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

Increasing Uptake of Federal Funding to Support California's Regional Center System

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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."[1] 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.[2]

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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[1] CAL. WELF. & INST. CODE § 4501 (2019).

[2] *See* GRETCHEN ENGQUIST ET AL., CTR. FOR HEALTH CARE STRATEGIES, INC., SYSTEMS OF CARE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A SURVEY OF STATES (Sept. 2012), http://www.chcs.org/media/IDD_State_Priorities_and_Barriers_Snapshot_082812.pdf (last visited Feb. 14, 2019) (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).

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, *Increasing Uptake of Federal Funding to Support California's Regional Center System*, is to explore ways in which the RC system might increase its current recoupment of federal Medicaid funding. First, we attempt to clarify the convoluted regulations that determine eligibility in federal matching programs. Secondly, we identify ways in which DDS could collaborate with other stakeholders to determine which eligible services and supports are not being matched by federal funding and why. Finally, we suggest that DDS develop targeted interventions to nudge consumers and RCs toward increased drawdown of federal funds, and parlay any resulting cost savings into increasing the stock of affordable, community-based housing for individuals with I/DD.

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

II. Executive Summary

Several federally-matched programs administered by the Centers for Medicare and Medicaid Services (CMS) support the provision of home- and community-based services (HCBS) to individuals with intellectual and developmental disabilities (I/DD). The first program, the Section 1915(c) HCBS Waiver for Individuals with Developmental Disabilities (HCBS Waiver),[3] is the state's largest source of federal funding for regional center consumers.[4] The second program, the 1915(i) HCBS Medicaid State Plan Amendment (1915(i) SPA), accounts for a modest yet increasing proportion of federal HCBS funds.[5] A third program, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), comprises only a small fraction of HCBS funding yet provides an exceptionally wide array of benefits to Medi-Cal recipients under age 21.[6]

Although these programs are not the only ones that enable the state to claim federal dollars,[7] they are the focus of this report because they account for the vast majority of federal matching funds used to support regional center consumers, and as such will affect the state's capacity to carry out the Lanterman Act for years to come.

Although any Medi-Cal recipient under age 21 is eligible to receive EPSDT services that are deemed medically necessary, qualifying for services under the HCBS Waiver and 1915(i) SPA programs is considerably more complex. The process consists of at least five steps. First, the individual must be found eligible for services under the Lanterman Act. Second, the regional center (RC) must confirm that the consumer meets the community residence requirement. Third, the consumer must enroll in federally-funded Medi-Cal through a county department of social services. Fourth, the consumer must receive at least one purchase of service (POS) from his/her regional center (RC) that qualifies for federal reimbursement. Fifth, a determination may be made regarding whether the individual's disability is sufficiently severe to qualify him/her for an

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[3] *See 1915(c) Waivers by State: California (8)*, CTRS. FOR MEDICARE & MEDICAID SERVS. [hereinafter *1915(c) Waivers by State: California (8)*], https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/1915-c-waivers-by-state.html#california (last visited July 3, 2019) (noting that technically, California's HCBS Waiver program is called the "CA HCBS Waiver for Californians w/ DD"). There are other 1915(c) HCBS Waivers besides the HCBS Waiver for the developmentally disabled, *see* CAL. DEP'T HEALTH CARE SERVS., HOME AND COMMUNITY-BASED SERVICES (HCBS) 4 (Jan. 2012) [hereinafter HOME AND COMMUNITY-BASED SERVICES (HCBS)], https://files.medi-cal.ca.gov/pubsdoco/publications/masters-mtp/part2/home_o07.doc (last visited July 3, 2019) (noting other waivers, including the Multi-Purpose Senior Services Program (MSSP), Developmentally Disabled (DD) Waiver, and AIDS Waiver).

[4] CAL. DEP'T DEVELOPMENTAL SERVS., 2018 MAY REVISION A-2 (2018) [hereinafter 2018 MAY REVISION], https://www.dds.ca.gov/Budget/Docs/2018_2019_RC-DCMayEstimate.pdf (last visited Jan. 17, 2019) (noting the HCBS Waiver constitutes approximately 68% of all of DDS's federal funding at $1.7 billion per year).

[5] *Id.* (noting the 1915(i) SPA constitutes approximately 10% of all of DDS's federal funding at $250 million per year).

[6] *See id.* (noting that EPSDT constitutes approximately 1% of all of DDS's federal funding at $26 million per year); *see also* CAL. DEP'T HEALTH CARE SERVS., MEDI-CAL COVERAGE FOR EPSDT 1, https://www.dhcs.ca.gov/services/medi-cal/Documents/Medi-Cal-Coverage-for-EPSDT.pdf (last visited June 18, 2019) (describing EPSDT).

[7] *See* 2018 MAY REVISION, *supra* note 4, at A-2 (showing other federal-match programs benefitting California).

institutional level of care. If this determination take place and the consumer meets the applicant standard, (s)he may consent to enroll in the HCBS Waiver consent. If the fifth step does not take place or the consumer does not meet the requirement, (s)he may still consent to enroll in the 1915(i) SPA.

We believe the available data support several broad conclusions regarding California's success to date in accessing federal matching funds. First, the state has made progress in recent years: the fraction of Lanterman Act beneficiaries who are enrolled in the HCBS Waiver is larger today than it was in 2008. Secondly, there is still a sizable number of regional center consumers who do not enroll in federally-funded Medi-Cal, and even among Medi-Cal recipients who qualify for federal funding, a significant fraction do not receive services through either the HCBS Waiver or the 1915(i) SPA. We suspect that consumers falling into the latter two groups could number as high as 50,000 or more, although data limitations preclude us from calculating any precise estimates. Third, many consumers who fail to access federal matching funds likely could do so with relatively modest guidance or assistance. If all of these inferences are correct, the state could potentially recoup an additional $500,000,000 or more in federal matching funds by increasing participation in federally-matched programs administered by CMS.

We suggest that the state employ a participatory re-design process to increase enrollment in federally-funded Medi-Cal, and in related Medicaid programs for which Medi-Cal enrollment is a prerequisite. By determining which consumers are dropping out of the enrollment process and why, the state could develop strategies in consultation with those consumers to expand enrollment and, in turn, increase uptake of federal matching funds. To illustrate the potential benefits of this approach, we describe several techniques that might be used to reduce barriers to Medi-Cal enrollment.

Since any successful effort to increase enrollment in Medi-Cal or to increase participation in the HCBS Waiver and 1915(i) SPA could increase the state's long-term vulnerability to future budget cuts, we recommend that the state parlay any cost savings achieved into long-term investments in a stock of stable, community-based housing dedicated to the support of individuals with I/DD.

III. Introduction

In addition to conferring the intrinsic benefit of health insurance, enrollment in Full-Scope, Federally-Matched (FSFM) Medi-Cal is a prerequisite for participation in several programs administered by the Centers for Medicare and Medicaid Services (CMS) that provide important services and supports to individuals with I/DD.[8] All of these programs involve federal financial participation, which means that state expenditures are matched by federal dollars at a fixed percentage, which we refer to as the "federal match rate" throughout this report. For example, if a given service is subject to a federal match rate of 88%, then the state could recover 88% of the cost of that service from CMS.

We focus on three programs administered by CMS that support the provision of home- and community-based services (HCBS) to regional center (RC) consumers. As of this writing, the federal match rate for services and supports billed under these programs typically ranges from 50% to 88%.[9]

The 1915(c) HCBS Waiver for Individuals with Developmental Disabilities (HCBS Waiver) is the first, and by far the most important, of the three programs. At $1.7 billion per year, the HCBS

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[8] *Medi-Cal Waivers*, CAL. DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/Pages/Medi-CalWaivers.aspx (last visited July 2, 2019) (noting "Participation in any waiver, however, requires the establishment of Medi-Cal eligibility").

[9] Although the federal match rates (i.e., levels of federal financial participation) for any given aid code are uniform across the state, the average dollar amount that CMS will reimburses for any given service can vary across counties, and can vary even between individuals in a given county. The reason for this disparity is that some counties require Medi-Cal recipients to enroll in a single (monopolistic) managed care plan; some counties require Medi-Cal recipients to enroll in one of several managed care plans; and some counties offer both managed care and fee-for-service options. Whether the federal match rate is applied to the actual itemized total cost expended for a particular service or applied to a negotiated capitated rate for the service will depend on the consumer's county and insurance type. For Medi-Cal consumers in counties with mandatory managed care plans, the federal match rate will only apply to a capitated rate for services, whereas Medi-Cal consumers in counties with voluntary managed care plans may select fee-for-service care in which case the federal match rate would apply to the actual itemized cost for services, *see* CAL. DEP'T HEALTH CARE SERVS., MEDI-CAL MANAGED CARE PLANS MANDATORY OR VOLUNTARY ENROLLMENT BY MEDI-CAL AID CODES 2 (Jan. 8, 2019) [hereinafter MEDI-CAL AID CODES], https://www.dhcs.ca.gov/services/Documents/MMCD/AidCodeChartv.1.9.19.pdf (last visited July 2, 2019) (showing that different aid codes have different federal match rates (in bold text for each aid code box) and different enrollment structures based on the consumer's county (columns "COHS" and "SB," for example)). The match rate associated with the majority of Medi-Cal programs is 50%, but there are certain programs for which the federal match rate is currently as high as 88% (MCHIP), 93% (Title XIX), or even 100% (Refugee Cash Assistance), *see id.* at 47 (showing that aid code "M1" for Title XIX Medi-Cal is associated with a 95% federal match rate); *see also id.* at 2 (showing that aid code "0A" for Refugee Cash Assistance is associated with a 100% federal match rate); *see also* CAL. DEP'T HEALTH CARE SERVS., RES. & ANALYTICAL STUD. DIV., MEDI-CAL STATISTICAL BRIEF: MEDI-CAL'S CHILDREN'S HEALTH INSURANCE PROGRAM (CHIP) POPULATION 1 (Oct. 2017) [hereinafter MEDI-CAL STATISTICAL BRIEF], https://www.dhcs.ca.gov/dataandstats/statistics/Documents/CHIP_Paper_FINAL-ADA.pdf (last visited July 2, 2019) (noting MCHIP's federal match rate of 88%). See generally CAL. DEP'T HEALTH CARE SERVS., AID CODE MASTER CHART 24–58 (Oct. 18, 2017) [hereinafter AID CODE MASTER CHART], https://www.dhcs.ca.gov/services/MH/Documents/FMORB/Aid_Code_Master_Chart_10-18-17.pdf (last visited July 2, 2019), for table showing that each aid code is linked to a form of Medi-Cal eligibility. Because aid codes drive EPSDT eligibility and aid codes in turn drive federal match rates, some consumers receiving EPSDT (such as those that carry MCHIP aid codes) are eligible for federal match rates higher than 50%.

Waiver accounts for more than two-thirds (about 68%) of all federal funding of the Lanterman Act.[10] The benefits available through it are broad and extensive, including services such as behavioral intervention, community living arrangements, day programs, supported employment, home health, occupational therapy, physical therapy, speech/language therapy, skilled nursing, financial management, community-based training, and respite care; and supports such as specialized medical equipment, communication aides, and vehicle modifications.[11] Many of these benefits are vital to enable individuals with I/DD to live successfully in community-based settings.

At about $250 million per year, the second program, the 1915(i) HCBS Medicaid State Plan Amendment (1915(i) SPA), accounts for another ten percent of federal funding sources.[12] The services and supports available through the 1915(i) SPA are virtually identical to those available through the HCBS Waiver.[13]

The third program, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), accounts for just $27 million per year (1% of all federal funding sources).[14] EPSDT differs from the HCBS Waiver and the 1915(i) SPA programs in important regards. First, the program is only available to Medi-Cal recipients under age 21.[15] Secondly, receipt of EPSDT services does not require special enrollment procedures and is not limited to individuals with I/DD; *every* individual under age 21 who receives FSFM Medi-Cal can receive medically necessary services through EPSDT.[16] Importantly, however, the services available to younger consumers through EPSDT are far more extensive than those available to adult Medi-Cal recipients, and some of them—such as intensive in-home services, intensive care coordination, private duty nursing,

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[10] 2018 MAY REVISION, *supra* note 4, at A-2.

[11] U.S. DEP'T HEALTH & HUMAN SERVS., APPROVED APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER 60 (Dec. 7, 2017) [hereinafter 2018 APPROVED WAIVER APPLICATION], http://www.dds.ca.gov/waiver/docs/waiverApplication122017.pdf (last visited Jan. 18, 2019) (noting "Waiver Services Summary").

[12] 2018 MAY REVISION, *supra* note 4, at A-2. To avoid semantic confusion, throughout this subsection, we refer to the 1915(c) HCBS Waiver as the HCBS Waiver, and we refer to the 1915(i) HCBS Medicaid State Plan Amendment as 1915(i) SPA.

[13] U.S. DEP'T HEALTH & HUMAN SERVS., APPROVED STATE PLAN AMENDMENT 1 (Sept. 29, 2016) [hereinafter 2016 APPROVED 1915(I) SPA], http://www.dds.ca.gov/waiver/docs/spa16_016.pdf (last visited Jan. 18, 2019) (noting "Services" under the 1915(i) HCBS State Plan). While all services available under the HCBS Waiver are apparently available under the 1915(i) SPA, it appears that at least one service, community based adult services, is available under the 1915(i) SPA but not the HCBS Waiver, *compare id.* at 1 (noting the availability of "Community Based Adult Services" under the 1915(i) SPA), *with* 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 60 (lacking an explicit mention of "Community Based Adult Services" in its listing of all services available under the HCBS Waiver).

[14] 2018 MAY REVISION, *supra* note 4, at A-2.

[15] CAL. DEP'T HEALTH CARE SERVS., MEDI-CAL COVERAGE FOR EPSDT 1, https://www.dhcs.ca.gov/services/medi-cal/Documents/Medi-Cal-Coverage-for-EPSDT.pdf (last visited June 18, 2019).

[16] *Id.*

physical therapy, occupational therapy, and speech/language therapy—are particularly important for many consumers with I/DD.[17]

From a policy standpoint, it is important to know whether the state is accessing as much federal funding as possible to defray the cost of providing needed services and supports to Lanterman Act beneficiaries. Unfortunately, because of the limitations of the data available for analysis, we cannot provide a definitive answer to this question. This uncertainty arises from several sources. First, we have no information on how many consumers receive services through the second-largest federal matching program, the 1915(i) SPA. Nor can we ascertain how many consumers are automatically disqualified from FSFM Medi-Cal (and, in turn, all of the other programs discussed here) because of their undocumented immigration status.

Yet there is another, more subtle, reason why we cannot calculate the magnitude of lost federal dollars: the federal match rate for any given service depends not on the program through which the service is obtained, but on the "aid code" of the consumer who receives it. An individual's personal characteristics and financial circumstances—such as his/her age, savings, income, familial status, immigration status, and disability status—determine the aid codes for which (s)he can qualify. For example, through the Medi-Cal Targeted Low-Income Federal Poverty Line for Children Program, a child one to six years of age with satisfactory immigration status, whose family income is above 150% but less than 250% of the federal poverty line, qualifies for aid code H3, which (as of this writing) carries a federal match rate of 88%.[18] Young adults between the ages of 18 and 21 who were in foster care on their eighteenth birthday qualify for aid code 4M, which carries a federal match rate of 50%.[19] And as discussed in more detail later in this report, individuals with developmental disabilities that are sufficiently severe to warrant an institutional level of care qualify for aid codes 6V or 6W, which likewise carry a federal match rate of 50%.[20] Although a single individual may qualify for multiple aid codes (for example, a 23-year-old former foster care recipient with severely disabling developmental disabilities could

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[17] *See id.*; *see also* U.S. DEP'T OF HEALTH & HUMAN SERVS., EPSDT – A GUIDE FOR STATES: COVERAGE IN THE MEDICAID BENEFIT FOR CHILDREN AND ADOLESCENTS 9 (June 2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf (last visited July 2, 2019).

[18] AID CODE MASTER CHART, *supra* note 9, at 53 (noting that under aid code "H3" children with "unverified citizenship" are qualified to enroll in this aid code with a federal match rate of 88%). This program is one of a class of similar programs targeted at low-income children created by the Affordable Care Act of 2010. Although these programs carry dozens of different aid codes, as of this writing, they all carry a federal match rate of 88%, and are commonly referred to as "MCHIP" (Medicaid Children's health Insurance Program), *see id*. at 49–58 (providing "MCHIP" aid codes); *see also infra* Table 2.

[19] AID CODE MASTER CHART, *supra* note 9, at 34 (providing information for aid code "4M"). This program is one of a class of similar programs targeted at youth who are (or until age 18, were) in need of "substitute parenting" and were placed in foster care or raised by extended family members, *see id*. at 33–35 (providing information for aid codes beginning with "4" that generally apply to consumers eligible for programs such as adoption assistance, kinship guardianship (Kin-GAP), or foster care assistance). Although they encompass many different aid codes, these programs usually carry a federal match rate of 50% and are referred to in this report as "Title IV-E" programs, s*ee infra* Table 2; *see also* AID CODE MASTER CHART, *supra* note 9, at 34 (where the column indicates a 50% federal match rate).

