to people with disabilities.")

[123] To calculate expenditures per consumer, we divided real (inflation-adjusted) total expenditures in a given fiscal year by the number of consumers served by DDS in that year. For nominal total expenditures data (the numerator), we first collected nominal (inflation-unadjusted) total expenditure data from both Governor's Budgets and Enacted Budgets dating back to FY 1980–81, *see supra* note 117 and accompanying text. We collected Governor's Budget data for all fiscal years in this span and for Enacted Budget data when available online, *see id.* To convert nominal total expenditures to real FY 2018–19 dollars, we used the CPI Inflation Calculator, converting nominal total expenditures from December of the first calendar year of a fiscal year to December 2018 dollars, e.g., for FY 2009–10, we converted from December 2009 nominal dollars to December 2018 real dollars, *see CPI Inflation Calculator*, *supra* note 17. For the consumer count data (the denominator) since CY 2001, we used data from DDS' Monthly Consumer Caseload Reports, counting the number of Status 0, 1, and 2 consumers from December of the first calendar year of a fiscal year dating back to FY 1993-94, *see Previous Monthly Consumer Caseload Reports*, CAL. DEP'T DEVELOPMENTAL SERVS., *https*://www.dds.ca.gov/FactsStats/Caseload_Previous.cfm (last visited Mar. 21,

Finally, compared to other states, California spends a relatively small fraction of its total wealth on I/DD services.[124] In 2015, thirty-six US states spent a higher fraction of statewide personal income on disability services than did California.[125] Whereas California spent $3.50 of every $1,000 on services for people with I/DD in 2015,[126] the average across all 50 states was $4.30.[127] At face value, California's participation in federal matching programs also appears to be well below the national average.[128] For example, at $23,100 per participant, California's (state and

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2019). For FY 2019-20, we used caseload data from March 2019, since it was the most recent caseload data available as of this writing. Although our budget data dates back to FY 1980–81, our caseload data only dates back to FY 1993–94. As a result, Figure 6 only presents inflation-adjusted expenditures per consumer back to FY 1993–94. Between CY 2009 and CY 2011, DDS had a Status P for Early Start consumers under 36 months of age, and we included these consumer counts for these three years. For consumer counts from before CY 2001, we made use of various editions of DDS' Fact Books, *see DDS Fact Books*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/FactsStats/Factbooks.cfm (last updated June 19, 2018) (last visited Mar. 21, 2019). We then generated our estimates by dividing real total expenditures by the consumer count for a given fiscal year. Interestingly, our estimates of expenditures per consumer differ from estimates published by Lanterman Regional Center and DDS, *see* STRENGTHENING, *supra* note 4, at 3-39 (Lanterman Regional Center (LRC) noting "[t]he annual budget for regional centers is $941,515,000. The 21 centers serve 129,230 clients at an average cost of $7,285 per person" in 1995, as opposed to our real estimate of $19,114 per consumer and nominal estimate of $11,389 per consumer); *see also* CAL. DEP'T DEVELOPMENTAL SERVS., CONTROLLING REGIONAL CENTER COSTS 2, 18 (2007) [hereinafter CONTROLLING REGIONAL CENTER COSTS], http://www.dds.ca.gov/Publications/docs/ControllingRCCosts2007.pdf (last visited Apr. 15, 2019) (DDS reporting that "In fiscal year 1993–94, regional center expenditures per consumer averaged $6,633 per year" based on $742,767,000 total actual expenditures, as opposed to our real estimate of $19,575 per consumer and nominal estimate of $11,360 per consumer based on $1,347,079). The FY 1993–94 estimate from DDS closely tracks LRC's estimate for the 1995 fiscal year, but both are substantially lower than our estimates. The discrepancy between our estimates and those published by DDS likely reflects the fact that DDS uses actual as opposed to budgeted RC expenditures. It could also arise from the fact that DDS excludes state mandate expenditures—i.e., state expenditures to repay county mental health agencies incurred by counties assigned responsibility for services in certain contexts by statute, *see id.* at 18—and we do not. Explaining the discrepancy between our estimates and LRC's is more challenging since LRC does not explain how it formulated expenditures per consumer. LRC's estimate of the number of consumers served across all RCs is similar to ours, suggesting that the discrepancy in expenditures per consumer may arise from a discrepancy in the expenditures data. For both 1995 and 2001, LRC's figures for expenditures per consumer were substantially below our estimates ($7,285 versus $18,840 and $11,522 versus $21,972, respectively). It is possible that LRC only used POS expenditures or authorizations, whereas we use POS and OPS expenditures. LRC may also have used nominal as opposed to inflation-adjusted expenditures. Because LRC does not explain its methodology, we do not have sufficient information to fully explain these discrepancies.

[124] *See* DAVID L. BRADDOCK ET AL., THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: 2017 14 tbl.6 (11th ed. 2017) [hereinafter STATE OF THE STATES] (compiling "Total and Community Fiscal Effort for IDD Services in the States Per $1,000 of Statewide Aggregate Personal Income").

[125] *Id.* (where California ranked 37th in "Total and Community Fiscal Effort for IDD Services in the States" in FY 2015).

[126] *Id.*

[127] *Id.* (New York led the way among high-spending states, with an average expenditure of $9.06 per $1,000 of personal income, while Nevada—with expenditures of just $1.57 per $1,000 in personal income—ranked last).

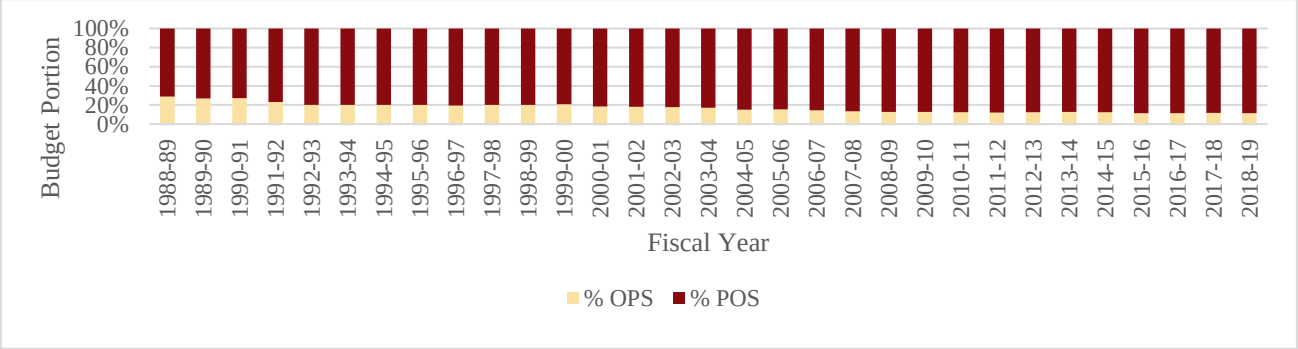
[128] Because California is unique among the fifty states in offering all Lanterman-eligible individuals with I/DD an entitlement to supports and services, and also accepts undocumented residents as RC clients. Nonetheless, the available evidence suggests that California lags behind many other states in its matching of federal funds, *see id.* at 8; *see also* STEVE EIKEN ET AL., TRUVEN HEALTH ANALYTICS, MEDICAID EXPENDITURES FOR LONG-TERM SERVICE

federal) expenditures in 2015 on Home- and Community-Based Services Waiver[129] services lagged considerably behind the nationwide average of $53,639 per participant.[130] It should be noted, however, that the unique aspects of California's service system make the latter comparison of HCBS Waiver spending per person potentially misleading.[131]

C. Overview of DDS Expenditure Categories

DDS's annual RC budget is broken down into two broad categories: operations (OPS) and purchase of services (POS). As shown in Figure 7, below, the OPS budget constituted as much as 29% of the total DDS budget in the late 1980s. However, beginning in the early 1990s, this share has steadily declined. In FY 2018–19, RC OPS accounts for just 11% of the total budget.[132]

Figure 7: DDS Budget, OPS v. POS, Enacted Budget FY 1988–89 to FY 2018–19[133]



AND SUPPORTS (LTSS) IN FY 2015 tbl. AA (2017) [hereinafter MEDICAID EXPENDITURES FOR LTSS], https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf (last visited Jan. 18, 2019) (ranking California 40th among US states in terms of HCBS Waiver expenditures per resident; California spent a combined (federal and state match) $64.02 on the HCBS Waiver per resident, compared to the nationwide average of $100.45 per resident).

[129] STATE OF THE STATES, *supra* note 124, at 49.

[130] *Id.* (compiling "Waiver Cost per Participant" for all 50 states and D.C. from their state profiles and then calculating the national average of HCBS Waiver expenditures per HCBS Waiver participant, which we found to be $53,639).

[131] *See* CARLY HITE ET. AL., STANFORD INTELLECTUAL & DEVELOPMENTAL DISABILITIES LAW AND POLICY PROJECT, INCREASING UPTAKE OF FEDERAL FUNDING TO SUPPORT CALIFORNIA'S REGIONAL CENTER SYSTEM § IV (2019) [hereinafter FUNDING REPORT], (noting that California "does not cap HCBS waiver enrollment or keep an HCBS Waiver waitlist…these features could increase the total number of HCBS Waiver-enrolled consumers in California, and likewise deflate HCBS Waiver expenditures per consumer" compared to other states' HCBS Waiver expenditures per consumer).