[20] *See* AID CODE MASTER CHART, *supra* note 9, at 37 (providing information for aid codes "6V" and "6W" that possess a 50% federal match rate); *see also* MEDI-CAL AID CODES, *supra* note 9, at 24 (also providing information for aid codes "6V" and "6W" and indicating a 50% federal match rate).

qualify for aid codes 4M and 6V), each person may be assigned to only one aid code at a time. Moreover, the Medi-Cal aid code to which an individual is assigned determines the federal match rate for *all* of the CMS-funded benefits that (s)he receives, including any benefits that are received through EPSDT, the HCBS Waiver, and/or the 1915(i) SPA.

Because of the inherent complexity of this federal-state cost sharing arrangement, we cannot calculate the precise amount of additional revenue that the state could recoup if all eligible services and supports provided to regional center consumers were matched with federal dollars. To calculate such a figure, we would need to obtain detailed data on which regional center (RC) consumers are enrolled in FSFM Medi-Cal and their respective aid codes; the personal characteristics of each RC consumer with sufficient granularity to enable one to identify the most remunerative aid code for which they could qualify; the cost of all federally-reimbursable purchases of services (POS) made on each consumer's behalf; the number of consumers who are already enrolled in the 11915(i) SPA; and the number of consumers who are ineligible for all federally-matched programs because of their immigration status. Since we lack all of this information, we are unable to calculate the magnitude of lost federal revenue.

Nevertheless, based on the available data, we believe there are compelling reasons to doubt that California is recouping as much federal funding as possible for the services it provides to Lanterman Act beneficiaries. Although the state is unique in important respects, which makes "apples to apples" comparisons with other states difficult, its participation in the HCBS Waiver appears to be well below the national average.[21] In 2015, for example, New York spent a total (including both state and federal monies) of approximately $5.13 billion on its 73,815 HCBS Waiver enrollees, while California spent only $2.48 billion on its 116,232 HCBS Waiver enrollees.[22] Given that California's total population is twice as large as New York's,[23] this comparison suggests that California is both under-enrolling consumers in the HCBS Waiver and purchasing fewer HCBS Waiver-eligible services for those that do enroll.[24] It is also noteworthy

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[21] California is unique among the fifty states in providing all Lanterman-eligible individuals with an entitlement to supports and services, and in accepting undocumented residents as RC clients. Nonetheless, the available evidence suggests that California lags behind many other states in its matching of federal funds, *see* DAVID L. BRADDOCK ET AL., THE STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: 2017 8 (11th ed. 2017) [hereinafter STATE OF THE STATES]; *see also* STEVE EIKEN ET AL., TRUVEN HEALTH ANALYTICS, MEDICAID EXPENDITURES FOR LONG-TERM SERVICE AND SUPPORTS (LTSS) IN FY 2015 58 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 $64.02 on the HCBS Waiver per resident, compared to the nationwide average of $100.45 per resident).

[22] *See* STATE OF THE STATES, *supra* note 21, at 49, 161 (providing the number of state HCBS Waiver enrollees); MEDICAID EXPENDITURES FOR LTSS, *supra* note 21, at 58 tbl.AA (providing FY 2015 state expenditures on the HCBS Waiver).

[23] U.S. CENSUS BUREAU, COMPARE QUICKFACTS: CALIFORNIA (2017), https://www.census.gov/quickfacts/CA (last visited Jan. 18, 2019) (estimating California's 2017 population at 39,536,653); *see* U.S. CENSUS BUREAU, COMPARE QUICKFACTS: NEW YORK (2017), https://www.census.gov/quickfacts/NY (last visited Jan. 18, 2019) (estimating New York's 2017 population at 19,745,289).

[24] The two states differ in important regards. As discussed later in this report, California, unlike New York, does not cap HCBS Waiver enrollment or keep an HCBS Waiver waitlist, *see infra* Section IV; *see also* N.Y. DEP'T HEALTH, REQUEST FOR AN AMENDMENT TO A §1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER B-3:2, https://www.health.ny.gov/health_care/medicaid/redesign/behavioral_health/children/docs/hcbs_waivers_applicatio

that in 2017-18, 22.21% ($1.41 billion) of California State General Fund (General Fund) expenditures on RCs were not matched by any federal funding.[25]

Based on the analysis presented in this report, we believe there is a significant likelihood that a sizable number of additional Lanterman Act beneficiaries receiving POS from their regional centers—potentially as many as 50,000 or more—could qualify for federally-matched programs administered by CMS. In such a scenario, the state could likely recoup more than $500,000,000 in additional federal matching funds.[26]

Our argument unfolds in four stages. First, we seek to untangle the thicket of convoluted statutes and regulations that determine eligibility for the programs that account for the largest shares of federal reimbursements for Lanterman Act services, the HCBS Waiver and 1915(i) SPA. In so doing, we describe the sequence of tasks that each consumer must navigate in order to access federal matching funds, which we refer to as the "Federal Match Eligibility Pathway." Secondly, we estimate the number of consumers at each step of the Federal Match Eligibility Pathway who are not advancing to the next step, and justify our belief that these consumers' failure to enroll in federally-matched programs may be costing the state hundreds of millions of dollars. Third, we propose that DDS, through a participatory re-design process, collaborate with system stakeholders to determine which eligible services and supports are not being matched by federal funding and why. Using Medi-Cal enrollment as an illustrative example, we argue that DDS could develop targeted interventions to nudge consumers and RCs toward greater drawdown of federal matching funds. Finally, we recommend that any resulting cost savings be used to expand the stock of affordable, community-based housing for individuals with I/DD.

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n_ny_4125_r05_02.pdf (last visited Apr. 4, 2019) ("The State is reserving capacity to ensure that children transitioning from the former children's waivers will have at least the same access to care as today through the transition to July 1, 2022 when the waiting list is anticipated to be completely removed. The methodology uses the 2018 existing slots, projects forward the expected growth in the number of new 1915(c) slots.") In theory, the absence of an HCBS Waiver cap (or waiting list) in California could increase the total number of HCBS Waiver-enrolled consumers and likewise deflate HCBS Waiver expenditures per consumer. Interestingly, however, California seems to enroll a *smaller* proportion of its total population than New York. This puzzling disparity could be explained, at least in part, by California's higher percentage of residents who are ineligible for the HCBS Waiver because of their immigration status, *see U.S. Unauthorized Immigrant Population Estimates By State, 2016*, PEW RES. CTR. (Feb. 5, 2019) [hereinafter *U.S. Unauthorized Immigrant Population Estimates By State*], https://www.pewhispanic.org/interactives/u-s-unauthorized-immigrants-by-state/ (last visited Apr. 11, 2019) (noting that, in 2016, California's "unauthorized immigrant population" is 2,200,000, or 5.6% of California's population and that New York's "unauthorized immigrant population" is 725,000, or 3.6% of New York's population); *see also List of U.S. states by population*, WIKIPEDIA, https://simple.wikipedia.org/wiki/List_of_U.S._states_by_population (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 New York is estimated at 19,542,209). Finally, at least one source suggests that most enrollees in the 1915(i) SPA who have I/DD reside in California, which could explain some of the disparity in HCBS Waiver enrollment between California and New York, *see* MARYBETH MUSUMCI ET AL., MEDICAID HOME AND COMMUNITY-BASED SERVICES ENROLLMENT AND SPENDING 4 (Apr. 4, 2019) [hereinafter KAISER 2019 REPORT], http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending (last visited July 8, 2019).

[25] 2018 MAY REVISION, *supra* note 4, at B-1 (2018) (we assume that the category "GF Other" refers to funds that are not matched by the federal government).

[26] *See infra* Section VI (estimating the magnitude of lost federal funding).

IV. Federal Match Funding for Home- and Community-Based Services

For much of the Twentieth Century, federal support for persons with I/DD was limited to those residing in state institutions. Since the 1980s, however, the federal government has offered states more flexibility in accessing federal funds to support those who reside in community-based settings.

The first change came in 1981 with the creation of the HCBS Waiver.[27] Part of a broader push for deinstitutionalization,[28] the HCBS Waiver allows people with I/DD who would otherwise require institutional care to access services in their respective communities. The program is referred to as a "waiver" because when it was first authorized, federal Medicaid only paid for services provided in institutional settings; thus, the government "waived" its usual rules to allow Medicaid to fund community-based services.

The HCBS Waiver program expanded dramatically in the years that followed. By Fiscal Year (FY) 2017-18, the HCBS Waiver constituted 27.20% of DDS's total budget and 67.55% of DDS's federal funding.[29]

Meanwhile, in 2005, the federal government augmented the HCBS Waiver with a new program to support people with I/DD, the 1915(i) HCBS State Plan Amendment (1915(i) SPA). Unlike the HCBS Waiver, which can only be used to fund services for individuals whose care needs are significant enough for them to qualify for institutional placement, the 1915(i) SPA does not require a federal waiver, and allows states to provide HCBS to *any* person with I/DD regardless of the level of care (s)he requires.[30] The 1915(i) SPA program comprises another 3.94% of DDS's 2018-19 Enacted Budget funding, which amounts to 9.97% of the federal funding DDS receives.[31]

CMS affords states considerable discretion over the design of their HCBS Waiver and 1915(i) SPA programs. In California, the HCBS Waiver and 1915(i) SPA programs cover more than thirty community-based services that are not covered under standard Medi-Cal, including respite

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[27] Mary Jean Duckett and Mary R. Guy, *Home and Community-Based Services Waiver*, 22 HEALTH CARE FIN. REV. 123, 123 (2000).

[28] MARYBETH MUSCUMECI & HENRY CLAYPOOL, THE HENRY J. KAISER FAMILY FOUND., OLMSTEAD'S ROLE IN COMMUNITY INTEGRATION FOR PEOPLE WITH DISABILITIES UNDER MEDICAID: 15 YEARS AFTER THE SUPREME COURT'S OLMSTEAD DECISION 6 (2014), http://files.kff.org/attachment/issue-brief-olmsteads-role-in-community-integration-for-people-with-disabilities-under-medicaid-15-years-after-the-supreme-courts-olmstead-decision (last visited Jan. 18, 2019).

[29] 2018 MAY REVISION, *supra* note 4, at A-3.

[30] STAN DORN ET AL., U.S. DEP'T HEALTH & HUMAN SERVS., THE USE OF 1915(I) MEDICAID PLAN OPTION FOR INDIVIDUALS WITH MENTAL HEALTH AND SUBSTANCE ABUSE DISORDERS 15 (Nov. 30, 2016), https://aspe.hhs.gov/system/files/pdf/255716/1915iSPA.pdf (last visited Jan. 18, 2019); *see also Home and Community-Based Services Programs*, CAL. DEP'T DEVELOPMENTAL SERVS., http://www.dds.ca.gov/waiver/index.cfm (last visited Jan. 18, 2019).

[31] 2018 MAY REVISION, *supra* note 4, at A-4 (noting DDS received $271,298,000 in 1915(i) SPA reimbursements in the May Revision Budget. 1915(i) SPA comprises 3.94% of DDS's total funding at $6,879,880,000, and it comprises 9.97% of total federal reimbursements at $2,720,154,000).

care, habilitation services, and day services.[32] Moreover, unlike many other states, California does not cap enrollment[33] and maintains no waiting lists.[34]

Table 1: Residential Settings among Regional Center Consumers (as of January 2017)[35]

	Setting	January 2017 Population	Percentage Total	
HCBS Community Placement	Own/Parents' Home	239,221	78.4%	**96.4%**
	Licensed Community Care Facility	29,158	9.6%	
	Independent Living / Supported Living	25,767	8.4%	
Non-HCBS Community Placement	Skilled Nursing / Intermediate Care Facility	8,342	2.7%	**3.6%**
	Developmental Center	901	0.3%	
	Other[36]	1,871	0.6%	
	Total consumers	**305,260**		

As shown in Table 1, more than 96% of all RC consumers lived in community placements, and thus potentially were eligible for HCBS Waiver or 1915(i) SPA funding, in 2017.

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[32] 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 60. As discussed elsewhere in this report, however, some of the services available through the HCBS Waiver and 1915(i) programs are available to Medi-Cal recipients under age 21 through the EPSDT program, *see supra* Section II, V.C. (discussing EPSDT for consumers below age 21).

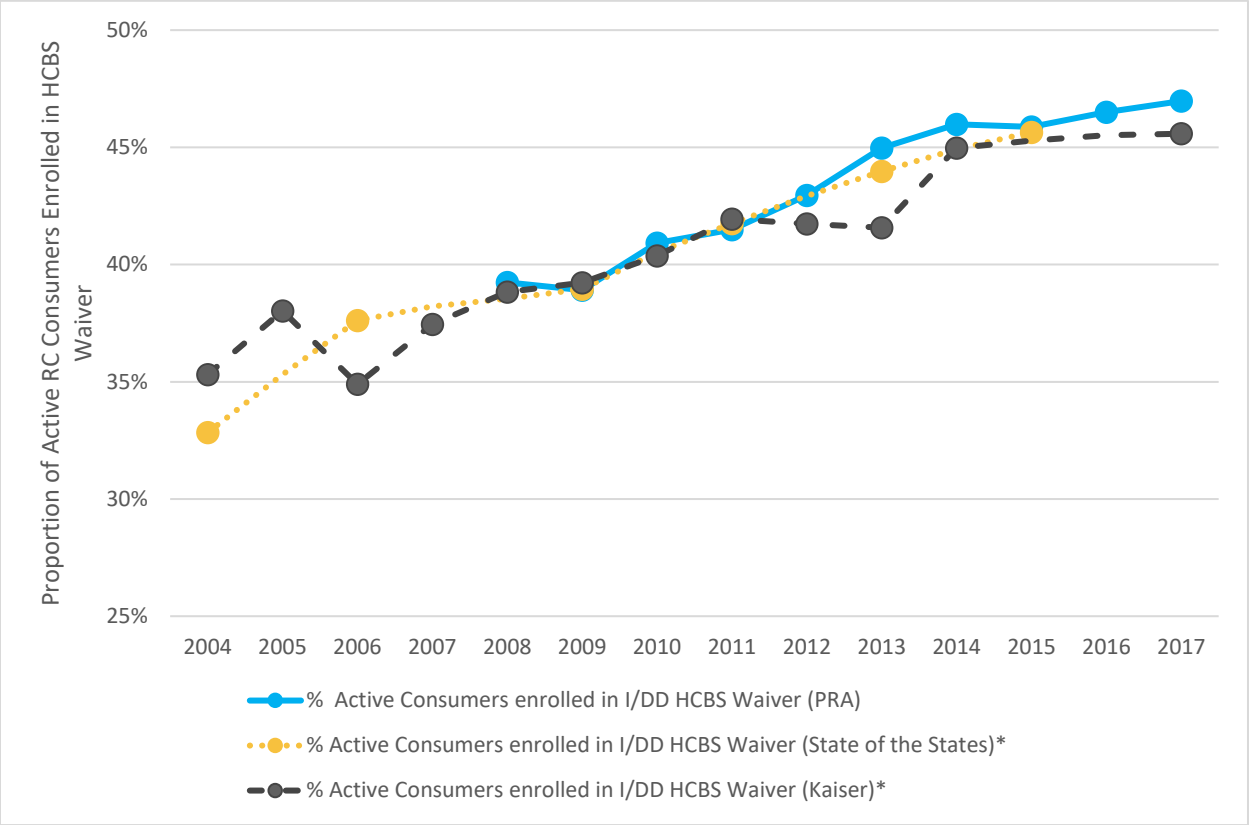
[33] *Id.* at 44 ("All individuals who express an interest and are eligible for enrollment are enrolled in the IDD Waiver. California will submit necessary IDD Waiver amendments to accommodate all individuals who are eligible for and express an interest in participating in the IDD Waiver should the approved IDD Waiver capacity be insufficient to accommodate all interested persons."); *see also* 2016 APPROVED 1915(I) SPA, *supra* note 13, at 1 ("Per 42 CFR §441.745(a)(i), the state will annually provide CMS with the projected number of individuals to be enrolled in the benefit and the actual number of unduplicated individuals enrolled in SPA/the 1915(i) State Plan HCBS in the previous year.")

[34] The other states with no waiting list are Delaware, District of Columbia, Hawaii, Idaho, Iowa, Michigan, New York, North Dakota, Oregon, and South Dakota, *see How Many People with IDD Are Waiting for Long-Term Supports and Services?*, SUPPORTING INDIVIDUALS & FAMILIES INFO. SYS. PROJECT, https://fisp.umn.edu/chart-gallery/waiting (last visited Jan. 18, 2019).

[35] CAL. DEP'T DEVELOPMENTAL SERVS., FACT BOOK: 15TH ED. 11 (2018) [hereinafter 15TH FACT BOOK], https://www.dds.ca.gov/FactsStats/Factbooks.cfm (last visited Jan. 18, 2019). Though DDS includes skilled nursing and intermediate care facilities as community settings, we do not because these settings are ineligible for federal HCBS funds.

[36] *Id.* at 10 (noting the "Other" category includes "[s]ettings such as hospitals, community treatment facilities, rehabilitation centers, psychiatric treatment centers, correctional institutions, and other settings in the community"). Since DDS does not break down this category further, we err on the side of caution throughout this report in excluding these individuals from the category that is eligible for HCBS Waiver funds. Since at least some portion of those in "Other" residence types probably could, in fact, enroll in the HCBS Waiver or 1915(i) SPA, the fraction of consumers in HCBS Community placements in Table 1 should probably be viewed as a slight underestimate.

Figure 1 - Proportion of Active Consumers Enrolled in the HCBS Waiver[37]



[37] Figure 1 depicts the proportion of consumers who are both "active" (defined as those who are Lanterman eligible and are not served in developmental centers) and are enrolled in the HCBS Waiver. We use the same denominator (the number of "active" consumers) is for all estimates, which was calculated using DDS's monthly consumer caseload reports for each December from 2004 to 2017, *see Previous Monthly Consumer Caseload Reports*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/FactsStats/Caseload_Previous.cfm (last visited Jan. 18, 2019) (providing counts of "Active" consumers in monthly caseload reports). Since the numerator–the number of consumers enrolled in the HCBS Waiver for residents with I/DD–is not always consistently reported, we present estimates using data from three different sources. The first set of estimates, represented by the grey dashed line, relies on data published by the Kaiser Family Foundation, *see* MOLLY O'MALLEY WATTS & MARYBETH MUSUMECI, KAISER FAMILY FOUND., MEDICAID HOME AND COMMUNITY-BASED SERVICES: RESULTS FROM A 50-STATE SURVEY OF ENROLLMENT, SPENDING, AND PROGRAM POLICIES 25 (Jan. 2018) (providing the number of participants on all 1915(c) HCBS Waivers for years 2004 to 2014 by state and providing the number of participants in the I/DD 1915(c) HCBS Waiver only for 2014 by state); *see also* KAISER 2019 REPORT, *supra* note 24, at 12 tbl.4 (providing the number of participants in the I/DD 1915(c) HCBS Waiver only for 2017 by state). As noted earlier, the 1915(c) HCBS Waiver for California residents with I/DD is only one of eight waivers that fall under the 1915(c) HCBS Waiver program, *see supra* note 3 and accompanying text. Unfortunately, the Kaiser data only break down the number of 1915(c) participants by demographic group for the years 2014 and 2017. For all other years since 2004, they only estimate the number of participants in *all* 1915(c) HCBS Waiver programs. However, comparing the enrollment figures for individuals with I/DD with the total enrollment figures for the same years (2014 and 2017) reveals that approximately 85% of participants in *all* of California's 1915(c) HCBS Waiver programs were on the HCBS Waiver for residents with I/DD. For years prior to 2014, therefore, we discounted Kaiser's estimates of participation in all 1915(c) HCBS Waivers by 15% to approximate the number of participants in the I/DD-specific HCBS Waiver. Readers should bear in mind, however, that estimates for years prior to 2014 might underestimate

Yet as shown in Figure 1, only about 40-50% of active consumers were enrolled in the HCBS Waiver in 2017.[38] Data on 1915(i) SPA enrollment were not available, but since California received nearly seven times as much federal money through the HCBS Waiver as it did through the 1915(i) SPA in 2017 it is unlikely that many of the remaining 50-60% of consumers were enrolled in the 1915(i) SPA.[39]

The 40-50% Waiver enrollment figure for 2017 represents a noteworthy gain since 2004, when only 30-40% of consumers were Waiver enrolled. Nevertheless, this preliminary overview of

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the fraction of consumers enrolled in the I/DD HCBS Waiver, since some of the (1915(c) HCBS Waiver programs serving other populations were not approved until after 2004, *see 1915(c) Waivers by State: California (8)*, *supra* note 3 (noting, for example, that the "In Home Operations" HCBS Waiver was not approved until 2007 and implemented in California until 2010 and the "Assisted Living" HCBS Waiver was not approved until 2005 and implemented in California until 2014). The second set of estimates, represented by the yellow dotted line, is based on data obtained from multiple editions of State of the States, *see* STATE OF THE STATES, *supra* note 21, at 49. State of the States only publishes data from the years 2004-2015, but not all years are made publicly available. For several missing years within this range, we had to extrapolate the number of HCBS Waiver-enrolled consumers with I/DD. Because State of the States' most recent estimate is of HCBS Waiver participation is from 2015, its trend line terminates in that year. The third and final set of estimates, represented by a blue solid line, relies on data obtained from DDS through a Public Records Act (PRA) request, *see* Letter from Rapone Anderson, Regional Center Branch Manager, Cal. Dep't Developmental Servs., to Lane Zuraw, J.D. Candidate, Stanford Law Sch. (Jan. 24, 2018) (on file with authors). No PRA data was provided for years prior to 2008, so the trend line for PRA data starts in that year. For all three trends lines, we used simple linear extrapolation to estimate the numerator (i.e., number of HCBS Waiver enrolled consumers) for each missing year, and obtained the denominator (the total number of active RC consumers) directly from DDS's online monthly caseload reports, *see Previous Monthly Consumer Caseload Reports*, *supra* note 37. Finally, in all three trend lines, the solid circles represent years for which we obtained precise estimates, while the remaining portions of each line represent extrapolated values. Although the trend lines differ slightly across sources, it clear that HCBS Waiver increased steadily over the period examined, and that the total percentage of enrolled consumers reached about 45% by 2017.

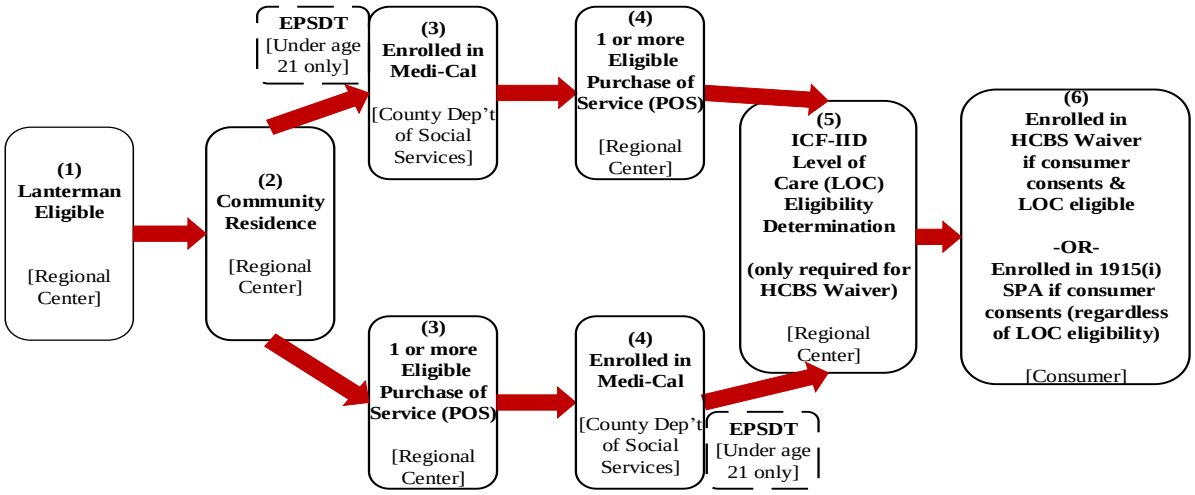
[38] *See* 15TH FACT BOOK *supra* note 35, at 8. Figure 1 displays the percentage of "active" consumers (defined by DDS as those who are Lanterman Act eligible and do not reside in developmental centers) who are enrolled on the HCBS Waiver. This measure is imprecise, however, because DDS's definition of "active" or "status 2" consumers fits very awkwardly within the statutory scheme. In DDS's terminology, "active" consumers are defined as those who receive case management services and are "served in the community rather than a developmental center," *see id*. The difficulty is that some consumers living in equally if not more restrictive settings—such as skilled nursing facilities, intermediate care facilities, institutions for mental disease, state institutions, and even correctional institutions—are categorized as "active" even though they are neither served "in the community" in any meaningful sense, nor are eligible for HCBS Waiver funding. Although we occasionally provide counts of "active" consumers in this report because DDS publishes the data in that form, it should be borne in mind that the term is over-inclusive and includes some consumers residing in highly restrictive environments who are ineligible for HCBS Waiver funds.

[39] E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't Developmental Servs., to Alison Morantz, Stanford Law Sch. (April 19, 2018) (figures presented in this table were presented as Microsoft Excel attachments to e-mails received from DDS in response to PRA requests sent by the research team. The column "Year" is the fiscal year running from Sept. 30 to August 1 of the year in question. For example, Year 2012 is Sept. 30, 2011 – Aug. 30, 2012. The column "Active RC Consumers" is a count provided by DDS of all status 2 consumers in the I/DD system. The column "Number of Active RC Consumers, Enrolled in HCBS Waiver" is a count provided by DDS of all status 2 consumers enrolled in the HCBS Waiver. The column "Percentage of Active RC Consumers Enrolled in HCBS Waiver" is the quotient of "Number of Active RC Consumers, Enrolled in HCBS Waiver" and "Active RC Consumers").

system-wide trends lends credence to concerns that California could do more to increase levels of HCBS Waiver and 1915(i) SPA enrollment.

To explore the barriers to full enrollment in federal match programs, we now turn to an investigation of the procedural pathways whereby a RC, with the support of its local county department of social services (CDSS), can enroll a consumer in the HCBS Waiver or 1915(i) SPA programs.[40] Figure 2, below, presents the Federal Match Eligibility Pathway.[41]

Figure 2: Federal Match Eligibility Pathway to Enrollment in HCBS Waiver or SPA[42]



As illustrated in **Figure 2,** the first four steps of the Federal Match Eligibility Pathway are identical for the HCBS Waiver and 1915(i) SPA programs. First, the RC finds the consumer eligible for Lanterman Act services. Second, the RC Qualified Intellectual Disability Professional (QIDP)[43] confirms that the consumer resides in a qualified home or community-based setting. These first two steps are, essentially, threshold criteria that must be met before a consumer can be deemed a potentially-plausible candidate for enrollment in any HCBS-match program. Third, after the CDSS deems the consumer eligible for full-scope, federally-matched

[40] While the RC is the main actor, the CDSS plays an important role since receipt of Medi-Cal is a basic requirement for both the HCBS Waiver and 1915(i) SPA programs.

[41] For clarity, our map is arranged in (roughly) sequential order. In reality, many of the steps are interchangeable, *see* 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 52 (citing CAL. CODE REGS. tit. 22, §§ 51343, 51343.1-.2 (2019)).

[42] CAL. DEP'T DEVELOPMENTAL SERVS., THE HCBS WAIVER PRIMER AND POLICY MANUAL 8 (2008) [hereinafter HCBS WAIVER PRIMER AND POLICY MANUAL], http://www.dds.ca.gov/Waiver/docs/WaiverManual2008.pdf (last visited Jan. 18, 2019); *see also* 2016 APPROVED 1915(I) SPA, *supra* note 13, at 5-6. In this report, we adjust Figure 2 to fit each Step in the enrollment process. We do not label each slightly-adjusted figure as a new figure in-text.

[43] *See* 42 C.F.R. § 483.430(a) (2018) (explaining that "each client's active treatment program must be integrated, coordinated and monitored by a qualified intellectual disability professional" and then establishing the credentials required to be a QIDP).

(FSFM) Medi-Cal benefits, the consumer enrolls in Medi-Cal and is assigned an aid code.[44] Fourth, the QIDP includes at least one HCBS Waiver- or 1915(i)-SPA-eligible service in the consumer's Individual Program Plan (IPP). As shown in the figure, the sequence of the third and fourth steps can be reversed, since neither is a precondition for completion of the other.

At the fifth step, the QIDP determines whether the consumer requires the level of care (LOC) that would otherwise be provided in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID). If so, the consumer is qualified to enroll in the HCBS Waiver; if not, (s)he may still qualify to receive benefits through the 1915(i) SPA. (If the RC intends at the outset to enroll the consumer in the 1915(i) SPA, they may skip the fifth step.) In the sixth and final step of the Federal Match Eligibility Pathway, the consumer enrolls in either the HCBS Waiver or the 1915(i) SPA program.[45] In order to enroll in either program, however, the consumer must sign a form granting his/her consent.[46]

The following section delves further into each of these steps, explaining at a more granular level how consumers can qualify for federal matching funds.

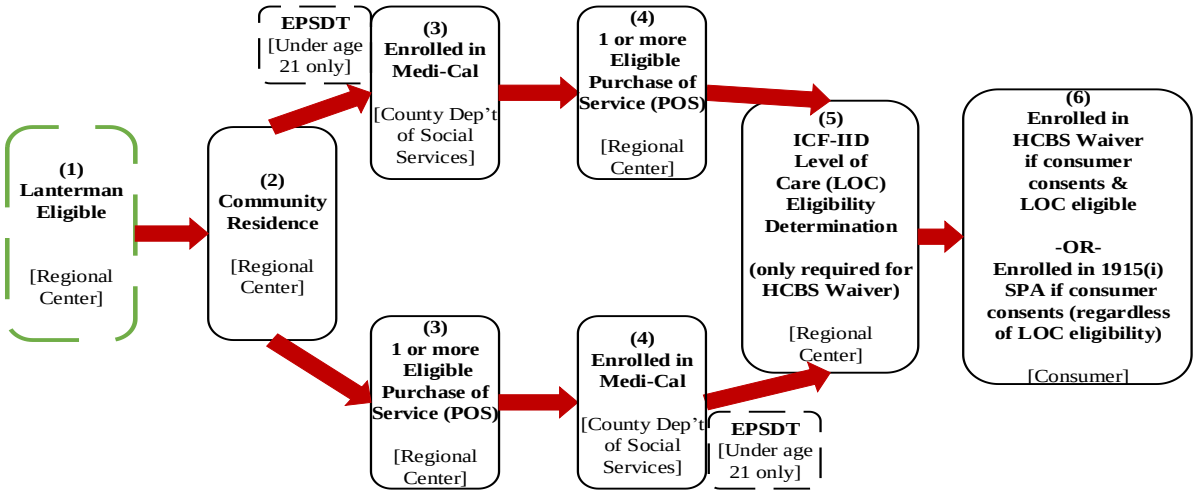
[44] *See supra* Section III (discussing aid codes); *see also* discussion *infra* Section V.C.

[45] An HCBS Waiver participant "may be enrolled in only one HCBS Waiver program at a time. If enrolled in the Multi-Purpose Senior Services Program (MSSP), Developmentally Disabled (DD) Waiver or AIDS Waiver, a recipient must first disenroll to be eligible for one of IHO's HCBS Waivers," *see* CAL. DEP'T HEALTH SERVS., HOME AND COMMUNITY-BASED SERVICES (HCBS) 4 (Jan. 2012), https://files.medi-cal.ca.gov/pubsdoco/publications/masters-mtp/part2/home_o07.doc (last visited Apr. 27, 2019).

[46] 42 C.F.R. §§ 441.301(c), 441.725(b) (2019) (noting that enrollment in both the HCBS Waiver and 1915(i) SPA, respectively, require "the informed consent of the individual in writing").

V. The Enrollment Process: A Closer Look

A. Step 1: Certification of Lanterman Act Eligibility



To enroll in either the HCBS Waiver or 1915(i) SPA, a consumer must first qualify for Lanterman Act services. To do so, the applicant must be deemed developmentally disabled by his/her RC.[47] Importantly, eligibility does not depend on immigration status; even undocumented residents are entitled to receive benefits under the Lanterman Act.[48]

An applicant is developmentally disabled under California law if (s)he developed a disability:

- before turning 18;
- that continues, or can be expected to continue, indefinitely;
- that constitutes a substantial disability; and
- that includes an intellectual disability, cerebral palsy, epilepsy, autism, and/or a disabling condition that is closely related to intellectual disability or requires treatment similar to that required for individuals with an intellectual disability.[49]

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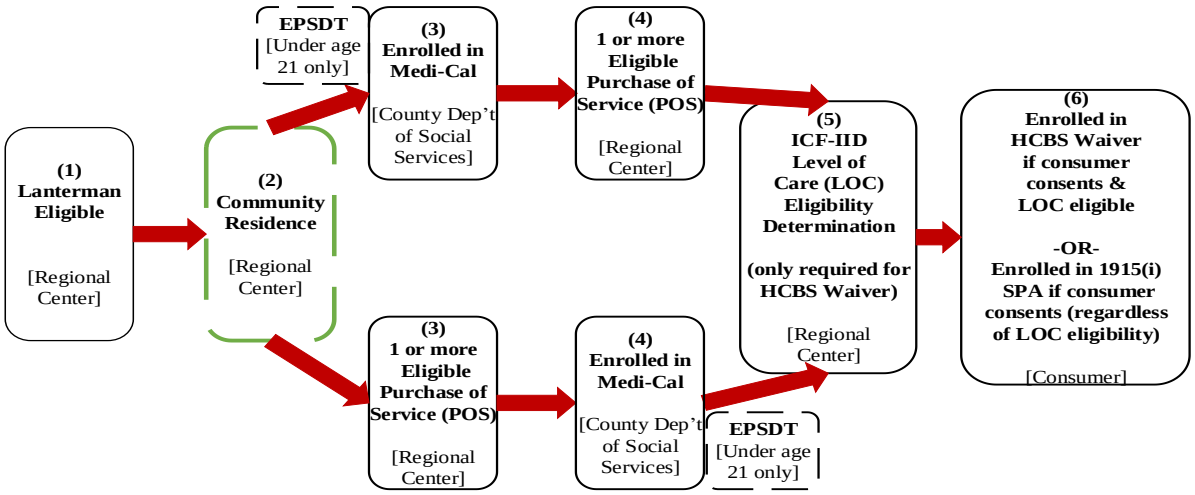
[47] Any Californian believed to have I/DD is eligible for an initial intake and assessment by his/her local RC, *see* CAL. WELF. & INST. CODE § 4512(l)(1) (2019).