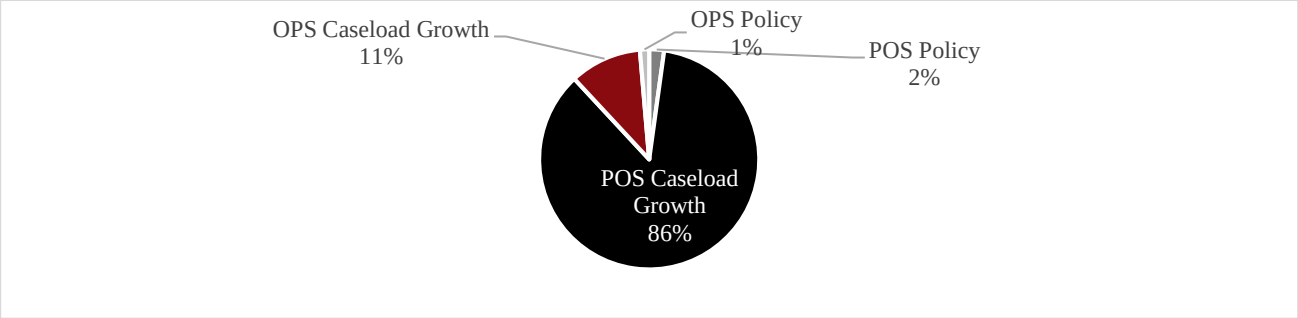
[132] *See* CAL. DEP'T DEVELOPMENTAL SERVS., 2018 MAY REVISION A-3, A-4 (2018) [hereinafter 2018 MAY REVISION], https://www.dds.ca.gov/Budget/Docs/2018_2019_RC-DCMayEstimate.pdf (last visited Jan. 17, 2019).

[133] *See* ASSOC. REG. CTR. AGENCIES, FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS 11–12 chart.5 (2013) [hereinafter FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS], https://www.dds.ca.gov/DSTaskForce/docs/DSTF_RC_7-FundingWorkCA-RCsReport.pdf (last visited Feb. 14, 2019) (figures for FY 1988–89 to FY 2012–13 are calculated using citizens of the general population (not RC consumer) as the denominator); *See Budget Information*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/Budget/Home.cfm (last visited Jan. 17, 2019) (figures for FY 2013–14 to FY 2018–19).

The projected level of OPS funding for a RC in any given year is a function of anticipated changes in two cost drivers: caseload and policy initiatives. Caseload growth is calculated using an algorithmic projection of the funding needed to continue providing services to existing consumers and to expand services to new consumers.[134] The algorithm inputs the number of anticipated consumers into the "core staffing formula," which is used to forecast the number and type of personnel needed for a RC to comply with its mandated and contractual obligations.[135] Policy initiative funding is allocated, in accordance with the formula, to achieve discrete policy goals established by DDS or the legislature.[136] Examples of policy initiatives include DC closures, reducing average caseloads, and ensuring HCBS compliance. OPS budget allocations in any given year, then, are a function of each RC's projected costs in both of these areas.

The POS budget serves a different purpose: it does not pay for RCs' operational costs, but for community-based services and supports that are provided to consumers and their families.[137] Nevertheless, POS budgets, like OPS budgets, are an algorithmic function of caseload growth and policy initiatives.[138] Figure 8, below, displays the share that each of these four budget categories–POS caseload growth, POS policy, OPS caseload growth, and OPS policy–contributes to total costs. The largest category is POS caseload growth, which accounts for 86% of costs. OPS caseload growth makes up another 11%, and the remaining 3% consists of the two "policy" categories.

Figure 8: DDS RC Budget POS and OPS Appropriations, Enacted Budget FY 2018–19[139]



[134] FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS, *supra* note 133, at 10.

[135] *Id.*

[136] *Id.* at 14.

[137] *Id.* at 7.

[138] *Id.* at 10

[139] 2018 MAY REVISION, *supra* note 132, at A-1.

Table 1, below, further breaks down the OPS and POS budgets for FY 2018–19. Each budgetary category is subdivided into two headings, "consumer caseload growth" and "policy," which in turn encompass a number of more specific program types. The OPS budget funds two types of RC expenses: *direct service expenditures* for activities such as service coordination, assessment, diagnosis, and clinical services; and *administrative costs* associated with accounting, budgeting, managerial compensation, facility rentals, and the like.[140] By statute, at least 85% of each RC's OPS budget must fund direct service expenditures.[141] Importantly, each RC's projected level of OPS and POS expenditures for the upcoming year (particularly for "caseload growth," which constitutes most of total expenditures) is derived from its base level of expenditures in the prior year.[142] In other words, a great deal of inertia is built into the formula allocating each RC's year to year funding. As a result, it is not surprising that variations across RCs in aggregate (and per-consumer) levels of POS funding are highly persistent over time.[143]

[140] CONTROLLING REGIONAL CENTER COSTS, *supra* note 123, at 16.

[141] CAL. WELF. & INST. CODE § 4629.7 (2017).

[142] *Ensuring Fair & Equal Access to Regional Center Services for Autism Spectrum Disorder Before the S. Comm. On Autism & Related Disorders*, 2012 Leg., 10-11 (Cal. 2012) [hereinafter DELGADILLO], http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/Regional%20Services%20hearing%20-full%20transcript.pdf (last visited Jan. 17, 2019) (Terri Delgadillo, Department of Developmental Services, explaining that "historically, [DDS] had allocated money to purchase services, was based on what the regional center, each individual, had spent the prior year…So whatever they spent the prior year, they got the next year. And then if there was any additional money, it was distributed for caseload and for utilization growth").

[143] *See* PUBLIC COUNSEL, ASSURING EQUITABLE FUNDING OF SERVICES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES 13 fig.1 (2017), https://issuu.com/publiccounsel/docs/assuring_equitable_funding_of_servi?e=29495352/49041713 (last visited Jan. 17, 2019).

Table 1: FY 2018–19 DDS Enacted Budget (thousands of dollars)[144]

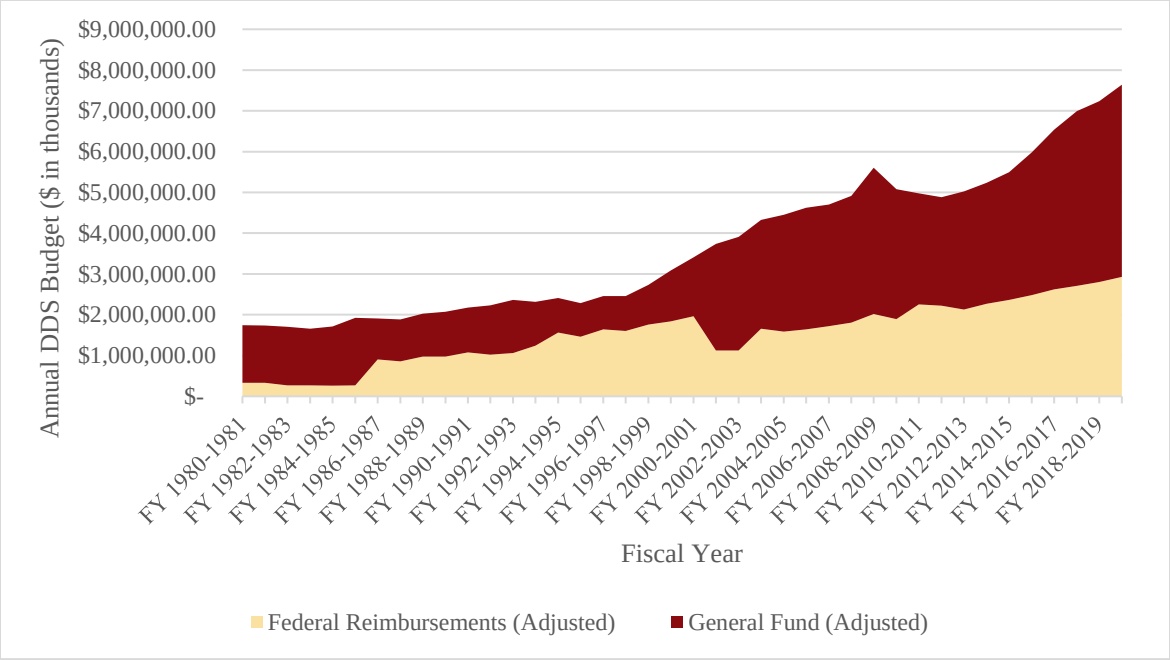
OPS	**Caseload Growth**	Staffing	$588, 266	$669,580	$755,466
		Compliance	$47,403		
		Projects	$26,777		
		Agnews Ongoing Workload	$2,894		
		Lanterman Ongoing Workload	$2,392		
		ICF-DD	$1,848		
	Policy	DC Closure	$5,434	$85,886	
		Compliance with HCBS Reg's	$1,422		
		Improving SC Caseloads	$17,000		
		BHT Psych Eval's for Fee-for-Service Consumers	$1,266		
		RC Operations Increase	$56,600		
		Resources to Implement AB X21	$4,164		
POS	**Caseload Growth**	Community Care Facilities	$1,460,469	$5,445,675	$5,584,003
		Medical Facilities	$12,817		
		Day Programs	$1,097,795		
		Habilitation: WAP	$45,431		
		Habilitation: SEP-G	$94,761		
		Habilitation: SEP-I	$28,844		
		Transportation	$346,053		
		Support Services	$1,314,398		
		In-Home Respite	$409,937		
		Out of Home Respite	$46,119		
		Health Care	$114,829		
		Miscellaneous	$464,245		
	Policy	DC Closure	$20,244	$138,328	
		Compliance w/ HCBS Reg's	$15,000		
		BHT Consumers w/out ASD diag.	–$1,985		
		Safety Net Resources	$5,622		
		CIE Incentives	$29,000		
		SB 3 Minimum Wage Increase	$66,862		
		Best Buddies	$1,600		
Early Start/Part C: Other Agency Costs					$19,109
Early Start Family Resources Services					$2,003
Total Budget					**$6,360,581**

[144] 2018 MAY REVISION, *supra* note 132, at A-5.