[48] *See Estimating the Cost of Expanding Full-Scope Medi-Cal Coverage to Undocumented Adults*, CAL. LEGISLATIVE ANALYST'S OFFICE (May 10, 2018), https://lao.ca.gov/Publications/Report/3827 (last visited Jan. 18, 2019) (noting "[A]vailable health interview survey data . . . show a lower disabled rate among undocumented adults"); *see also* CAL. CODE REGS. tit. 17, § 54010(a) (2019) (providing that, in addition to being deemed developmentally disabled by his/her local RC, a consumer may be deemed Lanterman eligible if (s)he is a California resident and need not provide an RC his/her immigration status).

[49] *See* CAL. WELF. & INST. CODE § 4512(a) (2019) (laying out these requirements for Lanterman Act eligibility and clarifying that a Californian is not considered disabled because of a "handicapping condition" that is "solely physical in nature").

A "substantial disability" is defined as one that causes "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-sufficiency."[50] Any applicant who is deemed to meet these criteria may proceed to Step Two.

B. Step 2: Certification of Community Residence



The second step in the Federal Match Eligibility Pathway requires the QIDP to confirm that the consumer resides in a qualified home- or community-based setting, as opposed to an institutional placement (to which the HCBS Waiver program is intended to provide an alternative).

As of this writing, consumers can satisfy this requirement if they reside in their own/parents' home, a community care facility, or an independent or supported living arrangement. Consumers residing in a Developmental Center (DC), skilled nursing facility (SNF), Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID), or Institution for Mental Disease (IMD) do not qualify. Since, as illustrated in Table 1, more than 96% of consumers reside in HCBS qualified settings, few consumers are likely to lose eligibility at Step 2.[51] As discussed in a separate report, however, this state of affairs may change soon.[52] Although it is unlikely to be enforced until 2022, CMS adopted a regulation (Final Settings Rule) in 2014 that more stringently defines the requirements that putative community-based settings must meet in order

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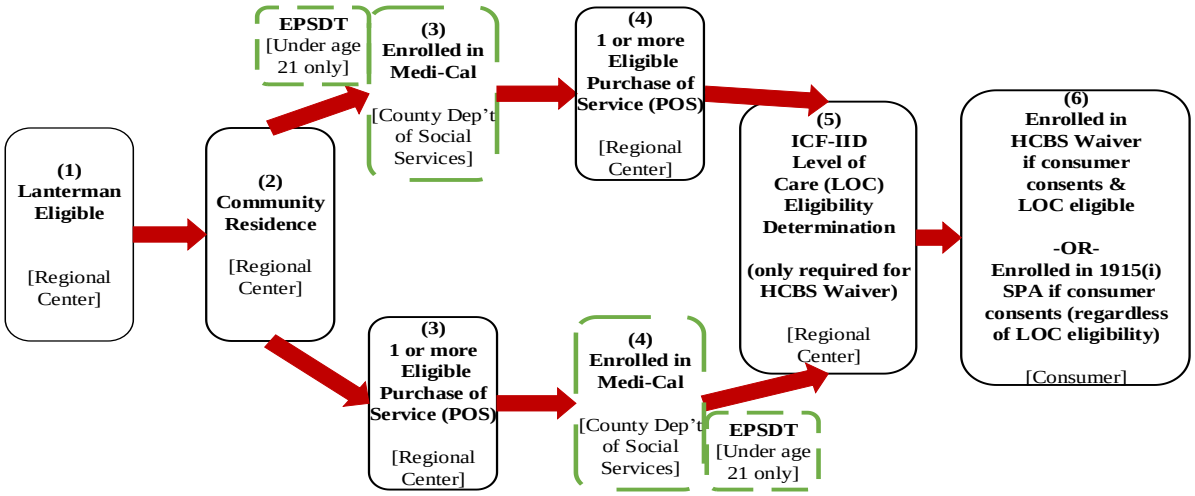
[50] *Id.* § 4512(l)(1).

[51] 15TH FACT BOOK, *supra* note 35, at 11 (Though DDS includes skilled nursing and intermediate care facilities as community settings, we do not because these settings are ineligible for federal HCBS funds).

[52] PETER VOGEL ET AL., STANFORD INTELLECTUAL & DEVELOPMENTAL DISABILITIES LAW AND POLICY PROJECT (SIDDLAPP), A FISCAL PRIMER ON CALIFORNIA'S REGIONAL CENTER SYSTEM § V.G. (2018) [hereinafter LANTERMAN PRIMER].

to qualify for HCBS funding.[53] When the Final Settings Rule goes into effect, consumers residing in homes that are not HCBS-complaint may have difficulty completing the second step of the Federal Match Eligibility Pathway.

C. Step 3: Full-Scope Medi-Cal Enrollment



The third, and by far most complicated, step of the Federal Match Eligibility Pathway is enrollment in Full-Scope, Federally-Matched (FSFM) Medi-Cal. The term "full-scope" refers to the scope of benefits available; unlike recipients of restricted-scope Medi-Cal, full-scope recipients can access a comprehensive array of services including medical, dental, mental health, and vision care. The term "federally-matched" refers to the ability of the state to obtain federal reimbursement for the services a given Medi-Cal recipient receives. The latter qualifier is important because California provides full-scope Medi-Cal to some undocumented immigrants who are ineligible for federal matching funds, such as children under age 19 who meet certain income requirements.[54] Although recent estimates indicate that undocumented immigrants comprise about 5.6% of the state's total population,[55] the (scant) available evidence suggests that they comprise a smaller fraction of RC consumers.[56] In any event, since the focus of this report

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[53] *See id.* at 53 n.236; *see also* 42 C.F.R. § 441.530(a)(1) (2019).

[54] *Senate Bill (SB) 75: Full Scope Medi-Cal Coverage for All Children – Frequently Asked Questions*, CAL. DEP'T HEALTH CARE SERVS., http://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/SB75_FAQ_1.aspx (last visited Jan. 18, 2019).

[55] *U.S. Unauthorized Immigrant Population Estimates By State*, *supra* note 24 (noting that, in 2016, California's "unauthorized immigrant population" is 2,200,000, or 5.6% of California's population).

[56] Although DDS does not provide data on the immigration status of Lanterman Act beneficiaries, one estimate suggests that the proportion of undocumented residents among RC consumers may be lower than it for in the general population, *see* Brian Metzker, *Estimating the Cost of Expanding Full-Scope Medi-Cal Coverage to Undocumented Adults*, CAL. LEGISLATIVE ANALYST'S OFFICE, http://www.lao.ca.gov/Publications/Report/3827 (last visited Jan. 18, 2019) (noting "[A]vailable health interview survey data . . . show a lower disabled rate among undocumented

is on increasing the uptake of federal funding, the discussion that follows explores ways to increase Medi-Cal enrollment among those RC consumers whose immigration status (and other characteristics) could entitle them to receive FSFM Medi-Cal.

What makes the third step of the Federal Match Eligibility Pathway particularly complex is that, as discussed earlier, there are dozens of different aid codes through which RC consumers can enroll in FSFM Medi-Cal.[57] Depending on their personal characteristics and financial circumstances, some consumers may be eligible for multiple aid codes, yet each consumer can only be assigned to one of them at a given point in time. The Medi-Cal aid code to which an individual is assigned determines the federal match rate for all of the CMS-funded benefits that (s)he receives, including any services or supports obtained through EPSDT, the HCBS Waiver, and/or the 1915(i) SPA. Since federal match rates can vary widely across aid codes (with most falling in the 50%-88% range[58]), ensuring that each RC consumer is assigned to the aid code with the highest federal match rate is an important revenue-maximizing strategy.

In the remainder of this section, we describe eight eligibility categories through which RC consumers can potentially qualify for FSFM Medi-Cal.[59] This list is not intended to be exhaustive, and since the categories are described at a high level of generality—without the detail that would be required to determine the eligibility of any specific individual—they usually correspond to not just one but a cluster of aid codes.

Broadly speaking, there are three different types of Medi-Cal eligibility categories: those that involve income-based means testing; those that involve income-based *and* asset-based means testing; and those that involve no means testing at all.

The first program type, which relies on income-based means testing, includes several different eligibility categories. The largest grouping, Modified Adjusted Gross Income (MAGI), encompasses numerous programs created under the Affordable Care Act[60] for which eligibility depends on whether a consumer's modified adjusted gross income falls below a fixed

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adults"); *see also U.S. Unauthorized Immigrant Population Estimates By State*, *supra* note 24 (noting that, in 2016, California's "unauthorized immigrant population" is 2,200,000, or 5.6% of California's population).

[57] *See supra* Section III (discussing the wide variety of aid codes in California).

[58] *See supra* note 9 and accompanying text (noting that most aid codes carry federal match rates that vary between 50% and 88% but that a few aid codes carry federal match rates as high as 93% or even 100%).

[59] In addition to the eight methods of FSFM Medi-Cal eligibility described here, there are other eligibility methods that, at least in theory, could pertain to regional center consumers, *see* MEDICAID.GOV, LIST OF MEDICAID ELIGIBILITY GROUPS, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/Downloads/List-of-Eligibility-Groups.pdf (last visited May 3, 2019) (listing 27 "Mandatory Categorically Needy" categories, 32 "Optional Categorically Needy" categories, 9 "Medically Needy" categories who qualify for FSFM Medi-Cal). Discussion of these alternative eligibility pathways is beyond the scope of this report.

[60] W. CTR. ON LAW & POVERTY, CHAPTER 2: MAGI MEDI-CAL PROGRAMS 2.36–3.61, HTTPS://WCLP.ORG/WP-CONTENT/UPLOADS/2016/04/WESTERNCENTER_2016_HCGUIDE_CHAPTER2.PDF (last visited June 25, 2019) (noting various Medi-Cal programs that use the MAGI method for eligibility determinations).

threshold.[61] One particularly prominent class of MAGI programs is the Medi-Cal Children's Health Insurance Program (MCHIP), which provides FSFM Medi-Cal to approximately 1.3 million low-income children in California.[62] Before the passage of the Affordable Care Act (ACA) in 2010, California implemented the same program (then called Children's Health Insurance Program) through a handful of child health insurance programs.[63] After the passage of the ACA and the associated Medicaid expansion, California children insured under CHIP programs were absorbed into Medi-Cal, leading to the use of "MCHIP" as an umbrella term.[64] As of this writing, MCHIP aid codes generally carry federal match rates of 88%.[65]

The income-based eligibility categories also encompass what we refer to as "Pickle-type" cases. A so-called "Pickle" case (named for former U.S. Representative James Pickle, the Congressional sponsor of the bill that created the program),[66] arises when a Supplemental Security Income (SSI) recipient receives a benefit from the Social Security Administration (SSA), such as survivors' benefits, and by virtue of receiving the latter benefit (including cost of living adjustments), exceeds the unearned gross income threshold for SSI eligibility, thereby losing SSI eligibility and, in turn, eligibility for SSI-linked Medi-Cal. [67] The Pickle Amendment to the Social Security Act[68] provides that if a consumer's SSA income multiplied by a certain discount factor[69] is less than the SSI-income eligibility threshold, the consumer is potentially eligible for SSI-linked Medicaid even though (s)he is no longer eligible to receive SSI.[70] Likely even more pertinent to RC consumers is a variant of the Pickle category called the "Pseudo Pickle DAC." Any individual who meets three criteria (is unmarried; was diagnosed with a qualifying disability that began before age 22; and is a dependent of a parent at the time of application, the parent's death, or the onset of the parent's disability) may be eligible to receive

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[61] CAL. HEALTHCARE FOUND., HEALTH REFORM IN TRANSLATION: WHAT IS MAGI? 1–2 (2014), https://www.chcf.org/wp-content/uploads/2017/12/PDF-HealthReformTranslationMAGI.pdf (last visited Jan. 18, 2019).

[62] MEDI-CAL STATISTICAL BRIEF, *supra* note 9, at 1. For MCHIP, California has an income threshold of 266% of the federal poverty line, *see California Early Childhood Profile*, NAT'L CTR. FOR CHILDREN IN POVERTY (Oct. 29, 2015), http://www.nccp.org/profiles/CA_profile_18.html (last visited June 17, 2019).

[63] MEDI-CAL STATISTICAL BRIEF, *supra* note 9, at 1 (these programs included the Healthy Families Program (HFP) and Access for Infants and Mothers (AIM)).

[64] *Id*. at 3.

[65] *Id.*

[66] *Screening for Medicaid Eligibility Under the Pickle Amendment*, CLEARINGHOUSE CMTY. (2018) [hereinafter *Screening for Medicaid Eligibility Under the Pickle Amendment*], https://www.povertylaw.org/clearinghouse/pickle (last visited July 5, 2019) (noting "[t]he Pickle Amendment [is] named after its congressional sponsor and enacted in 1977").

[67] *Id*. Children may also gain Medi-Cal eligibility under the Pickle Amendment because children are eligible for certain SSA benefits, such as survivors' benefits, *see* SOC. SECUR. ADMIN., BENEFITS FOR CHILDREN 1 (Mar. 2018), https://www.ssa.gov/pubs/EN-05-10085.pdf (last visited May 7, 2019).

[68] *See* 42 C.F.R. §§ 435.134–137 (2019).

[69] *See Screening for Medicaid Eligibility Under the Pickle Amendment*, *supra* note 66 (referring to "Reduction Factors for Calculating Medicaid Eligibility Under the Pickle Amendment During 2019").

[70] *Id.* ("If the resulting total [of SSA benefit multiplied by a specific discount factor] is less than the current SSI income criteria in your state, the individual is Pickle eligible, from the standpoint of income, for Medicaid benefits.")

Title II Disabled Adult Child benefits (DAC) from the SSA.[71] For individuals who meet these criteria but are also enrolled in SSI-linked Medicaid, the receipt of DAC benefits may cause them to exceed the SSI income eligibility threshold, thereby rendering them ineligible for SSI-linked Medicaid. Yet under the Pseudo Pickle DAC program, the consumer will remain eligible for SSI-linked Medicaid if (s)he would meet the SSI income requirement absent the receipt of DAC.[72] The Pseudo Pickle DAC also protects consumers against cost-of-living adjustments (COLA), meaning that if the level of DAC benefits increases to include a COLA, causing consumers to exceed the SSI income eligibility threshold, they will remain eligible for SSI-linked Medicaid despite receipt of the COLA.[73] We refer to both of these programs—the Pickle program and the Pseudo Pickle DAC program—as "Pickle-type" categories.

The second type of eligibility category, which relies on income-based *and* asset-based means testing, generally requires the recipient to meet the definition of "disabled" adopted by the Social Security Administration (SSA). Five eligibility categories discussed here exemplify the second type: eligibility based on receipt of Supplemental Security Income (SSI), which we refer to as "SSI-Linked Medi-Cal"; [74] Continued Eligibility Medicaid (SSI 1619(b));[75] Aged and Disabled Federal Poverty Level (A&D FPL);[76] Aged, Blind, and Disabled Medically-Needy (ABD-MN);[77] and the 250% Working Disabled Program (WDP).[78] We refer to the last four categories collectively as "Alternative SSA Medicaid Programs."

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[71] *See* 42 U.S.C. § 402(d)(1)(B) (2019); *see also* 20 C.F.R. § 404.350(a)(4) (2019); *see also* W. CTR. ON LAW & POVERTY, CHAPTER 3: NON-MAGI MEDI-CAL 3.71–3.72, https://wclp.org/wp-content/uploads/2016/06/WesternCenter_2016_HCGuide_Chapter3_rev.1.pdf (last visited May 31, 2019).