D. Breakdown of State and Federal Funding Sources

The Lanterman Act has always been funded through a federal-state partnership, but the relative shares contributed by the federal and state governments have evolved over time. In 1965, the original RC pilot programs drew approximately 30% of their funding from the federal government.[145] By FY 2018–19, about 40% of DDS's total funding came from CMS.[146] As shown in Figure 9, below, these relative proportions have fluctuated noticeably in recent decades. Outlays from the state's General Fund increased markedly after the turn of the millennium, and since 2012, they have increased more rapidly (in real dollars) than federal reimbursements. As a consequence, the share of federal (CMS) reimbursements in total DDS funding, although still far larger than it was at the time of the Lanterman Act's passage, has declined in recent years.

Figure 9: DDS Inflation-Adjusted Spending from CMS & State General Fund (FY 1980–81 to FY 2019–20)[147]



[145] A PROPOSAL TO REORGANIZE, *supra* note 12, at H2–H3 (calculated as "Federal Share" of daily costs for "all mentally retarded patients" divided by "Combined Federal, State, County" daily costs).

[146] 2018 MAY REVISION, *supra* note 132, at A-2 (dividing "Reimbursements" total by "Grand Total").

[147] As in Figure 5 and Figure 6, above, we used inflation-unadjusted data on federal reimbursements and the general fund from Governor's Budgets dating back to FY 1980-81, *see* notes 117, 123 and accompanying text. Here again, to adjust for inflation, we used the CPI Inflation Calculator, converting nominal federal reimbursements and total general fund expenditures from December of the initial calendar year of each fiscal year to December 2018 dollars, e.g., for FY 2009–10, we converted from December 2009 nominal dollars to December 2018 real dollars, *see CPI Inflation Calculator*, *supra* note 17.

Table 2, below, summarizes all state and federal funding sources that made up DDS's budget for the 2018-19 fiscal year. The subsections that follow describe these sources in more detail.

Table 2: DDS Budgetary Funding Sources, Enacted Budget FY 2018–19
(thousands of dollars)[148]

State	General Fund Total	General Fund-Match	$2,329,835	$3,742,305	$3,745,448
		General Fund-Other	$1,412,470		
	Program Dev. Fund/Parental Fees			$2,253	
	DD Services Account			$150	
	Mental Health Services Fund			$740	
Federal	Reimbursements	HCBS Waiver	$1,729,570	$2,560,388	$2,613,352
		HCBS Administration	$14,700		
		Medicaid Admin.	$16,132		
		TCM	$204,777		
		TCM Administration	$7,377		
		Title XX Block Grant	$213,421		
		ICF-DD SPA	$61,600		
		QAF	$10,901		
		1915(i) SPA	$250,838		
		TMFTP	$11,396		
		EPSDT	$26,538		
		BHT Fee-for-Service	$11,138		
	Other	Early Start/Part C Grant	$51,867	$52,964	
		Foster Grandparent Program	$1,097		
Grand Total					**$6,358,800**

(1) Description of State Funding Sources

State funding sources consist of four different categories: the General Fund, Program Development/Parental Fees, the Developmental Disabilities Account, and the Mental Health Services Fund. Virtually all state monies come from the General Fund; the last three categories account for only a negligible sliver (about 0.1%) of total funding.

As illustrated in Figure 10, below, the General Fund (GF) can be subdivided into two components: the "GF-Match" (62%) and "GF-Other" (38%). The "GF-Match" portion consists of expenditures that are under the purview of the Department of Health Care Services (DHCS), the state agency that oversees the funding of programs matched by the federal government.[149] Each federal funding program requires a state to contribute a fixed percentage of the total programmatic cost.[150] To take advantage of a 50% match Medicaid program, for example,

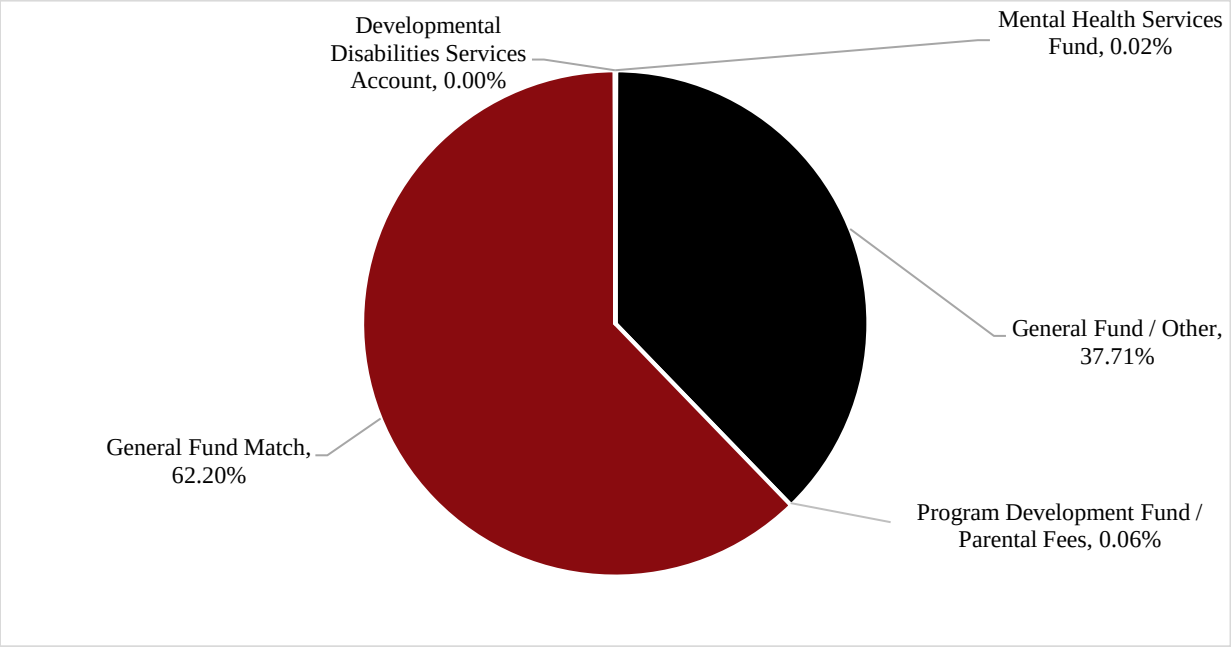
[148] 2018 MAY REVISION, *supra* note 132, at A2.

[149] *See* 2018 MAY REVISION, *supra* note 132, at I-1.

[150] *Id.* at F-17

California would need to expend $500 of its own monies (out of a total $1,000 in expenditures) to receive $500 in federal matching funds. The "GF-Other" category, in contrast, consists of RC expenditures that are *not* matched by the federal government.[151]

Figure 10: DDS' State Funding Sources, Enacted Budget FY 2018–19[152]



(2) Description of Federal Funding Sources

Table 2, discussed above, shows that federal funding encompasses three different categories: Reimbursements, Early Start, and the Foster Grandparent Program. Since the latter two categories jointly comprise just 2% of all federal funds, we confine our attention to the first category, Federal Reimbursements, which constitute 98% of all federal funding and about 40% of DDS's total budget.

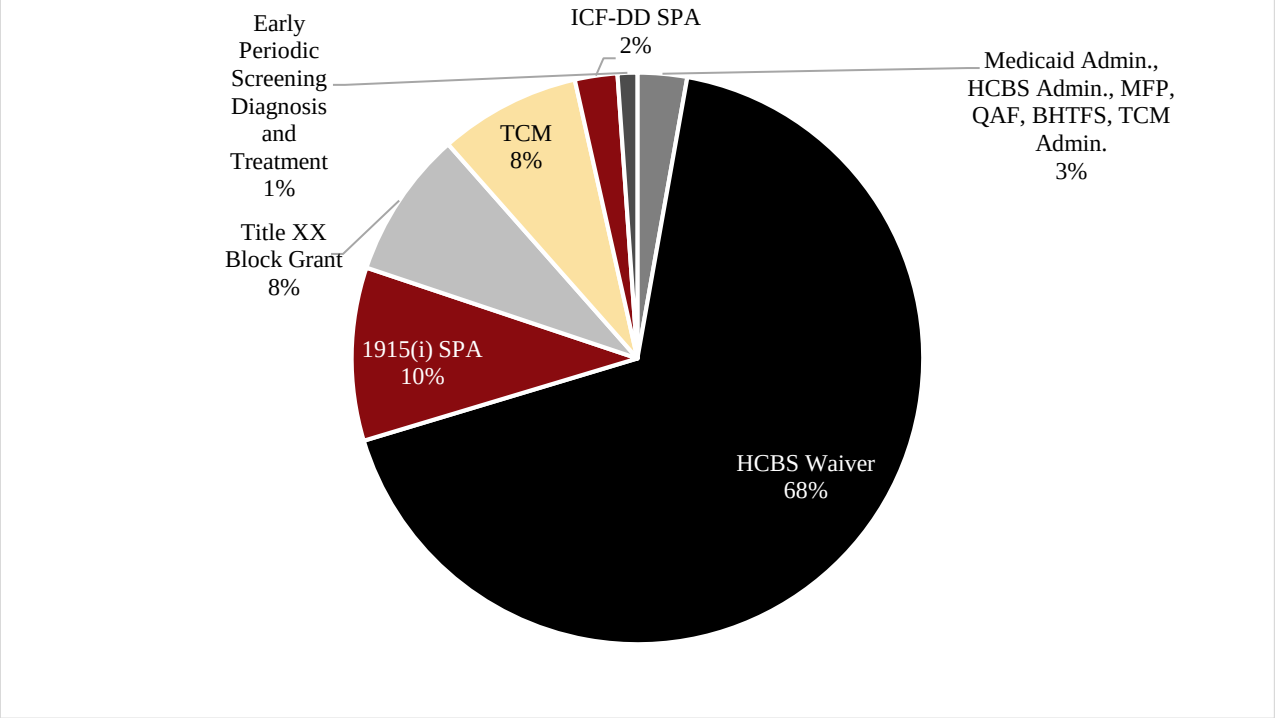
As illustrated in Figure 11, below, Federal Reimbursements are administered through thirteen different federal programs/grants administered by CMS: (1) the 1915(c) Home and Community-Based Services Waiver (HCBS Waiver); (2) the 1915(i) State Plan Amendment (SPA); (3) Targeted Case Management (TCM) funding; (4) Title XX Block Grants; (5) the ICF-DD State Plan Amendment (SPA 07–004); (6) the Early Periodic Screening Diagnosis & Treatment