[72] 42 U.S.C. § 1383c(c) (2019); *see also* W. CTR. ON LAW & POVERTY, *supra* note 71, at 3.72–3.73; *see also* Memorandum from Frank S. Martucci, Chief, Medi-Cal Eligibility Branch, Cal. Dep't Health Servs., to All Cty. Welf. Dirs. & All Cty. Admin. Officers on Treatment of Disabled Adult Children who have been Discontinued from SSI/SSP 1 (May 9, 1991), https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/c91-47.pdf (last visited May 31, 2019) (noting that to be pseudo Pickle DAC-eligible the "Medi-Cal to Disabled Adult Children (DAC) who lose SSI/SSP eligibility because their Title II/RSDI increases or because of initial entitlement to Title II").

[73] 42 U.S.C. § 1383c(c)(2) (2019) (noting that if any individual "ceases to be eligible for benefits under this subchapter because of such child's insurance benefits or *because of the increase in such child's insurance benefits*") (emphasis added); *see also* W. CTR. ON LAW & POVERTY, *supra* note 71, at 3.72–3.73.

[74] SOC. SECUR. ADMIN., SUPPLEMENTAL SECURITY INCOME (SSI) 1 (2019), https://www.ssa.gov/pubs/EN-05-11125.pdf (last visited June 25, 2019) (noting SSI-linked Medi-Cal requirements).

[75] *Continued Medicaid Eligibility (Section 1619(B))*, SOC. SECUR. ADMIN. [hereinafter *Continued Medicaid Eligibility (Section 1619(B))*], https://www.ssa.gov/disabilityresearch/wi/1619b.htm (last visited June 25, 2019) (noting that 1619(b) Medicaid is primarily intended for working individuals whose income is too high for SSI-linked Medicaid but not high enough to offset the complete loss of Medicaid).

[76] *Medi-Cal: The Details*, DISABILITY BENEFITS 101 (Apr. 30, 2019) [hereinafter *Medi-Cal: The Details*], https://ca.db101.org/ca/programs/health_coverage/medi_cal/program2a.htm (last visited June. 25, 2019) (noting that A&D FPL is primarily intended for aged or disabled consumers who are over 65 years old with incomes too high for SSI-linked Medicaid but assets below $2,000 for individuals and $3,000 for couples).

[77] *Id.* (noting that the ABD-MN program is intended for consumers who are over 65 years old, blind or disabled, with incomes above the cutoff for A&D FPL, and willing to incur a monthly share of cost).

[78] *Id.* (noting that the 250% WDP program is intended for SSA "disabled" consumers whose countable monthly income is below 250% of the Federal Poverty Line and whose assets are below $2,000 for individuals and $3,000 for couples; also noting that consumers must pay a monthly premium).

The third type of eligibility category, which does not employ means testing, is represented by the Title IV-E program.[79] Under this program, some current and former recipients of foster care under age 26,[80] some current and former recipients of kinship-guardianship assistance under age 21,[81] and some current and former recipients of adoption assistance under age 21[82] can qualify for FSFM Medi-Cal if they are currently or were previously under adoption assistance agreements,[83] recipients of foster care maintenance payments,[84] or recipients of kinship guardianship assistance payments.[85] Importantly, Title IV-E does not require recipients to meet the SSA definition of "disabled."[86] Although consumers between ages 21 and 26 who receive FSFM Medi-Cal based on their former foster care status are technically covered under a different statute,[87] we use the term "Title IV-E" broadly to encompass all current and former foster children and adoptees who qualify for FSFM Medi-Cal on that basis.[88]

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[79] This program is authorized by Title IV-E of the Social Security Act, *see Title IV-E Foster Care*, CHILDREN'S BUREAU, U.S. DEP'T HEALTH & HUMAN SERVS. (May 17, 2012), https://www.acf.hhs.gov/cb/resource/title-ive-foster-care (last visited July 5, 2019); *see also* 42 U.S.C. § 670–679c (2019) (Part E of Title IV of the Social Security Act on Federal Payments for Foster Care and Adoption Assistance).

[80] CHILDREN'S BUREAU, HEALTH-CARE COVERAGE FOR YOUTH IN FOSTER CARE—AND AFTER 4 (May 2015), https://www.childwelfare.gov/pubPDFs/health_care_foster.pdf (last visited June 25, 2019) (noting that former foster care recipients may continue to receive Medicaid until their 26th birthday).

[81] *See* All County Letter No. 11-86 from Gregory E. Rose, Dep. Dir. Child. & Family Servs. Div., Cal. Dep't Soc. Servs., to All Cty. Welf. Dirs. et al. (Mar. 1, 2012), http://www.cdss.ca.gov/lettersnotices/entres/getinfo/acl/2011/11-86.pdf (last visited June 25, 2019) (noting that kinship-guardianship recipients may have benefits extended from age 18 to age 21 if (a) they have a mental or physical disability that warrants continued assistance or (b) they meet one of the five educational participation criteria under CAL. WELF. & INST. CODE § 11403(b)); *see also* CAL. WELF. & INST. CODE § 11403(b) (2019) (listing the educational criteria that may allow for the extension of kinship-guardianship assistance through age 21).

[82] Consumers benefitting from adoption assistance under Title IV-E in California may remain Medi-Cal eligible until age 21 in some cases, *see California State Adoption Assistance Program*, N. AM. COUNCIL ON ADOPTABLE CHILDREN (June 2019), https://www.nacac.org/help/adoption-assistance/adoption-assistance-us/state-programs/california-adoption-assistance-program/ (last visited June 24, 2019) (noting that a consumer may continue receiving adoption assistance based on his/her mental or physical disability).

[83] *See* 42 C.F.R. § 435.145(b)(1) (2019); *see also* 42 U.S.C. §§ 673(b)(3)(A), 473(a)(2)(A) – (D) (2019).

[84] *See* 42 C.F.R. § 435.145(b)(2) (2019); *see also* 42 U.S.C. §§ 672(b), 673(b)(3)(B) (2019); *see also* Memorandum from Alice Mak, Acting Chief, Medi-Cal Eligibility Div., Cal. Dep't Health Care Servs., Health & Human Servs. Agency, on Enrollment in the Former Foster Care Children's (FFCC) Program for Mandatory Coverage Grp. & Optional Coverage Grp.—Cty. Process for Medi-Cal Applicants & Beneficiaries (Feb. 5, 2015), https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/ACWDL/2014/14-41.pdf (last visited May 28, 2019) (noting "youth who were receiving Medicaid (Medi-Cal) in foster care . . . on their 18th birthday or a later age…[are] now eligibile for benefits in the former foster care program until age 26 since January 1, 2014").

[85] *See* 42 C.F.R. § 435.145(b)(2) (2019); *see also* 42 U.S.C. §§ 673(b)(3)(C), 673(d)(1),(3) (2019).

[86] *See* 42 C.F.R. § 435.145 (2019); *see also* 42 U.S.C. §§ 1396(a)(10)(A)(i)(I), 673(b)(3) (2019).

[87] CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID AND CHIP FAQS: COVERAGE OF FORMER FOSTER CARE CHILDREN 1–2 (Dec. 2013), https://www.medicaid.gov/State-Resource-Center/Downloads/Medicaid-and-CHIP-FAQs-Coverage-of-Former-Foster-Care-Children.pdf (last visited July 5, 2019) (noting that former foster care children between ages 21 and 26 are entitled to FSFM Medi-Cal through the Affordable Care Act and that individuals "age out" of Title IV-E when an individual attains age 21 in some states).

[88] *See* CHILDREN'S BUREAU, U.S. DEP'T HEALTH & HUMAN SERVS., EXTENSION OF FOSTER CARE BEYOND AGE 18 1 (Feb. 2017), https://www.childwelfare.gov/pubpdfs/extensionfc.pdf (last visited July 5, 2019) (noting that Title IV-E benefits may extend until age 21 for some consumers).

Table 2: Requirements for Full-Scope, Federally-Matched (FSFM) Medi-Cal[89]

	MCHIP MAGI	Other MAGI	Pickle-type	SSI	SSI 1619(b)	A&D FPL	ABD-MN	250% WDP	Title IV-E
U.S. Citizen, National, or "Qualified" Immigrant[90]	✓	✓	✓	✓	✓	✓	✓	✓	✓
Adult income < 138% FPL		✓							
Child income < 266% FPL	✓	✓							
SSA "Disabled"				✓	✓	✓	✓	✓	
<$2,000-$3,000 in assets (excludes income in CalABLE Account)				✓	✓	✓	✓	✓	
Income < substantial gainful activity limit (SGA)			✓*	✓					
SSI-eligibility lost by returning to work					✓				
Require Medicaid to continue working					✓				
Annual income < SSA's 1619(b) Threshold[91]					✓				
Countable income < 100% FPL						✓			
Share of Cost							✓	✓	
Countable income < 250% FPL								✓	
Adoption assistance agreement, foster care maintenance payments, OR kinship guardianship assistance payments under 42 U.S.C. 673(a)(2),(b)(3)									✓

*Income < SGA, where income = EITHER: (1) SSA benefits adjusted by "Pickle" discount factor + all other countable income ["Pickle" case] OR (2) all countable income excluding DAC benefits ["Pseudo Pickle DAC" case].

Table 2, above, summarizes the basic requirements for the eight illustrative categories of eligibility for FSFM Medi-Cal discussed in this report.[92] The first three columns summarize

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[89] *Id.*

[90] "Qualified Immigrants" include a variety of diverse groups and must have been in the United States for at least five years to receive Medicaid, *see* 8 U.S.C. §§ 1613, 1641 (2018); however, California has chosen to fund Medi-Cal for qualified immigrants who are within the 5-year bar, as well as lawfully present immigrants who are not considered qualified immigrants, *see Eligibility and Immigration*, COVERED CAL., https://www.coveredca.com/individuals-and-families/getting-covered/immigrants/ (last visited Jan. 25, 2019). California also funds full-scope Medi-Cal for undocumented children under nineteen, *see* 2015 Cal. Legis. Serv. Ch. 18 § 34 (SB 75) (codified at CAL. WELF. & INST. CODE § 14007.5 (2019)).

[91] *See* Social Security Act § 1619(b), 42 U.S.C. § 1382h (2019); *see also Continued Medicaid Eligibility (Section 1619(B))*, *supra* note 75 (providing that threshold amount for disabled SSI beneficiaries is $37,202 in annual income).

[92] *Medi-Cal: The Details*, *supra* note 76.

basic requirements for several income-based eligibility categories: MCHIP MAGI, Other (non-MCHIP) MAGI, and Pickle-type cases. Columns 4-8 include five eligibility categories based on income *and* assets: SSI-linked Medicaid and the four alternative SSA Medicaid programs (SSI 1619(b), A&D FPL, ABD-MN, and WDP). The eligibility category displayed in the final column, Title IV-E, relies on neither income- nor asset-based means testing.

Importantly, some RC consumers whose income or assets initially disqualify them from FSFM Medi-Cal can utilize special procedures to overcome these eligibility barriers. We focus here on three such procedures: cafeteria plans, CalABLE accounts, and institutional deeming.

First, for families that are ineligible for FSFM Medi-Cal because their income exceeds the maximum allowable amount, *cafeteria plans* may provide a solution.[93] Under these plans, employees may opt to receive at least one item from a menu of two or more "cash or qualified benefits" offered by a participating employer—such as accident and health plans, group term life insurance plans, or reimbursement of childcare costs—in exchange for a reduction in gross income.[94] Families whose employers offer cafeteria plans may use them to reduce their gross income to a level that qualifies them for income-based FSFM Medi-Cal eligibility categories.[95]

Secondly, RC consumers whose assets exceed the pertinent maximum may consider opening a *CalABLE account*. These accounts allow consumers to establish accounts in their own names to cover qualified disability expenses. Importantly, funds held in CalABLE accounts are not treated as assets for purposes of evaluating eligibility for FSFM Medi-Cal.[96] Therefore, the creation of a

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[93] California is considered a "1634 state" because it has completed a "1634 agreement" with the SSA, which provides that the SSA, not the state, shall make eligibility determinations for SSI-linked Medicaid, *see* SOC. SEC. ADMIN., PROGRAM OPERATIONS MANUAL SYSTEM SEC. 01715.010 (2013), https://secure.ssa.gov/poms.nsf/lnx/0501715010 (last visited June 6, 2019). States subject to a 1634 agreement are forbidden from imposing restrictions on Medicaid eligibility that go beyond the SSA's restrictions for SSI-linked Medicaid, *see* 42 C.F.R. § 435.909(b) (2019). California can therefore not impose any more restrictive requirements on Alternative SSA Medicaid Programs than the requirements that exist for SSI-linked Medicaid. As a result, if cafeteria plans can be used to reduce a consumer's (or a family's) gross income below the income threshold for SSI-linked Medicaid, then cafeteria plans should also be available for consumers intending to enroll in any Medicaid program that imposes an income threshold, including MAGI-linked Medi-Cal, Pickle-type cases, and Alternative SSA Medicaid Programs.

[94] *Cafeteria Benefit Plans*, SOC. SEC. ADMIN. (Jan. 16, 2018), https://secure.ssa.gov/poms.nsf/lnx/0500820102 (last visited Apr. 29, 2019).

[95] *Id.*

[96] *See About the California Achieving a Better Life Experience (CalABLE) Program*, CAL. STATE TREASURER, http://www.treasurer.ca.gov/able (last visited June 10, 2019); *see also infra* note 191–192 and accompanying text (discussing CalABLE accounts in greater detail). Another method of avoiding loss of SSI or Medi-Cal eligibility is the creation of a special needs trust. Special needs trusts allow individuals to leave assets or property to a loved one with a disability, and a special needs trust has an appointed trustee who holds decision-making power over services that are purchased on the consumer's behalf, *see* Stephen Elias, *Special Needs Trusts – The Basics*, NOLO.COM, https://www.nolo.com/legal-encyclopedia/special-needs-trusts-30315.html (last visited Apr. 11, 2019). As in the case of CalABLE accounts, consumers do not have control over special needs trusts, and trust property is therefore not counted toward SSI or Medi-Cal eligibility, *see id*. Unlike CalABLE accounts, special needs trusts allow savings above $100,000; however, asset growth within special needs trusts, unlike asset growth CalABLE accounts, is taxable, *see CalABLE Accounts: What You Need to Know*,CUNNINGHAM LEGAL (Jan. 28, 2019), https://www.cunninghamlegal.com/calable-accounts-what-you-need-to-know/ (last visited Apr. 11, 2019). In

CalABLE account may allow some consumers who would otherwise be disqualified to preserve their eligibility for FSFM Medi-Cal programs that utilize asset-based means testing.

The third special procedure, *institutional deeming*, can be a particularly useful strategy for minor RC consumers whose families are relatively well-off. Through institutional deeming, CDSS can disregard parental income in evaluating a consumer's Medi-Cal eligibility as long as the consumer does not hold significant assets or income in his/her own name. As discussed later in this report,[97] any RC consumer under the age of 18 who meets the institutional level-of-care requirement, lives in the community, and receives at least one eligible service can qualify for institutional deeming.[98] From a regulatory perspective, institutional deeming is regarded as a "last resort" method for enrolling RC consumers on FSFM Medi-Cal (and the HCBS Waiver) in circumstances where they cannot qualify through other (mostly income- or asset-based) tests.[99] With a federal match rate of 50%, the aid codes associated with institutional deeming are also less remunerative than the means-tested aid codes for which some RC consumers may qualify.[100]

Table 3, below, illustrates the potential value of cafeteria plans, CalABLE accounts, and institutional deeming by listing five categories of consumers (A, B, C, D and E) who are presumptively ineligible for FSFM Medi-Cal but can, in some cases, utilize these strategies to overcome eligibility barriers. The table also makes note of the fact that some consumers who do not qualify for MAGI, SSI-linked, or Alternative SSA Medi-Cal categories make be able to take advantage of the more specialized programs encompassed within the Pickle-type and Title IV-E categories. Finally, the table indicates that undocumented/unqualified immigrants—represented by row F—cannot qualify for FSFM Medi-Cal under existing federal law.

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this report, we focus our discussion on CalABLE accounts since they are widely accessible to families of varying means, whereas special needs trusts may be impractical for lower- and middle-income families.

[97] *See* discussion *infra* Section VII.B.(2) (discussing the increased use of institutional deeming).

[98] *See id.*; *see also* S. CENT. L.A. REG'L CTR., MEDICAID WAIVER INSTITUTIONAL DEEMING 1, https://www.sclarc.org/pdf/Medicaid%20Waiver%20Institutional%20Deeming.pdf (last visited June 25, 2019) (providing "Initial Criteria" for institutional deeming). Although the institutional deeming process can also be used to enable married adults whose spouses earn significant income to qualify for Medi-Cal, we do not focus on its population in this report, since it likely constitutes a far smaller percentage of RC consumers than minor children with higher-income parents.

[99] Letter No. 17-03 from Sandra Williams, Chief, Medi-Cal Eligibility Div., Cal. Dep't Health Care Servs., to All Cty. Welf. Dirs. et al. 4 (Jan. 25, 2017) (on file with authors) (noting that institutional deeming rules should be followed after exhausting MAGI Medi-Cal and non-MAGI Medi-Cal groups).

[100] Consumers receiving FSFM Medi-Cal through institutional deeming are eligible for a 50% federal match rate, which is much lower than the federal match rate available under certain income means tested programs like MCHIP, which uses the MAGI Medi-Cal methodology, *see* AID CODE MASTER CHART, *supra* note 9, at 37, 49–58 (detailing 50% match rate for aid codes "6V" and "6W" (institutional deeming) and 88% match rate for MCHIP-related aid codes, respectively).

Table 3: Eliminating Potential Barriers to Eligibility for FSFM Medi-Cal[101]

Presumptively Ineligible Categories	Potential Solution(s)	Current Enrollment Incentives
A. Children under 18 who are MAGI *income-ineligible* and SSI *income-* or *asset-* ineligible	--Institutional deeming --Cafeteria plan --CalABLE Account [Title IV-E/Pickle-type]	*For children under 18*: • No Family Cost Participation Program fee[102] • No Annual Family Program Fee[103] • Expanded array of benefits through EPSDT *For all categories*: • Full-scope Medi-Cal benefits • Potential access to IHSS • Potential access to case manager with lower caseload
B. Married Adults who are MAGI *income-ineligible* and SSI *income-* or *asset-* ineligible[104]		
C. Adults or Children we are *asset-ineligible* for both SSI and institutional deeming	--CalABLE Account [Title IV-E/Pickle-type]	
D. Single or Married Adults who are MAGI *income-ineligible*, and despite being SSI *income-eligible* are not *SSA "disabled"*	--Cafeteria plan --SSI Appeal [Title IV-E/Pickle-type]	
E. Adults who are SSA "disabled" but are *income-ineligible* for SSI and/or MAGI	--Cafeteria plan --Alternative SSA --Institutional deeming [Title IV-E/Pickle-type]	
F. Undocumented/Unqualified Immigrants	NONE[105]	

[101] *Medi-Cal: The Details*, *supra* note 76.

[102] *Family Cost Participation Program*, CAL. DEP'T DEVELOPMENTAL SERVS., https://www.dds.ca.gov/FCPP/Index.cfm (last updated Apr. 2, 2019) (last visited Apr. 12, 2019).

[103] *Annual Family Program Fee*, REG'L CTR. OF THE E. BAY, http://www.rceb.org/annual-family-program-fee (last visited Apr. 12, 2019).

[104] For some I/DD consumers with a "wealthy" spouse (as defined by the Community Spouse Resource Allowance threshold), the spousal impoverishment rule provides a method of obtaining Medi-Cal. Under the spousal impoverishment rule, "Medi-Cal allows the at-home spouse, or community spouse, to retain additional income and assets, while still paying for the other spouse to receive care in a nursing home," or for the other spouse to remain a "Medi-Cal beneficiary[y] living at home or in the community and receiving Home and Community Based Services (HCBS)," *see* CAL. ADVOCATES FOR NURSING HOME REFORM, USING CALIFORNIA'S SPOUSAL IMPOVERISHMENT RULE FOR HOME AND COMMUNITY BASED SERVICES 1-2 (Dec. 22, 2017), http://www.canhr.org/factsheets/medi-cal_fs/PDFs/FS_Spousal_Impoverishment_HCBS.pdf (last visited Apr. 12, 2019). These rule can enable some consumers to access services at home and avoid premature placement in a nursing home" or other institutionalized setting, *see id.* at 2.

[105] In California, the scope of state services available to undocumented or unqualified immigrants is largely based on immigrants' status as permanently residing under color of law ("PRUCOL"). To gain PRUCOL status, an undocumented non-citizen must demonstrate that "(1) the Immigration and Naturalization Service (INS) knows he/she is in the U.S.; and (2) INS does not intend to deport him/her, either because of the person's status category or individual circumstances," *see* CAL. DEP'T HEALTH CARE SERVS., MEDI-CAL'S NON-CITIZEN POPULATION: A BRIEF OVERVIEW OF ELIGIBILITY, COVERAGE, FUNDING, AND ENROLLMENT 4 (Oct. 2015), https://www.dhcs.ca.gov/dataandstats/statistics/Documents/noncitizen_brief_ADAfinal.pdf (last visited Apr. 12, 2019). Individuals who are classified as PRUCOL are "entitled to full-scope State Plan Medi-Cal benefits; however, the federal government only finances those benefits or services classified as emergency and pregnancy-related," *see id.* at 2. Services that are neither emergency nor pregnancy-related "must be financed fully by state funds," *see id.* at 4. However, individuals who are not classified as PRUCOL "are entitled to emergency and pregnancy-related services only. The Federal government finances its share of the limited-scope services, and Medi-Cal does not award services beyond emergency and/or pregnancy-related services," *see id.* Regardless of PRUCOL status, undocumented immigrants are not entitled to FSFM nor HCBS Waiver-related services.

The first group depicted in the table (**A**) consists of children whose family income and/or assets are too high to qualify them for the MAGI and/or SSI-linked Medi-Cal, but who could possibly overcome these hurdles through institutional deeming, CalABLE accounts, or cafeteria plans. The second group (**B**) consists of married adults who face comparable eligibility barriers and could explore similar solutions. The third group (**C**) consists of children and adults whose assets make them ineligible for both SSI and institutional deeming, but might overcome these barriers through the creation of CalABLE accounts.[106] The fourth group (**D**) consists of single or married adults who are income-eligible for SSI (although not MAGI Medi-Cal[107]), but have not been deemed "disabled" under the SSA's definition. For this group, reversing the SSA's disability determination on appeal would remove the barrier to SSI-linked Medi-Cal, and establishing a cafeteria plan could remove the barrier to MAGI Medi-Cal.[108] The fifth and final group (**E**) of potentially eligible consumers includes adults who are SSA "disabled," but who are income-ineligible for SSI and/or MAGI. In addition to considering the Alternative SSA Medi-Cal programs listed in Table 2,[109] consumers in this group might explore institutional deeming or cafeteria plans. It is also worth noting that in unusual circumstances, some individuals in all of the above categories could qualify for Title IV-E or a Pickle-type programs. Only the final group (**F**), consisting of undocumented/unqualified immigrants, is categorically barred from FSFM Medi-Cal.

Figure 3A and Figure 3B depict these same processes in a different way by mapping the complex pathways whereby Lanterman consumers can enroll in FSFM Medi-Cal.[110] Figure 3A depicts the pertinent pathways for adult consumers (age 18 and up), while Figure 3B shows the pathways for minors. Metaphorically, one can conceptualize these flowcharts as circuitous irrigation systems designed to ensure that as much fluid as possible is deposited into two types of "eligibility reservoirs." The first type of eligibility reservoir, represented by green boxes, indicates that the consumers in question are FSFM Medi-Cal eligible, or at least could become so through the use of cafeteria plans. The second type, represented by yellow boxes, indicates that the consumers in question could become FSFM Medi-Cal eligible if they opened CalABLE accounts. Red boxes represent "exit valves" that allow consumers—and in turn, the possibility of accessing federal matching funds—to exit the system. Each of the five groups of potentially-eligible consumers presented in Table 3 is displayed (in brackets) in its corresponding box.

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[106] *Medi-Cal: The Details*, *supra* note 76.

[107] As of April 2, 2018, $16,754 (or 138% of the Federal Poverty Line) "represents the maximum income level for MAGI Medi-Cal for a family size of one," and for a family size of two, the maximum income level for MAGI Medi-Cal is $22,715, *see* Memorandum from Chris Unzueta, ADAP Operations and Eligibility Sec. Chief, Cal. Dep't Pub. Health, to ADAP Enrollment Workers (Mar. 29, 2018), https://www.cdph.ca.gov/Programs/CID/DOA/CDPH%20Document%20Library/2018-05%20%20MAGI-Medi-Cal%20Qualifying%20Federal%20Poverty%20Levels.pdf (last visited Apr. 4, 2019).

[108] SOC. SECUR. ADMIN, THE APPEALS PROCESS 1 (Jan. 2018), https://www.ssa.gov/pubs/EN-05-10041.pdf (last visited July 6, 2019).

[109] *See supra* Table 2.

[110] *Id.*

Figure 3A: Lanterman Consumers Aged 18+ Full-Scope, Federally-Matched Medi-Cal Eligibility Flowchart

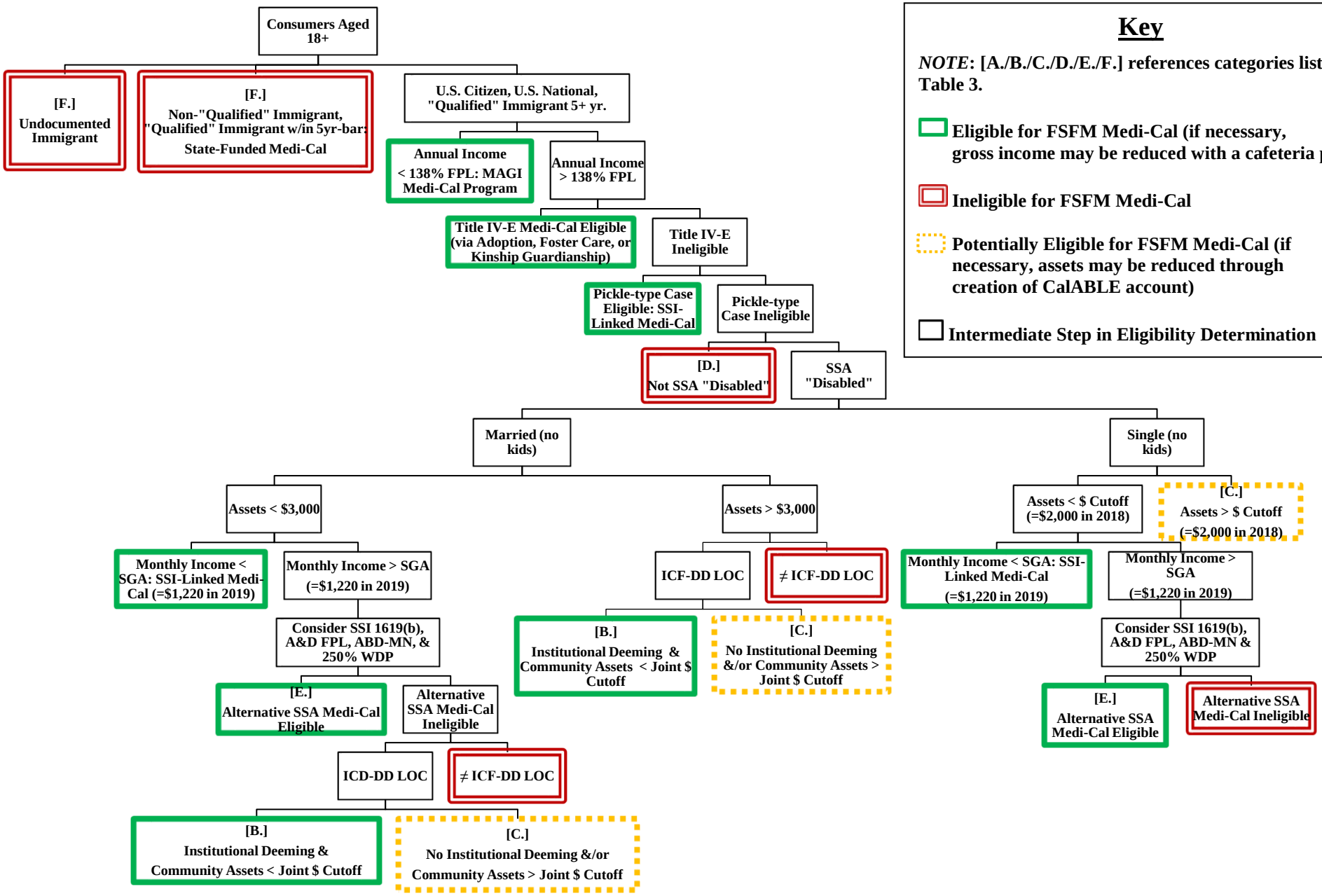
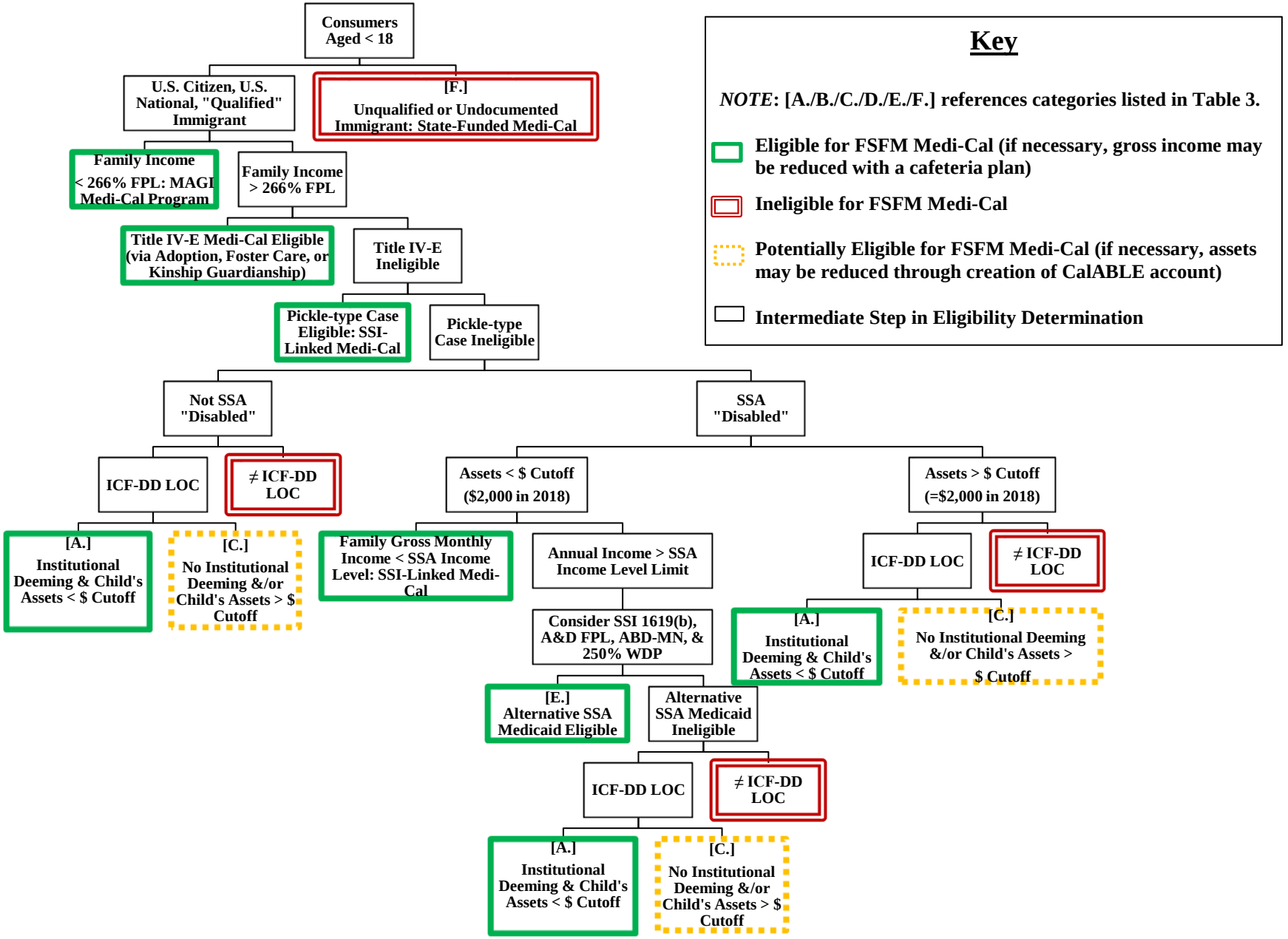


Figure 3B: Lanterman Consumers under Age 18 Full-Scope, Federally-Matched Medi-Cal Eligibility Flowchart



It is important to bear in mind that the red boxes in these figures are not "leaks" or design flaws; they simply indicate consumers who are entitled to benefits under the Lanterman Act, but for whom the state cannot recoup federal matching funds. Moreover, the flowchart maps pathways to *eligibility*, not enrollment; consumers themselves must play an active role. For example, individuals who reach the step of FSFM Medi-Cal eligibility must still take the lead on applying for and enrolling in FSFM Medi-Cal with their CDSS. (The sole exception to this rule pertains to consumers who undergo the institutional deeming process, which allows consumers to enroll simultaneously in FSFM Medi-Cal and the HCBS Waiver.[111]) Enrollment in the HCBS Waiver and the 1915(i) SPA programs likewise cannot occur without the consumer's written consent.[112]

The complexity of Figures 3A and 3B underscores that the third step of the Federal Match Eligibility Pathway poses special challenges. Not only must a feasible pathway to FSFM Medi-Cal eligibility be identified for each consumer, but the consumer must collaborate with his/her RC and CDSS in completing tasks along the way.