[151] *Id*. at I-1.

[152] *Id*. at A-2.

Program (EPSDT); (7) HCBS Waiver Administration funding; (8) Medicaid Administration funding; (9) Targeted Case Management Administration funding; (10) Medi-Cal; (11) the Quality Assurance Fees; (12) "The Money Follows the Person" (TMFTP); and (13) the Behavioral Health Treatment (BHT) Fee-for-Service.[153]

Figure 11: CMS Reimbursements, Enacted Budget FY 2018–19[154]



Of these thirteen federal programs, the HCBS Waiver is the largest by far. At $1.7 billion per year, it constitutes approximately 68% of all federal funding and 27% of DDS's entire budget.[155] The HCBS Waiver allows states to finance a wide array of community services by, in effect, asking the federal government to waive the requirement that recipients dwell in state institutions and enable them to receive services in the community.[156] Figure 12, below, illustrates that HCBS

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[153] As previously discussed, the "GF-Match" component of the General Fund consists of expenditures that are under the purview of DHCS, the "federally-recognized single state agency for Medicaid" that oversees federal reimbursements of state Medicaid expenditures, *see id.* at I-1. Some of the federally-matched programs administered by DHCS are not reimbursed by CMS at a uniform rate, but at a varying rate that is determined by the Medi-Cal category to which each recipient belongs, *see* FUNDING REPORT, *supra* note 131 § V.C. (discussing the fact that each Medi-Cal recipient's "aid code" determines the federal match rate for services (s)he receives through the HCBS Waiver, 1915(i) SPA, and/or EPSDT).

[154] MAY REVISE, *supra* note 132, at A-2.

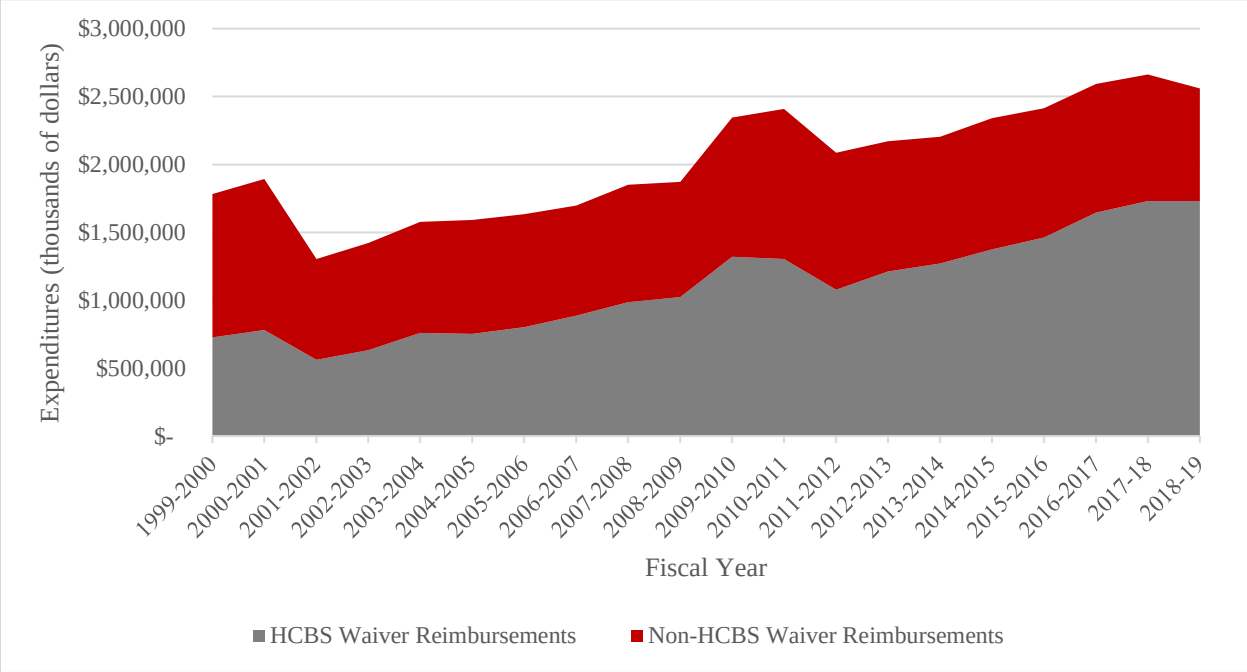
[155] *Id.* (calculated percentage of DDS's entire budget as HCBS ($1,729,570) / Grand Total ($6,358,800) = 27.2%).

[156] *See Home & Community-Based Services 1915(c)*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html (last visited Apr. 15, 2019) (noting that the HCBS Waiver is designed to "meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting).

Waiver reimbursements as a share of all CMS Reimbursements have grown markedly since the turn of the millennium.

The second largest contributor to total CMS reimbursements is the 1915(i) State Plan Amendment (1915(i) SPA). A program created by Congress under the Deficit Reduction Act of 2005, the 1915(i) SPA gives states the option to provide HCBS to *any* person with I/DD, regardless of the level of care (s)he requires.[157] In 2018–19, 1915(i) SPA funds totaled $250,838,000, which constituted 9.8% of all federal funding and 4% of DDS's total budget.[158]

Figure 12: HCBS Waiver v. Non-HCBS Waiver Funds as Percentage of All CMS Reimbursements FY 1999–2000 to FY 2018–19 (Inflation-Adjusted)[159]



Tied for third place are the Title XX Block Grant and Targeted Case Management (TCM) programs, each of which accounts for 8% of federal funds and 3% of the total DDS budget.[160] Title XX Social Services funds may be used flexibly by a state to achieve five broad service goals, and Title XX Temporary Assistance for Needy Families (TANF) funds may be used to cover expenditures for disabled children whose family income is less than 200% of the federal

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[157] *See Home and Community-Based Services Programs*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/waiver/index.cfm (last visited June 28, 2019).

[158] 2018 MAY REVISION, *supra* note 132, at A-2 (calculated percentage of DDS's entire budget as 1915(i) SPA ($250,838) / Grand Total ($6,358,800) = 3.94%).

[159] See *Budget Information*, *supra* note 133, for data dating back to FY 2010–11. Underlying data from other years are on file with the authors.

[160] 2018 MAY REVISION, *supra* note 132, at A-2 (calculated percentage of DDS's entire budget by dividing May Revision budget values for Title XX Block Grant ($213,421) and TCM ($7,377) by the Grand Total ($6,358,800).

poverty line.[161] The TCM program provides matching federal Medicaid funds for RC case management services for specific client groups.[162] According to DDS, the TCM program provides federal financial support for most of the hours that RCs' service coordinators (also sometimes known as case managers) spend on Medi-Cal eligible activities.[163]

Since the remaining nine programs (ICF-DD State Plan Amendment, the Early Periodic Screening Diagnosis & Treatment program, HCBS Waiver Administration funding, Medicaid Administration funding, TCM Administration funding, Medi-Cal, Quality Assurance Fees, TMFTP, and BHT Fee-for-Service) jointly constitute only 7% of the DDS's annual budget, we do not examine them in detail here.[164]

[161] *Id.* at I-18.

[162] *Id.* at I-16.

[163] *Id*.

[164] *See id.* at I16-28 (providing information on Medicaid Administration, Targeted Case Management, Targeted Case Management Admin., Medi-Cal, ICF-DD/State Plan Amendment, Quality Assurance Feed (DHCS), Money Follows the Person, Early Periodic Screening Diagnosis & Treatment, and Behavioral Health Treatment FFS).