Although it is clear from Table 3 that enrolling in Medi-Cal can be financially advantageous for many consumers, enrollment can also pose financial risks. These risks arise from the fact that whenever it is feasible and legally permissible to do so, states are obliged under the Medicaid program to transfer financial responsibility for funding Medicaid-eligible services and supports onto private parties, and to recoup monies previously spent by Medicaid on services and supports from private parties—and even from consumers themselves—if the circumstances warrant.[113] We collectively refer to such contingencies as "Medicaid recoupment provisions," and we are aware of three situations in which they can arise.[114]

The first scenario applies to regional center consumers who bring tort claims against third parties for injuries that were treated, at least in part, with Medicaid funds (including EPSDT, HCBS Waiver, and 1915(i) SPA). This group might include, for example, a consumer whose cerebral palsy or intellectual disability was caused by the negligence of the obstetric staff who assisted in his/her hospital delivery, or a consumer whose intellectual disability arose from a traumatic brain injury caused by a vehicular collision with a drunk driver. Under state and federal law, the state may recoup the portion of any tort award or settlement that covers the cost of the consumer's

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[111] *See* discussion *infra* Section VII.B.(2). (discussing "Increasing Use of Institutional Deeming").

[112] 42 C.F.R. §§ 441.301(c), 441.725(b) (2019) (HCBS Waiver and 1915(i) SPA enrollment, respectively, require "the informed consent of the individual in writing").

[113] *See* 42 U.S.C. § 1396a(25) (2019) (federal mandate that states must establish Medicaid recoupment provisions); *see also* CAL. WELF. & INST. CODE §§ 14124.70-14124.94 (2019) (California's Medicaid recoupment provisions).

[114] California's Medicaid recoupment provisions are also referred to as "third party liability" rules, *see* CAL. WELF. & INST. CODE §§ 14124.70-14124.94 (2019) (Article 3.5 on "Third Party Liability").

medical care.[115] Yet if the consumer declines to enroll in Medi-Cal, (s)he may be able to retain the entire award.[116]

The second scenario pertains to deceased consumers who received Medicaid services during their lifetimes. Under Medi-Cal's Estate Recovery Program, the state may recoup from the consumer's estate the cost of certain expenditures made on or after the consumer's 55th birthday.[117] Here again, consumers who receive no services through Medi-Cal (or the other federally-matched Medicaid programs discussed in this report) would not be subject to this posthumous recoupment provision.

The final situation that can trigger Medicaid recoupment provisions pertains to school-age consumers who receive ancillary educational therapies (such as occupational therapy, physical therapy, or speech and language therapy) from public schools.[118] Under the Individuals with Disabilities Education Act (IDEA), every student with a disability is entitled to a Free and

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[115] *See* 42 U.S.C. § 1396a(25) (2019) (federal Medicaid recoupment provision); *see also* CAL. WELF. & INST. CODE. §§ 14124.72(d), 14124.78 (2019) (state Medicaid recoupment provisions); *see also* Ark. Dep't of Health & Human Servs. v. Ahlborn, 547 U.S. 268, 269 (2006) (noting "Federal Medicaid law does not authorize [assertion of] a lien on [a] settlement in an amount exceeding" the portion of the settlement that "constituted reimbursement for medical payments made").

[116] CAL. WELF. & INST. CODE. § 4659.11 contains its own recoupment provisions, which in theory permit DDS or RCs to recoup medical expenses from the proceeds of tort awards or settlements on behalf of the state, even from consumers whose services and supports are funded exclusively with state funds (i.e., who are neither enrolled in Medi-Cal nor on the HCBS Waiver). Our conversations with stakeholders, however, suggested that this authority has rarely, if ever, been exercised. We do not know whether private insurance carriers include contractual provisions that entitle them to claw back a portion of award or settlement proceeds, and if so, how frequently private insurers attempt to enforce these provisions; *see also id.* §§ 4659.12–4659.24 (outlining various facets of state recoupment provisions, including attorney's fees provisions, lien application prior to settlement, and limitations on recoupment amounts); *see also* DISABILITY RIGHTS CAL., RIGHTS UNDER THE LANTERMAN ACT—THE MEDI-CAL DEVELOPMENTAL DISABILITY WAIVER 13-6 (Dec. 1, 2012) [hereinafter RIGHTS UNDER THE LANTERMAN ACT: DEVELOPMENTAL DISABILITY WAIVER], https://www.disabilityrightsca.org/system/files/file-attachments/506301Ch13.pdf (last visited May 30, 2019) (noting "Any Medi-Cal services you receive for your injury and recovery may be subtracted from the money you may win from your lawsuit…[c]overage under the DD Waiver [the HCBS Waiver] *may* reduce the amount of money you receive from your lawsuit").

[117] *See Estate Recovery Program*, CAL. DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/Pages/TPLRD_ER_cont.aspx (last visited May 30, 2019); *see also* 42 U.S.C. § (b)(1)(B) (2019). Where estate "means all real and personal property and other assets in the individual's probate estate that are required to be subject to a claim for recovery," *see* CAL. WELF. & INST. CODE § 14009.5(f)(3) (2019). Repayments from a decedent's estate will be limited to the costs of "nursing facility services, home and community-based services, and related hospital and prescription drug services, or…any items or services under the State Plan," *see* 42 U.S.C. §§ 14009.5(b)(1)(B)(i)–(ii) (2019). The state may waive its estate recovery procedures under certain circumstances, *see id.* § 1396p(b)(3)(A) (noting "[t]he State agency shall establish procedures…under which the agency shall waive the application of this subsection…if such application would work an undue hardship as determined on the basis of criteria"); *see also* CAL. WELF. & INST. CODE § 14009.5(c) (2019) (noting "[t]he department shall waive its claim, in whole or in part, if it determines that enforcement of the claim would result in substantial hardship to other dependents, heirs, or survivors of the individual against whose estate the claim exists"). The state may also waive estate recovery procedures if the decedent is survived by his or her spouse, surviving registered domestic partner, a surviving child under age 21, or a surviving child who is blind or disabled, *see id.* § 14009.5(b)(2)(B).

[118] *See supra* note 162 and accompanying text (discussing the entitlement to occupational therapy, physical therapy, or speech and language therapy).

Appropriate Public Education (FAPE),[119] which includes ancillary therapies as well as formal classroom instruction. Yet under federal law, public school districts may bill Medi-Cal for the cost of such therapies.[120] If a consumer's family carries private insurance, however, Medi-Cal may ask that insurer (which is always designated as primary[121]) to pay the costs in its stead.[122] Consumers in this situation may face negative financial repercussions from having enrolled in Medi-Cal, although the passage of the Affordable Care Act seemingly lessened the likelihood of this scenario.[123]

In short, the third step of the Federal Match Eligibility Pathway, enrollment in FSFM Medi-Cal enrollment, poses unique policy challenges. First and foremost, the dizzying array of eligibility categories (and aid codes) whereby individuals can potentially qualify for FSFM Medi-Cal vastly complicates the task of determining eligibility in each individual case. Additionally, although enrollment in Medi-Cal is beneficial for many consumers, it can also impose risks for certain individuals—especially those that carry private insurance coverage—in situations that trigger Medicaid recoupment provisions.

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[119] 34 C.F.R. § 300.101 (2019).

[120] *Id.* § 300.154(d) (2019).

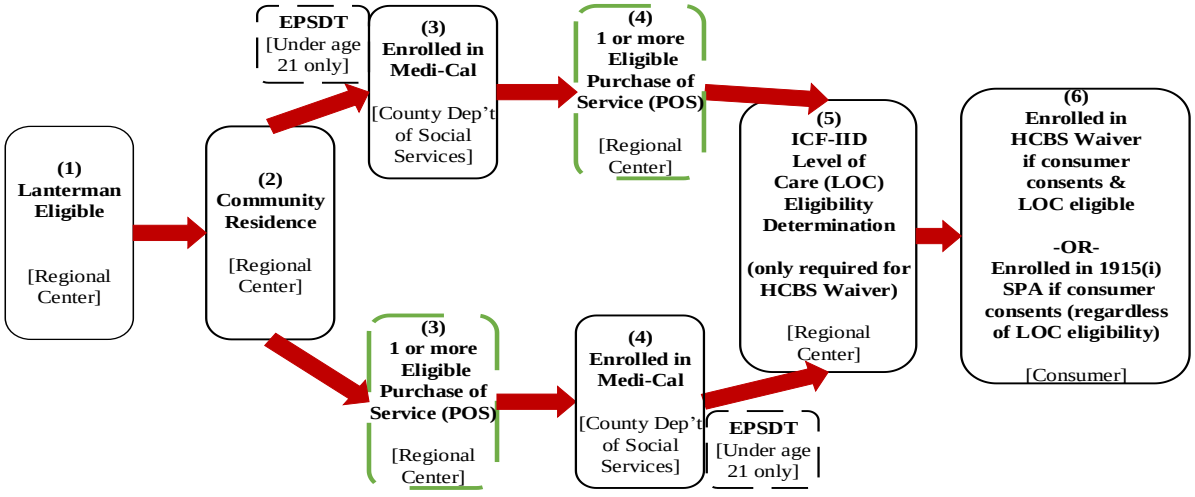
[121] *See Medicaid Third Party Liability & Coordination of Benefits*, MEDICAID.GOV, https://www.medicaid.gov/medicaid/eligibility/tpl-cob/index.html (last visited June 3, 2019) ("By law, all other available third party resources must meet their legal obligation to pay claims before the Medicaid program pays for the care of an individual eligible for Medicaid.")

[122] 34 C.F.R. § 300.154(e) (2019).

[123] Before recent policy changes under the Affordable Care Act (ACA), these negative effects arose in situations where a school-age consumer's private insurance plan imposed a total or lifetime cap on benefits. When the cost of school-based services was displaced from the school district onto Medi-Cal, and in turn from Medi-Cal onto private insurance, the consumer reached his/her lifetime cap on benefits more quickly that (s)he otherwise would, thereby effectively reducing her private insurance coverage. Although this reduction in the consumer's lifetime coverage ran afoul of the IDEA's mandate that public education be provided free of charge, *see id.* § 300.154(d)(2)(iii), it was sometimes difficult for families of school-age consumers to prevent it from happening, and if it did occur, to restore their lifetime private insurance coverage, *see* Letter from Brian Capra, Clients' Rights Advocate, Prot. & Advocacy, Inc., to Complaint Mgmt. & Mediation Unit, Cal. Dep't Educ. (March 6, 2006) (on file with authors) (regarding case in which a young consumer's enrollment in the HCBS Waiver substantially reduced his private insurance coverage without his parents' consent); *see also* Memorandum from Maria Iriarte & Brian Capra to Lanterman and Benefits Workgroups on Request for Approval to Litigate Medi-cal Lien Issue (Oct. 18, 2005) (on file with authors). In 2014, the ACA prohibited group health plans and health insurers from imposing annual dollar limits on insurance plans, *see* 26 C.F.R. §§ 54.9815–1251(g)(vi) (2019). Although the elimination of lifetime benefit caps has seemingly mitigated the risk of third-party recoupment provisions occurring in the educational context, as of this writing, it is unclear whether school-age consumers covered by private insurance may be financially disadvantaged in other ways by enrolling in Medi-Cal.

D. Step 4: Receipt of at Least One Eligible Service

By definition, every consumer who completes the first three steps of the Federal Match Eligibility Pathway has been deemed eligible for Lanterman Act services, resides in the community, and is enrolled in FSFM Medi-Cal. To enroll in the HCBS Waiver or 1915(i) SPA, however, a consumer also must receive at least one HCBS Waiver- or 1915(i) SPA-eligible purchase of service (POS) expenditure per month.[124] Mere receipt of case management services is insufficient.[125] Examples of allowable POS expenditures include behavioral intervention services, day services, respite care, and occupational therapy.[126] Since the Lanterman Act provides eligible consumers with an independent entitlement to services, enrollment in FSFM Medi-Cal is *not* a precondition for receipt of an HCBS-Waiver- or 1915(i) SPA-eligible POS.[127] Therefore, Step Four of the Federal Match Eligibility Pathway may occur before Step Three (enrollment in FSFM Medi-Cal).



Notably, a consumer who receives no POS may still have his/her case management costs federally matched through the Targeted Case Management (TCM) program. Yet such an individual still cannot receive services through the HCBS Waiver or 1915(i) SPA programs, because the lack of any qualifying POS is an absolute bar to enrollment. Many children are in precisely this situation,[128] because school districts provide all of their services and supports.

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[124] 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 51 ("In order for an individual to be determined to need waiver services, an individual must require: (a) the provision of at least one waiver service, as documented in the service plan, and (b) the provision of waiver services at least monthly.")

[125] *Id.* at 196 ("Case management is furnished . . . as a Medicaid State plan service under § 1915(g)(1) of the Act (Targeted Case Management)").

[126] *Id.* at 60.

[127] *See* CAL. WELF. & INST. CODE § 4501 (2019); *see also* LANE ZURAW ET AL., THE SCOPE OF THE LANTERMAN ACT ENTITLEMENT § IV (July 1, 2019) [hereinafter LANTERMAN ENTITLEMENT REPORT].

[128] *See, e.g.*, GOLDEN GATE REG'L CTR., PURCHASE OF SERVICE DEMOGRAPHICS FISCAL YEAR 2016–17 1 (2017), http://www.ggrc.org/storage/documents/Budget_and_Finances/POS_Demographics_FY_2016-17.pdf (last visited

Table 4: 2017-18 CA General Fund (GF)[129] & Federal POS Expenditures and Reimbursements (in thousands of dollars)[130]

	POS Expenditures			Federal Reimbursements for POS		
	2017-18 DDS Total $	**Total State GF $ (% Total $)**	**Unmatched State GF $ (% GF $)**	**HCBS Waiver**	**1915(i) SPA**	**HCBS Waiver + 1915(i) SPA % Total Expenditures[131]**
Community Care Facilities	$1,542,299	$896,059 (58%)	$257,232 (29%)	$586,979	$51,850	41%
Medical Facilities	$11,571	$11,571 (100%)	$11,571 (100%)	$0	$0	0%
Day Programs	$1,136,720	$626,961 (55%)	$182,357 (29%)	$316,106	$60,303	33%
Habilitation: WAP	$42,225	$22,551 (53%)	$2,878 (13%)	$16,516	$2,702	46%
Habilitation: SEP-G	$96,461	$72,156 (75%)	$47,851 (66%)	$18,002	$6,173	25%
Habilitation: SEP-I	$33,753	$28,398 (84%)	$23,044 (81%)	$3,167	$2,161	16%
Transportation	$366,672	$216,313 (59%)	$74,868 (35%)	$114,590	$11,293	34%
Support Services	$1,420,716	$786,118 (55%)	$227,340 (29%)	$483,156	$68,899	39%
In-Home Respite	$470,175	$266,587 (57%)	$102,060 (38%)	$145,209	$19,319	35%
Out-of-Home Respite	$47,698	$22,087 (46%)	$7,905 (36%)	$16,006	$1,628	37%
Health Care	$122,374	$101,617 (83%)	$83,948 (83%)	$13,276	$4,393	14%
Miscellaneous	$483,474	$359,138 (74%)	$295,549 (82%)	$48,155	$15,139	13%
Total	**$5,774,138**	**$3,409,556 (59%)**	**$1,316,603 (39%)**	**$1,761,162**	**$243,860**	**35%**

As shown in Table 4, above, a sizable proportion of expenditures in every POS category in 2017-18 were funded by state General Fund monies that were unmatched by federal dollars, suggesting that an appreciable number of consumers receiving POS funds were not enrolled in the HCBS Waiver or 1915(i) SPA programs.

Jan. 18, 2019) (Table titled "Consumers with No Purchase of Services by Diagnosis – Summary" reports that 34.9% of consumers aged 3-21 received no purchase of services in 2016–17, compared to 18.4% over all ages and 10.9% for consumers aged 22 and older).

[129] GF refers only to the state's General Fund and not to any federally-matched funds.

[130] 2018 MAY REVISION, *supra* note 4, at G-32–G-36.

[131] There are other federal reimbursement programs besides HCBS Waiver and 1915(i) SPA, but HCBS Waiver and 1915(i) SPA comprise the largest share of federal reimbursement programs for POS expenditures in California.

E. Step 5: Fulfillment of Level of Care Requirement

The fifth step in the process of enrolling consumers in the HCBS Waiver or 1915(i) SPA programs requires the RC to determine whether the consumer needs the level of care (LOC) required for placement in an ICF-I/DD. [132] If the consumer meets this LOC requirement, the QIDP documents this fact in the *Medicaid Waiver Eligibility Record*,[133] rendering the consumer eligible to enroll in the HCBS Waiver. If not, the consumer remains eligible for enrollment in the 1915(i) SPA as long as (s)he meets all of the other requirements.