V. Mounting Fiscal Pressures

As was revealed in Figure 5 and Figure 6, California's I/DD system has largely recovered from the effects of the Great Recession. Total expenditures, as well as real spending per consumer, have resumed their upward trajectories. [165] As is illustrated in Figure 9, above, DDS's total budget has likewise increased steadily. In FY 1980–81, DDS spent $1.90 billion (inflation adjusted), a figure that rose by about 2.5% annually in subsequent years and reached $7.74 billion by FY 2018–19. As of this writing, there are no apparent threats likely to imperil the basic functioning of the system in the near future.

To preserve the health and stability of California's I/DD system, it is important to identify the challenges on the horizon that could jeopardize the system's capacity to meet its goals over the long term. In this section, we identify nine trends that have already begun to tax the system's capacity to meet its statutory objectives, and whose impact is likely to escalate in the coming decades.[166]

A. An increasing percentage of California residents require services

As discussed in Section IV.(B)., California's I/DD population has already outgrown the RC System that Frank Lanterman envisioned. Between 2006 and 2016, the number of DDS consumers increased by 39.8%, compared to a general population growth of only 9.5%.[167] This trend is explained partly by the fact that California law entitles *every* individual with I/DD to receive needed services and supports, whereas in many other states, the total amount of resources is fixed and waiting lists are used to allocate scarce services and supports whenever demand outstrips supply.[168]

If the percentage of Californians requiring DDS services continues to grow faster than the population as a whole, the strain on the state budget will intensify in two ways. First, the total

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[165] As noted earlier, real spending per consumer is still below its 2007 level and the state has not restored camping, social recreation, and other suspended programs that were cut in 2009. *See supra* notes 120-122 and accompanying text.

[166] See ASS'N REG. CTR. AGENCIES, ON THE BRINK OF COLLAPSE: THE CONSEQUENCES OF UNDERFUNDING CALIFORNIA'S DEVELOPMENTAL SERVICES SYSTEM (2015) [hereinafter ON THE BRINK OF COLLAPSE], http://arcanet.org/wp-content/uploads/2015/02/on-the-brink-of-collapse.pdf (last visited Jan. 17, 2019), for a more detailed discussion of the RC perspective on funding threats calling for a one-time 10% increase in funding to community service providers and RCs; efforts to reform funding for service rates and RCs OPS budgets; and annual 5% funding increases to the I/DD system.

[167] 14TH DDS FACT BOOK, *supra* note 97, at 7; *see also*, MAC TAYLOR, CAL. LEG. ANALYST'S OFFICE, THE 2017–18 BUDGET: ANALYSIS OF THE DEP'T DEVELOPMENTAL SERVS. BUDGET 16 (2017), http://www.lao.ca.gov/reports/2017/3581/DDS-Budget-022417.pdf (last visited Jan. 17, 2019) (documenting that over the last ten years, California's population has grown at an annualized rate of 0.8% while the number of DDS consumers has increased at a rate of 3.7%).

[168] *See* discussion *supra* Section I.

cost of services and supports provided to residents with I/DD (as a percentage of total state income) will rise. Second, to the extent that individuals with I/DD have lower earnings than those without I/DD, an increase in the proportion of residents with I/DD could slightly reduce the state's tax base.[169]

Expanding employment opportunities for people with I/DD could help mitigate the latter trend. In 2017, almost one half (48%) of all Vermont residents with I/DD aged 18-64 worked for regular wages in integrated jobs,[170] whereas the comparable figure for California residents with I/DD in 2015 was only 1.4%.[171] Vermont's high rates of competitive integrated employment (CIE) were the result of a long-range effort since the 1990s to expand personalized job site supports, so that individuals with I/DD could "be employed in local jobs and work in a typical workforce with their fellow Vermonters."[172] For example, the 1,256 individuals served by Vermont's program in 2017 jointly earned $4,090,572, which reportedly produced approximately $1.5 million in "[t]otal [s]avings to Social Security" and "yielded a potential tax contribution of $613,585."[173] Although the population of Vermont is less than two percent as large as California's,[174] its successful expansion of personalized job supports for residents with I/DD illustrates the role of CIE in alleviating state budgetary pressures.[175]

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[169] *See* ON THE BRINK OF COLLAPSE, *supra* note 166, at 44 (explaining that in 2014 California was 661 service coordinators short of the number needed to comply with its required caseload ratio of coordinators to consumers); *see also* CAL. HEALTH & HUMAN SERVS. AGENCY, REGIONAL CENTER CASELOAD RATIOS: HISTORICAL INFORMATION 2 (2015), https://www.dds.ca.gov/DSTaskForce/docs/DSTF-RC_1-RCCaseloadRatiosHistoricalInfoUpdated20150127.pdf (last visited Jan. 17, 2019) (reporting that all 21 RCs were out of compliance with at least one caseload ratio requirement in 2014).

[170] VT. DEVELOPMENTAL DISABILITIES SERVS. DIV., VT. DEP'T DISABILITIES, AGING, & INDEP. Living, DEVELOPMENTAL DISABILITIES SERVICES STATE FISCAL YEAR 2017: ANNUAL REPORT 36 (Feb. 15, 2018), https://legislature.vermont.gov/assets/Legislative-Reports/DDS-Annual-Report-FY2017-FINAL.PDF (last visited Jan. 19, 2019).

[171] CAL. ST. COUNCIL DEVELOPMENTAL DISABILITIES, THE STATE OF EMPLOYMENT FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 4 (2015), https://scdd.ca.gov/wp-content/uploads/sites/33/2016/08/EFC-2015-Report-MM-Draft-2.pdf (last visited Jan. 17, 2019). Note that the California figure for the percentage of residents with I/DD working for regular wages in integrated jobs includes residents ages 65 and older. As a result, the 1.4% is a potential underestimate.

[172] VT. DEVELOPMENTAL DISABILITIES SERVS. DIV., *supra* note 170, at 34.

[173] *Id.* at 35-36 (the original source does not specify whether the "Total Savings to Social Security" apply to SSI or SSDI, or whether the "potential tax contribution" includes state and/or federal savings).

[174] *See List of U.S. states by population*, WIKIPEDIA, https://simple.wikipedia.org/wiki/List_of_U.S._states_by_population (last updated Apr. 11, 2019) (last visited Apr. 11, 2019) (noting, as of July 1, 2018, that the total state population for California is estimated at 39,559,045 and for Vermont is estimated at 626,299, or 1.58% of California's population).

[175] Although the passage of the Americans with Disabilities Act (ADA) encouraged states to provide employment supports to individuals with I/DD, they are still employed at much lower rates than individuals without disabilities, *see Disability Employment State Statute and Legislation Scan*, NAT'L CONF. ST. LEGIS. (Dec. 15, 2016), http://www.ncsl.org/research/labor-and-employment/employing-people-with-disabilities.aspx (last visited Apr. 15,

B. The consumer population is aging, which will likely increase costs

Middle-aged and elderly consumers constitute an increasing proportion of the I/DD population. In 2017, for example, the average RC consumer was 25.3 years old, up from 24.8 in 2006.[176] Meanwhile, the percentage of consumers over the age of 62 grew from 2.5% in 2006 to 3.8% in 2016.[177]

From a public health standpoint, this increase in life expectancy is a cause for celebration.[178] From a budgetary standpoint, it also poses significant challenges. According to California's Legislative Analyst's Office, RC "consumers are living longer and facing health issues associated with old age (for example, nearly all individuals with down syndrome [sic] will develop Alzheimer's Disease or dementia)."[179] This "greying" of the I/DD population will necessitate far greater outlays on medical treatment, behavioral support, and other services associated with dementia and end-of-life care. Although some of these added costs will be borne by other social service programs such as Medi-Cal, Social Security, and In-Home Supportive Services (IHSS), RCs as the "payers of last resort" are likely to bear some of this burden.[180] More research is required to understand the full budgetary implications of these developing trends.[181]

C. The caregiver population is aging

In 2016, 77.5% of all consumers lived at home with a parent or guardian.[182] Moreover, between 2006 and 2016, the percentage of *adult* consumers living at home with a parent or guardian increased from 50.6% to 59.9%.[183] As the I/DD population ages, so too will the family members

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2019) ("the most recent U.S. disability employment statistics show that only 20 percent of people with disabilities are participating in the workforce, compared to 69.1 percent of people without disabilities").

[176] 14TH DDS FACT BOOK, *supra* note 97, at 10.

[177] *Id.*

[178] *See Id.* at 43 ("In 2016, consumers are living longer. The pattern of decline in consumer population due to mortality now occurs after 55 years of age, whereas in 1996 the decline started before age 40").

[179] MAC TAYLOR, *supra* note 167, at 10.

[180] *See* BUDGET CHANGE PROPOSAL, *supra* note 113, at 4 ("life expectancy for individuals with. . . developmental disabilities is increasing[,] with more intensive health and safety requirements for daily living being needed as the population ages.")

[181] *See, e.g.*, DAPHNA GANS ET. AL., UCLA CTR. HEALTH & POL'Y RESEARCH, POLICY NOTE: CHALLENGES TO SUSTAINING CALIFORNIA'S DEVELOPMENTAL DISABILITY SERVICES SYSTEM 4 (2016), http://thearcca.org/policy/UCLA_Study.pdf (last visited Jan. 17, 2019) (documenting the steady increase in average annual expenditures per consumer by age group as consumers grow older).

[182] 14TH DDS FACT BOOK, *supra* note 97, at 8.

[183] *See Id.* at 13–14 (documenting the growth in the percentage of adult consumers who lived at home with a parent between 2006 and 2016—from 50.6% to 59.9%).

who care for them. As they enter old age, many family caregivers will be unable to care for their children (or other relatives) with I/DD without substantial state support, if at all.[184] Although augmenting IHSS benefits may be helpful to some family caregivers, it is unlikely to offer a complete solution since the program is capped at 283 hours per month,[185] and provides only basic (unskilled and low paid) forms of caregiving.[186] To ensure that adults with I/DD who live with relatives can continue to reside safely in the community, the state must provide additional in-home support to aging family caregivers, or find alternative community-based placements.

D. A growing percentage of consumers have autism, a uniquely costly disability

In the last ten years, a surge in the number of California residents diagnosed with autism has changed the demographic makeup of the consumer population. In 2006, 17.4% of all consumers were diagnosed with autism;[187] by 2019, this share had doubled to about 35%.[188]

The increased number of autistic consumers in the I/DD system is likely to drive up systemic costs. First, autism is generally the most expensive developmental disability to treat.[189] Second, most of these costs are not yet reflected in DDS's budget. As of July 2016, 80.6% of consumers with autism were aged 3-21,[190] and thus were likely to live at home and to receive most of their support through the public school system[191] or private insurance.[192] DDS may not feel the full impact of this demographic trend for another decade or more, when many of these children with autism come of age and DDS assumes primary responsibility for their ongoing care and support.

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[184] GANS ET. AL., *supra* note 181, at 4.

[185] CAL. WELF. & INST. CODE §14132.95(g) (2017) ("the maximum number of hours available under the In-Home Supportive Services . . . shall be 283 hours per month").

[186] *See In-Home Supportive Services Program*, CAL. DEP'T SOC. SERVS., http://www.cdss.ca.gov/In-Home-Supportive-Services (last visited January 19, 2019) (describing types of services that can be authorized through IHSS).

[187] 14TH DDS FACT BOOK, *supra* note 97, at 21.

[188] BUDGET CHANGE PROPOSAL, *supra* note 113, at 4.

[189] *Id.* at 40.

[190] *Id.* at 40.

[191] *Id.* at 40.

[192] S.B. 946, 2011 Leg., Reg. Sess. (Cal. 2011) (last visited Oct. 2, 2018) (This law took effect in 2012, required most health insurance providers to provide ABA services. Codified starting at CAL. HEALTH & SAFETY CODE § 1374.73), http://leginfo.ca.gov/pub/11-12/bill/sen/sb_0901-0950/sb_946_bill_20111009_chaptered.pdf (last visited Jan. 17, 2019).

The financial impact of this demographic shift is likely to be substantial. In 2006, for example, RCs spent (on average) more than three times as much on autistic consumers aged 22-45 as they did on those aged 3-21.[193]

E. Below-market rates are driving some service providers out of the industry

Many stakeholders have voiced concerns that the compensation levels authorized by DDS for many vital services and supports are inadequate, lowering the quality of services and leading, in some cases, to a shortage of qualified providers.[194] According to the Association of Regional Center Agencies (ARCA), for example, nominal rates increased only slightly from 1995 to 2015, even as inflation drove up the cost of providing services by approximately 50%.[195] Moreover, service providers in California appear to be less well compensated than their counterparts in states with similarly high costs of living. For example, California reimburses Work Activity Programs at $35.29 per day per individual served, whereas Oregon and New York reimburse the same service at twice this amount.[196]

Many service providers have responded to low compensation rates by closing their doors. In a 2015 survey of hundreds of providers that left the industry, the single most commonly reported reason for exiting was low reimbursement rates.[197] Several other reasons offered, such as low wages and high turnover, also probably stem, at least in part, from the low levels of reimbursement.[198]

With fewer providers available, California residents with I/DD face more difficulty in obtaining adequate services than their counterparts in other states. During the 2014–15 fiscal year, for instance, 30% of adults in California's RC system who responded to a national survey reported that some of their needs were not being met, whereas the comparable nationwide percentage was

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[193] GANS ET. AL., *supra* note 181, at 3–4.

[194] *See, e.g.*, CALIFORNIA DISABILITY COMMUNITY ACTION NETWORK, REPORT: DEPARTMENT OF DEVELOPMENTAL SERVICES SELECTS PHOENIX AZ FIRM TO CONDUCT LONG AWAITED REGIONAL CENTER PROVIDER RATE STUDY 2 (May 17 2017), https://lanterman.org/uploads/service_providers/CDCAN_REPORT_DDS_AZ_Rate_Study_Provider.pdf (last visited Jan. 17, 2019) (summarizing claims by various advocacy groups that claimed that inadequate rates in the I/DD system were creating significant unmet needs).

[195] ON THE BRINK OF COLLAPSE, *supra* note 166, at 19.

[196] *Id.* at 22.

[197] *Id.* at 41 (ARCA estimates that 263 community care facility service providers closed in 2015, and the overall number of provider closures varies significantly by program type); *See also* S.E. Smith, *Low Wages Are Driving a Shortage of Care Providers. Now Elders and the Disabled Face a Crisis*, IN THESE TIMES (June 28, 2018), http://inthesetimes.com/working/entry/21245/California-workers-disabled-elders-caregivers-low-wage-workers (last visited Jan. 17, 2019) (describing California's worsening shortage of care providers for individuals with I/DD).

[198] *Id.*

only 18%.[199] Moreover, during the 2015–16 fiscal year, 36% of families with children entitled to services said that at least one of their child's identified needs was not being met, whereas the corresponding national average was only 27%.[200] In an effort to address the concern that inadequate rates are contributing to shortage of providers, the legislature authorized DDS to carry out and submit to the legislature an independent rate study "addressing the sustainability, quality, and transparency of community-based services for individuals with developmental disabilities" by March 1, 2019.[201]

Consumers with severe behavioral challenges, such as aggression or self-injurious behavior, may find it almost impossible to hire qualified providers at standard authorized rates. To address this problem, various state regulations permit DDS to make case-by-case exemptions to rate freezes to mitigate health and safety risks,[202] which are generally known as "health and safety waivers." In theory, the availability of health and safety waivers helps to alleviate the shortage of providers willing to serve those individuals that are the hardest to safely support. However, Stakeholder Meetings conducted by DDS in 2017 revealed that in practice, the process is "too cumbersome, outdated, and/or lengthy" to effectively serve its intended purpose.[203] In September of 2018, DDS issued revised guidelines to all regional centers requiring them to submit health & safety waiver requests to DDS no more than 30 days after receiving them from providers. [204] The memo also indicated that DDS would "review the [health and safety waiver] request and respond to the regional center" within five working days."[205] As of this writing, no data has been made publicly available on the extent to which RCs and DDS have adhered to these new deadlines.

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[199] *See* HUMAN SERVICES RESEARCH INSTITUTE, NATIONAL CORE INDICATORS: ADULT CONSUMER SURVEY FY 2014–2015 91 (2015) [hereinafter NCI: ADULT FY 14/15], https://www.dds.ca.gov/QA/docs/adultConsumerSuryvey3FY14_15.pdf (last visited Jan. 17, 2019) (in response to the question, "Do you get the services you need," 19% of California respondents said "sometimes, or does not get enough services" and 11% said "no." Nationwide, 12% said "sometimes, or does not get enough services," and 6% said "no").

[200] HUMAN SERVICES RESEARCH INSTITUTE, NATIONAL CORE INDICATORS: CHILD FAMILY SURVEY FY 2015–2016 86 (2017) [hereinafter NCI: CHILD FAMILY FY 15/16], https://www.dds.ca.gov/QA/docs/reportCFS2.pdf (last visited Jan. 17, 2019) (in response to the question, "Does your family get the support needed," 36% of California respondents said "no," and, 27% of respondents said "no" in the 45 states surveyed).

[201] CAL. WELF. & INST. CODE § 4519.8 (2017) (requiring DDS to submit a rate study to the appropriate fiscal and policy committees of the legislature addressing the sustainability, quality, and transparency of community-based services for individuals with development disabilities).

[202] *See id.* §§ 4681.6(a)(1), 4648.4(b), 4681.5(a), 4684.55(a), 4689.8(a), 4691.6(b)-(e), 4691.9(a)(1).

[203] *See* CAL. HEALTH & HUMAN SERVS. AGENCY, CAL. DEP'T DEVELOPMENTAL SERVS., PLAN FOR CRISIS AND OTHER SAFETY NET SERVICES IN THE CALIFORNIA DEVELOPMENTAL SERVICES SYSTEM 24 (May 13, 2017), https://www.dds.ca.gov/Budget/Docs/20170513-PlanCrisis-OtherSafetyNetServices.pdf (last visited Jan. 23, 2019).

[204] Memorandum from Brian Winfield, Deputy Direct., Cmty Servs. Div., Cal. Dep't Developmental Servs. 3 (Sept. 13, 2018) (on file with authors).

[205] *Id.*

F. Regional centers struggle to recruit and retain qualified personnel

As discussed above, RCs' personnel and operational costs utilize a "core staffing formula" that was developed in 1978 in an effort to standardize salary and benefits ranges for each staff position.[206] ARCA, however, has criticized the formula as "an ad hoc creation developed without the benefit of the specialized study that such an important and complex statewide publicly-funded service system needed. There is no written analysis, justification, or documentation supporting the 1978 base formula, which is the same formula used today, except for some 'add-ons' and minor changes."[207] The salary for each position was originally intended to match the average salary for the equivalent state position at the time the position was added to the formula.[208] However, the state stopped indexing RC employees' salaries to cost-of-living adjustments in 1991.[209] Even though RCs have some leeway to exceed the specified rates, nearly every RC position pays less than the equivalent position in state government.[210] In FY 2013–14, for example, the core staffing formula set RC service coordinator salaries at $34,032, and the actual median salary for the position was $46,121.[211] Had the core staffing formula kept pace with increases to the average state salary, the RC service coordinator salary would be about $50,340.[212]

RCs' limited capacity to offer competitive salaries makes it difficult for them to hire and retain qualified personnel. As of 2017, 20 of 21 RCs failed to comply with at least one statutorily-mandated service-coordinator caseload ratio.[213] Meanwhile, California's average caseload ratio of 1:73 places it far above the 2005 nationwide median of 1:30-39.[214] Results from a national survey suggest that high caseload ratios negatively impact the quality of support that California consumers receive. For example, 79% of adult California consumers reported that their service

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[206] CONTROLLING REGIONAL CENTER COSTS, *supra* note 123, at 16.

[207] FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS, *supra* note 133, at 10.

[208] CONTROLLING REGIONAL CENTER COSTS, *supra* note 123, at 37–38.

[209] FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS, *supra* note 133, at 3.

[210] *Id.* at 22–23.

[211] *Id.* at 24.

[212] *Id.*

[213] *See* ASS'N REG. CTR. AGENCIES, DDS SERVICE COORDINATOR CASELOAD SURVEY (2017) [hereinafter DDS SERVICE COORDINATOR CASELOAD SURVEY], http://www.harborrc.org/files/uploads/Caseload_Ratio_Survey_-_March_2017.pdf (last visited Jan. 17, 2019).

[214] ROBIN COOPER, DIR. TECH. ASSISTANCE, NAT'L ASSOC. STATE DIRS. OF DEVELOPMENTAL DISABILITIES SERVS., SURVEY OF STATE CASE MANAGEMENT POLICIES AND PRACTICES 6 (2006), http://www.nasddds.org/uploads/documents/NASDDDS_CaseManagementPoliciesPractices_2006.pdf (last visited Jan. 17, 2019) (also finding that only 5 of 37 responding states had caseload ratios higher than 1 to 59).

coordinators helped them get what they needed, compared to 88% for the U.S. as a whole.[215] Similarly, only 61% of adult California consumers responded that their service coordinators called them back right away, compared to a national average of 74%.[216] Finally, 18% of parents in California reported that they were sometimes, seldom, or never able to contact their child's service coordinator when needed, compared to 12% of parents nationwide.[217] ARCA estimates that bringing California into compliance with service coordinator ratios would require hiring an additional 1,000 service coordinators.[218]

If California does not find a way to consistently recruit and retain enough qualified service coordinators, the I/DD system will suffer in two ways. First, consumers and their families will have more difficulty accessing the services they require to live in their communities. Second, by failing to maintain statutorily required coordinator-to-consumer ratios, California may run afoul of federal law and imperil its eligibility for significant amounts of federal funds.[219]

G. Rising labor costs are driving up the cost of direct services

Many direct service providers in California earn minimum wage,[220] and even those who do not are generally paid less than workers in other industries with similar qualifications.[221] As a result, RC vendors report that new staff members "often have less experience and lower levels of education than those whom they are replacing."[222]

The challenge of recruiting and retaining direct-care staff is likely to intensify in the coming years, as the state's minimum wage continues to rise. In January of 2017, the statewide minimum wage increased to $10.50 per hour,[223] and it was slated to reach $15 per hour by 2022.[224] However, it is important to note that state minimum wage laws set a floor, not a ceiling, for

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[215] NCI: ADULT FY 14/15, *supra* note 199, at 85.

[216] *Id.* at 86.

[217] NCI: CHILD FAMILY FY 15/16, *supra* note 199, at 69.

[218] FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS, *supra* note 133, at 24.

[219] *See* MAC TAYLOR, *supra* note 167, at 14–15 (noting that "federal [Home and Community-Based Services] rules require [regional centers] to maintain an average service coordinator-to-consumer ratio of 1-to-62 for consumers receiving services through the [Home and Community-Based Services] waiver" and that California risks losing "some amount of federal funding" if it fails to comply with this statute).

[220] *See* ON THE BRINK OF COLLAPSE, *supra* note 166, at 7 (citing a 2001 study finding that a fair market rate for direct support professionals was $10.00–10.99 at a time when the state's minimum wage was only $6.25).

[221] GANS ET. AL., *supra* note 181, at 5.

[222] *Id.*

[223] *Minimum Wage*, CAL. DEP'T INDUS. RELATIONS (Dec. 2016), https://www.dir.ca.gov/dlse/faq_minimumwage.htm (last visited June 28, 2019) ($10.50 per hour 2017 and $15.00 per hour in 2011 are the minimum wages for employers with 26 employees or more).

[224] *See* ON THE BRINK OF COLLAPSE, *supra* note 166, at 16.

individual municipalities. Some cities have already raised their minimum wages above the state floor, and some may continue doing so even after 2022.[225]

The scheduled increases in the statewide (and respective local) minimum wages will strain DDS' budget in two ways. First, these increases will increase the labor cost of minimum-wage workers who provide direct care. Second, workers who earn above the minimum wage are likely to demand pay raises, further increasing labor costs.[226]

The only apparent solution to this problem is to increase provider rates. As researcher David L. Braddock and colleagues concluded, "to meet the needs of people with IDD, we must. . . enhance [the] near-poverty level wages and benefits of direct support staff in community services programs, to improve the quality of the services they provide, and minimize staff turnover."[227] As noted earlier, DDS commissioned an independent rate study, scheduled for completion in March of 2019, to shed light on the (in)adequacy of provider rates across different service areas and regions of the state.[228]

Although there is a high degree of consensus regarding the inadequacy of the current rate structure, there is far less unanimity on the best way to address the problem. Should DDS authorize rate increases across the board, or target them toward areas where lagging rates have had the largest negative impact on the quality of care? Should *all* providers in a given industry receive them, or should they be tied to outcome-based measures of performance? As of this writing, these questions remain unresolved.

H. The high cost of housing is a barrier to community-based living

Fulfilling the Lanterman Act's core entitlement to community-based living has become increasingly expensive as housing prices continue to rise. A 2015 report found that the average rent for a studio apartment in California was 103% of a typical consumer's monthly Supplemental Security Income (SSI) stipend, and a one-bedroom apartment cost 121% of monthly SSI payments.[229] In San Francisco, these figures were 143% and 186%, respectively.[230]

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[225] *See Id.* (noting that in 2017 more than twenty cities in California mandated a local minimum wage that exceeded the minimum wage set by the legislature).

[226] *Id.*

[227] BRADDOCK ET AL., *supra* note 124, at 23.

[228] *See* CAL. WELF. & INST. CODE § 4519.8 (2017); *see also supra* note 201 and accompanying text.

[229] TECHNICAL ASSISTANCE COLLABORATIVE & CONSORTIUM FOR CITIZENS WITH DISABILITIES, PRICED OUT IN 2014: THE HOUSING CRISIS FOR PEOPLE WITH DISABILITIES 41 tbl.2 (2014) [hereinafter PRICED OUT IN 2014], http://www.tacinc.org/media/52012/Priced%20Out%20in%202014.pdf (last visited Jan. 17, 2019); *see also* CONTROLLING REGIONAL CENTER COSTS, *supra* note 123, at 89 –92 (highlighting affordable housing issue for people with I/DD); *see also* ON THE BRINK OF COLLAPSE, *supra* note 166, at 24.

[230] *See* PRICED OUT IN 2014, *supra* note 229, at 24 tbl.1.

In many regions of the state, it is thus not possible for consumers who qualify for Independent Living Services or Supported Living Services to afford monthly rent on SSI payments alone. As a result, high housing costs may force some consumers to reside in more restrictive settings than their needs would otherwise require. For instance, although community care facilities can bundle the cost of housing into their total monthly rate, the rates paid to providers—even if defrayed by residents' SSI payments—may not compensate vendors for the total costs of renting (or leasing) a suitable property, particularly in high-rent areas. In response, more and more vendors may be forced to close their doors. In short, rising housing costs may simultaneously force consumers into more restrictive settings and drive many vendors out of the market.

This is not a novel problem, and DDS has used several techniques in the past to mitigate its impact. On several occasions, DDS has used the closure of DCs as an opportunity to pilot creative initiatives to address the housing shortage. For example, the "Buy-it-Once" program allows RCs to use Community Placement Plan funds (intended to facilitate the transition of former DC residents to the community) to purchase residential properties for the perpetual use of RC consumers.[231] The goal of the program is to recoup the state's investment in housing, rather than merely to subsidize rental payments. In another model, implemented in 1981 following the closure of a section of the Fairview Developmental Center, DDS contracted with a private developer to create a mixed-income housing project called Harbor Village on a portion of Fairview's former grounds.[232] The lease specified that some of the housing would be set aside in perpetuity for former Fairview residents. Today, RC consumers occupy 31% of the available units at Harbor Village, for which they pay subsidized rent.[233] Another, similar project underway at the former Fairview site will generate additional housing units, of which at least 20% will be reserved for DDS consumers.[234]

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[231] *See* CAL. WELF. & INST. CODE § 4688.6(a) (2017) ("[T]he department may approve a proposal or proposals by any regional center to provide for, secure, and ensure the full payment of a lease or leases on housing . . . if . . . [t]he acquired or developed real property is occupied by individuals eligible for regional center services . . . [and t]he proposal includes a plan for a transfer at a time certain of the real property's ownership to a nonprofit entity."); *see also* CAL. DEP'T DEVELOPMENTAL SERVS., GUIDELINES FOR PURCHASING AND DEVELOPING PERMANENT HOUSING THROUGH THE REGIONAL CENTER COMMUNITY PLACEMENT PLAN 3 (2016), http://www.dds.ca.gov/CPP/docs/guidelines.pdf (last visited Jan. 17, 2019) ("[DDS] created these Housing Guidelines to achieve the development of safe, affordable, and sustainable housing for individuals with intellectual or developmental disabilities eligible to receive services from the RC (consumers). To protect the State of California's (State) interest, the Department uses CPP funds to facilitate the development of permanent housing in the community that will be used exclusively, in perpetuity, by consumers. In collaboration with the RC, a [non-profit organization] may purchase real property through the "Buy-it-Once" model").

[232] *See* MAC TAYLOR, Leg. ANALYST'S OFFICE, SEQUESTERING SAVINGS FROM THE CLOSURE OF DEVELOPMENTAL CENTERS 12 (2018), http://www.lao.ca.gov/reports/2018/3735/sequestering-savings-013118.pdf (last visited Jan. 17, 2019).

[233] *Id.*

[234] *Id.*

Although these models hold considerable promise, they are insufficient to address the mounting housing shortage. The state will need to continue developing new and innovative solutions, particularly in higher-cost regions of the state, to make good on the Lanterman Act's promise of enabling individuals with I/DD to reside in integrated, community settings. Although DDS will have to take the lead on some systemic reforms, especially those that require legislative or regulatory authorization, the nonprofit sector is likely to play an increasingly important role.[235]

I. California is not in compliance with the CMS Final Settings Rule

A requirement common to both the HCBS Waiver and the 1915(i) SPA programs is that the consumer must reside in a home or-community-based setting (HCBS). Until recently, however, there were no federally mandated criteria for how this requirement might be met. In 2014, CMS adopted regulations that more clearly—and stringently—defined what constitutes a HCBS.[236] During the Obama Administration, this so-called "Final Settings Rule" was scheduled to take effect in March 2019,[237] but the Trump Administration has chosen to delay its enforcement until

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[235] For example, a nonprofit organization based in San Francisco, The Kelsey, aims to "leverage existing public, private, and nonprofit partners" to create "mixed ability, mixed income housing communities where people of all abilities and backgrounds live, play, and serve together," *see Concept*, THE KELSEY, https://www.thekelsey.org/concept (last visited Jan. 23, 2019). The organization's first project, The Kelsey Ayer Station, will be a "fully inclusive mixed ability, mixed income housing community" of 111 apartment homes located in downtown San Jose, California, *see The Kelsey Ayer Station*, THE KELSEY, https://www.thekelsey.org/ayerstation (last visited Jan. 23, 2019). The building will include "community, commercial, and outdoor space -- a lobby lounge with on-site Inclusion Concierges™, terraces, rooftop gardens, and a community room on each residential floor. On the ground level, a café serves neighbors and passersbys by day and operates as a communal dining area by night," *see id.*

[236] 42 C.F.R. § 441.530(a)(1) (2019) (noting the new HCBS standard defines a HCBS Waiver- and SPA-eligible home and community-based setting as one that: "(i) Is integrated in and supports full access . . . to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS; . . . (ii) Is selected by the individual from among setting options; . . . (iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint; (iv) Optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact; [and] (v) Facilitates individual choice regarding services and supports, and who provides them. Moreover, in a provider-owned or controlled residential setting, units must be "owned, rented or occupied under a legally enforceable agreement" by the consumer, and the consumer must have control over: lockable doors, choice of roommate(s), furnishings and decorations, schedules and activities, food access, and visitors"). The regulations specifically exclude nursing facilities, institutions for mental diseases, *see* CAL. CODE REG. § 1810.222.1 (2017) (noting "'Institution for Mental Diseases' means a hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment or care of persons with mental disorders, including medical attention, nursing care, and related services." ICF-I/DDs (including developmental centers), state institutions providing long-term care services, and any other locations that have qualities of an institutional setting, as determined by the Secretary of Health and Human Services); *see also* 42 C.F.R. § 441.530(a)(2) (2018) (describing what home and community-based settings do not include).

[237] BRIAN NEALE, DIRECTOR, CENTERS FOR MEDICARE & MEDICAID SERVICES, INFORMATIONAL BULLETIN: EXTENSION OF TRANSITION PERIOD FOR COMPLIANCE WITH HOME AND COMMUNITY-BASED SETTINGS CRITERIA (May 9, 2017), https://www.medicaid.gov/federal-policy-guidance/downloads/cib050917.pdf (last visited Jan. 17, 2019).

March 17, 2022.[238] Although it is unclear what percentage of current community-based settings satisfy the new requirements,[239] it is likely that achieving full compliance will take years.[240]

History teaches that failure to comply with the Final Settings Rule in a timely fashion could put billions of dollars of federal funding at risk.[241] In 1997, CMS identified serious deficiencies in the state's provision of services and supports to people with I/DD.[242] HCBS Waiver enrollment was frozen from December 1997 to October 2000 while the state worked to reduce caseloads, resulting in an estimated $933 million loss of federal funds over six years.[243] In response, the legislature required that all RCs maintain average service coordinator-to-consumer ratios of 1 to 62, and that all RCs possess expertise in criminal justice, special education, family support, housing, community integration, and quality assurance.[244] Despite this clear directive, as of 2017, 16 of 21 RCs did not meet the coordinator-to-consumer ratios required under the HCBS Waiver.[245]

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[238] *Id.; see also* CTRS. MEDICARE & MEDICAID SERVS., DEP'T HEALTH & HUMAN SERVS., SMD # 19-001, FREQUENTLY ASKED QUESTIONS: HCBS SETTINGS REGULATION IMPLEMENTATION (2019), https://www.medicaid.gov/federal-policy-guidance/downloads/smd19001.pdf (last visited Apr. 15, 2019) (providing additional guidance responsive to frequently asked questions regarding *heightened scrutiny* review pertaining to settings identified by the regulation as being presumed to have the qualities of an institution).

[239] DDS "has provided relatively little guidance to the state's tens of thousands of service providers on what compliance means or what programmatic changes they will need to make to reach compliance," *see* MAC TAYLOR, *supra* note 167, at 4; *see also id.* at 13–14 (describing "the funding pressure on the system" from "the unknown cost to the state to provide financial assistance to service providers to bring them into compliance"); *id.* at 18 (expressing "concern" that "so little is known about the extent of [provider] non-compliance with the final rule").

[240] RALPH F. LOLLAR, DIRECTOR, DIVISION OF LONG TERM SERVICES AND SUPPORTS, CENTERS FOR MEDICARE & MEDICAID SERVICES, LETTER TO MARI CANTWELL, CHIEF DEPUTY DIRECTOR, HEALTH CARE PROGRAMS, CALIFORNIA DEPARTMENT OF HEALTH CARE SERVICES (Feb. 23, 2018), https://www.aucd.org/docs/policy/HCBS/CA%20Initial%20Approval.pdf (last visited Apr. 18, 2019); *see also* CMS. CAL. DEP'T OF HEALTH CARE SERVICES, STATEWIDE TRANSITION PLAN FOR COMPLIANCE WITH HOME AND COMMUNITY BASED SETTINGS RULE 17 30–32 (2017), http://www.dhcs.ca.gov/services/ltc/Documents/STP_1_September_2017.pdf (last visited Jan. 17, 2019) (establishing a procedure for classifying all HCBS settings into four categories based on the Final Settings Rule).

[241] ON THE BRINK OF COLLAPSE, *supra* note 166, at 33 (noting in 1998 the federal Health Care Financing Administration audited California's compliance with the HCBS Waiver in 1998 and issued a critical report. HCFA demanded a number of reforms as a condition of California's continued participation in the HCBS Waiver. The federal government froze HCBS Waiver enrollments as of December 1997 until each RC implemented the required changes; consequently, HCBS Waiver enrollment fell by 5,600 people from December 1997 until October 2000, costing the State an estimated $933 million in lost federal funds).

[242] FUNDING THE WORK OF CALIFORNIA'S REGIONAL CENTERS, *supra* note 133, at 32.

[243] CONTROLLING REGIONAL CENTER COSTS, *supra* note 123, at 29.

[244] 1998 Cal. Leg. Serv. Ch. 310 § 37 (A.B. 2780) (codified at CAL. WELF. & INST. CODE § 4640.6 (2019)).

[245] *See* DDS SERVICE COORDINATOR CASELOAD SURVEY, *supra* note 213 (reporting a statewide average of 1 service coordinator to 73 HCBS Waiver consumers, 17% higher than the statutory limit of 1 to 62).

VI. Conclusion

California's system for supporting residents with I/DD has evolved in dramatic ways since its inception half a century ago. Supports are presumptively provided in the community by independent RCs, supported by DDS. Due to the expansion of the RC system and the closure of developmental centers, the number of Californians with I/DD receiving community-based services has risen dramatically, and RC caseloads have likewise expanded to accommodate consumers' diverse needs. Though California's I/DD system is currently enjoying a period of relative calm and prosperity, an array of demographic and economic trends is likely to threaten the system's long-term viability. In anticipation of these trends, the state should consider taking decisive, proactive measures to protect the long-term viability of its I/DD service delivery system.

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