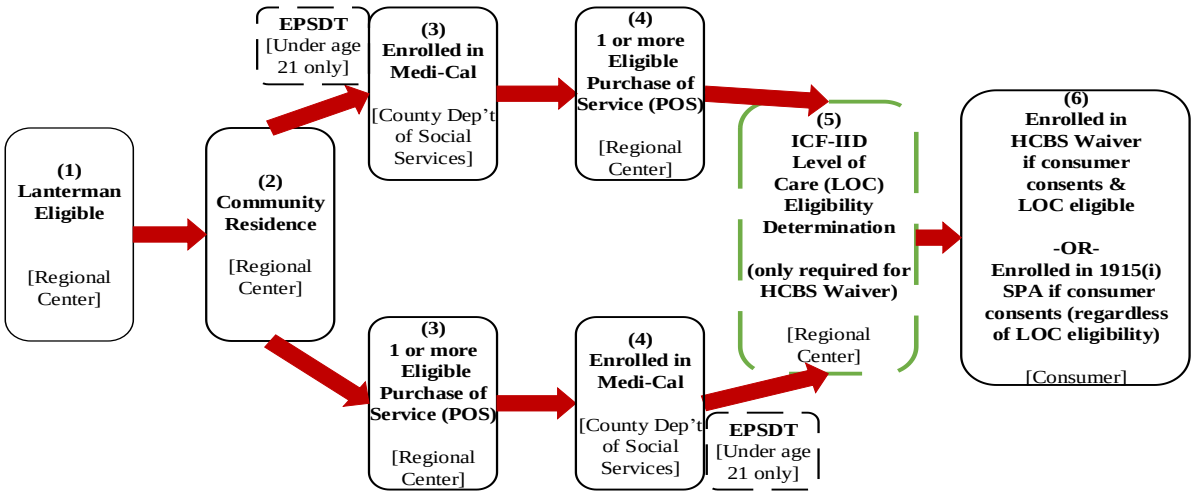

Table 5, below, compares the LOC requirements for ICF-IID placement and Lanterman Act eligibility. Taking these requirements at face value, it is difficult to envision a Lanterman Act consumer with "significant functional limitations" in *three or more* areas of major life activity who lacks at least *two* "moderate or severe" needs in the domains of self-help, social-emotional functioning, or health required for HCBS Waiver eligibility. Consequently, it seems reasonable to assume that most consumers who complete the first four steps of the eligibility pathway will also complete Step Five. That being said, the processes for establishing eligibility under the two programs are quite different. Lanterman Act eligibility is based on psychological assessments, medical records, and input from the RC intake coordinator; the final eligibility determination is made by a multidisciplinary team that uses the available evidence to determine whether three or

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[132] *See Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)*, CTRS. FOR MEDICARE & MEDICAID SERVS., https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/ICFIID.html (last visited Jan 18, 2019). Note that the terminology has evolved over time, and even within a given time period, is not always used consistently across programs or jurisdictions. As a result, the same facilities may be known as Intermediate Care Facilities for the Developmentally Disabled (ICF-DDs) or Intermediate Care Facilities for Persons with Mental Retardation (ICF-MRs).

[133] *See* CAL. HEALTH AND HUMAN SERVS. AGENCY, MEDICAID WAIVER ELIGIBILITY RECORD: DS 3770 (2016), http://www.dds.ca.gov/Forms/docs/ds3770.pdf (last visited Jan. 18, 2019); *see also* HCBS WAIVER PRIMER AND POLICY MANUAL, *supra* note 42, at 8.

more significant functional limitations are present.[134] To determine HCBS Waiver eligibility, the QIDP reviews the information that the service coordinator has inputted into the CDER throughout the IPP process, including the severity of each impairment,[135] then certifies eligibility based on the totality of these criteria.[136]

Table 5: Comparison of HCBS Waiver LOC and Lanterman Disability Requirements

HCBS Waiver LOC[137]	**Lanterman Disability**[138]
"An individual must have at least two moderate or severe support needs (qualifying conditions) in one or a combination of the following areas: self-help (e.g. dressing, personal care, etc.); social-emotional (e.g. aggression, running away, etc.); or health (e.g. tracheostomy care, apnea monitoring, etc.)."	" 'Substantial disability' means the existence of significant functional limitations in three or more of the following areas of major life activity . . . (A) Self-care, (B) Receptive and expressive language, (C) Learning,(D) Mobility, (E) Self-direction,(F) Capacity for independent living, (G) Economic self-sufficiency."

[134] DISABILITY RIGHTS CAL., RIGHTS UNDER THE LANTERMAN ACT – CHAPTER 2: DEVELOPMENTAL DISABILITIES 2-4–2-5 (Dec. 1, 2012) https://www.disabilityrightsca.org/system/files?file=file-attachments/506301Ch02.pdf (last visited May 14, 2019) (noting that Lanterman disability eligibility requires a consumer's "school records, medical records, work history, and [e]valuations, assessments, and any other information that correctly describes your abilities and your disabilities" and stating the regional center will "ask for [the consumer's] written permission to contact [the consumer's] doctors, schools, employers, and others who may have information about [the consumer]").

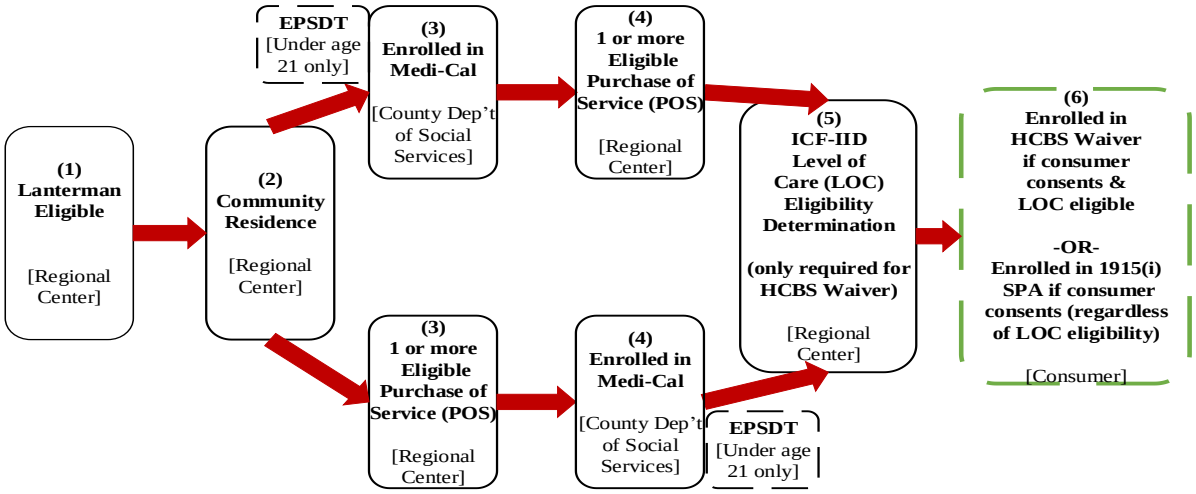
[135] U.S. DEP'T HEALTH & HUMAN SERVS., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 72 (2010 ed.), https://aspe.hhs.gov/system/files/pdf/76201/primer10.pdf (last visited July 6, 2019) (noting in the context of "HCBS Waiver Programs" that "[l]evel-of-care criteria explicitly describe the type and level (or severity) of functional limitations and/or medical and nursing needs an individual must have to be admitted to an institutional setting").

[136] HCBS WAIVER PRIMER AND POLICY MANUAL, *supra* note 42, at Appendix 2.1–2 CAL (outlining "Level-of-care Determination Using the Revised CDER"). Note that "Qualified Mental Retardation Professional (QMRP)," as used in this DDS source, is a now-outdated term that has been replaced by Qualified Intellectual Disabilities Professional (QIDP), which we use in this report, *see QDDP/QIDP Qualifications*, NAT'L ASS'N QDDPS, https://sites.google.com/site/naqddp/qddp-qmrp-qualifications (last visited May 14, 2019).

[137] 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 52 (citing CAL. CODE REGS. tit. 17, §§ 51343, 51343.1-.2 (2019)).

[138] CAL. WELF. & INST. CODE §§ 4512(a), (l) (2019).

F. Step 6: Enrollment in HCBS Waiver or 1915(i) SPA



In the sixth and final step, the consumer enrolls in the HCBS Waiver or 1915(i) SPA program. To enroll in either program, the consumer or his/her authorized representative must sign a form attesting to his/her desire to enroll in the program and live in a community setting.[139] Though this final step may seem pro forma, some stakeholders suggested that consumers' cooperation cannot always be taken for granted. For example, some consumers reportedly declined to enroll in the HCBS Waiver because they feared that it involved a "waiver" of their legal rights,[140] conferred social stigma,[141] or might be perceived by others as unjustly draining scarce public resources.[142] As discussed earlier, it is also possible that some consumers—especially those who carry private insurance—decline to complete the process because they are familiar with the Medicaid recoupment provisions discussed earlier, and are unwilling to accept the potential risks that Medi-Cal enrollment could bring.[143]

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[139] *See supra* note 46 and accompanying text (noting that both the HCBS Waiver and 1915(i) SPA require a consumer's "informed consent" for enrollment); *see also* CAL. HEALTH AND HUMAN SERVS. AGENCY, MEDICAID WAIVER CONSUMER CHOICE OF SERVICES/LIVING ARRANGEMENT STATEMENT 1 (2002), http://www.dds.ca.gov/Forms/docs/DS2200.pdf (last visited Jan. 18, 2019); *see also* HCBS WAIVER PRIMER AND POLICY MANUAL, *supra* note 42, at 9.

[140] The term "Waiver" may be inherently confusing to consumers and families. When a person signs a "waiver" in other contexts, she is often agreeing to forfeit a right.

[141] HCBS Waiver enrollment, in consumers' eyes, may signify that they "need" an institutional level of care, a designation which a consumer and/or his family may perceive as demeaning and stigmatizing.

[142] Higher-income families may believe that enrolling in Medi-Cal unfairly drains public resources, to the detriment of low-income families who truly need state-sponsored healthcare.

[143] *See supra* Section V.C.; *see also* RIGHTS UNDER THE LANTERMAN ACT: DEVELOPMENTAL DISABILITY WAIVER, *supra* note 116, at 13-6 (advising "If you are a regional center consumer involved in a lawsuit because of an injury, you may not want to be covered under the DD Waiver").

VI. Estimating the Magnitude of Lost Federal Funding

Thus far, we have described each step along the Federal Match Eligibility Pathway to eligibility for federal HCBS Waiver reimbursement. In this section, we explore how many additional RC consumers potentially could enroll in federally-matched Medicaid programs and, in turn, how much additional revenue the state could recoup as a result. As noted at the outset, we cannot calculate any of these figures with precision because we lack critical information that would be required to do so.[144] In light of these constraints, our goal is to generate plausible "back of the envelope" estimates for each of these figures with the limited data available.[145]

As was shown earlier in Figure 1, only about 50-60% of all active[146] consumers were enrolled in the HCBS Waiver in 2017. The important question is why. To understand enrollment trends in more detail, we submitted a series of Public Records Act (PRA) requests to DDS in an effort to quantify the amount of consumer attrition (i.e., failure to advance to the next step) at each step of the Federal Match Eligibility Pathway. Figure 4, below, indicates how many consumers advanced and dropped out, respectively, at each step of the process in 2017. As noted earlier, however, no data was available on the number of 1915(i) SPA enrollees, so the final step only includes those who enroll in the HCBS Waiver.

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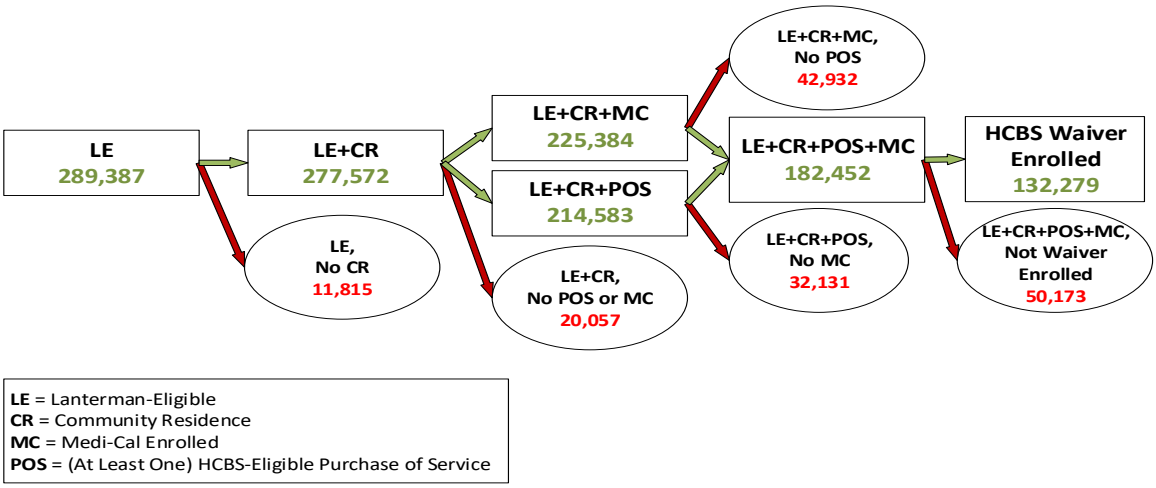
[144] *See supra* Section III; *see also supra* notes 55-56 and accompanying text (noting that DDS does not keep data on the "proportion of undocumented residents among RC consumers").

[145] The numbers on which we base our analysis were extracted by DDS from the Client Development Evaluation Report (CDER) database, whose reliability depends on the accuracy and completeness of the information inputted by RC personnel, *see* Telephone Call with Assistant Chief Counsel, Cal. Dep't Developmental Servs. (Oct. 1, 2018) (noting that the numbers inputted by RC staff into the CDER system could differ slightly from the expenditure information that state employees record in a separate database in order to calculate the amount of CMS-reimbursable expenses).

[146] *See supra* note 39 and accompanying text.

Figure 4: Consumer Advancement & Attrition on HCBS Waiver Eligibility Pathway (2017)[147]



As shown in the figure, 289,387 consumers were deemed eligible for Lanterman Act services in 2017.[148] Approximately 4.1% of this number (11,815) lost eligibility at Step 2, which requires certification of a consumer's residence in the community. The latter individuals resided in Developmental Centers, skilled nursing facilities, Institutions for Mental Disease, intermediate care facilities, correctional institutions, and other equally restrictive settings.[149]

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[147] *See supra* note 38 and accompanying text (providing citations to the e-mails sent to the authors with data responsive to PRA requests). In Figure 4, numbers in green represent the number of consumers that satisfied that step of the HCBS Waiver Eligibility Pathway. Numbers in red represent number of consumers that could not proceed further at a given step of the HCBS Waiver Eligibility Pathway. At Step 3, there is a divergence in the pathway based on whether the Lanterman-eligible consumer in the community first enrolls in Medi-Cal or first receives at least one HCBS Waiver- or 1915(i) SPA-eligible purchase of service. At Step 4, the HCBS Waiver Eligibility Pathway converges and attrition from the two groups at Step 3 are shown above and below Step 4 in red. Additionally, note that we call this figure the "HCBS Waiver Eligibility Pathway" as opposed to the "Federal Match Eligibility Pathway" since we are solely focusing on HCBS Waiver enrollment, not 1915(i) SPA enrollment.

[148] CAL. WELF. & INST. CODE §§ 4512(a), (l) (2017). No RC consumer can attrite at Step 1, since this step, by definition, requires that an applicant be deemed developmentally disabled by his/her local RC.

[149] As discussed earlier, we err on the side of caution in excluding all individuals in the "other" category even though some fraction of them might in fact meet the community residence requirement, *see supra* text accompanying note 36 (explaining why "other" category is not included in our counts), and/or qualify for a different Medicaid waiver program. For example, California has another HCBS Waiver, the Assisted Living Waiver (ALW), that primarily targets the elderly but is also available for elderly consumers with IDD. The ALW is an HCBS Waiver for consumers who currently receive care in nursing facilities but are "willing to live in an assisted living setting as an alternative to a Nursing Facility," *see Assisted Living Waiver*, CAL. DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/ltc/Pages/AssistedLivingWaiver.aspx (last visited May 2, 2019). To qualify, an individual must be age 21 or older, "have full-scope Medi-Cal eligibility with zero share of cost," "have care needs equal to those of Medi-Cal funded residents living and receiving care in Nursing facilities," be "willing to live in an assisted living setting as an alternative to a Nursing facility," and "be able to reside safely in an assisted living facility or public subsidized housing," *see id*. See *Medi-Cal Waivers*, CAL. DEP'T HEALTH CARE SERVS., https://www.dhcs.ca.gov/services/Pages/Medi-CalWaivers.aspx (last visited May 3, 2019) (under "Current Waivers" then "Current Waivers" and "1915(c) Home and Community-Based Services (HCBS) Waivers"), for more information about other HCBS Waivers.

A much larger number of Lanterman-eligible consumers lost eligibility at Steps 3 and 4. About 6.9% (20,057) neither received POS nor enrolled in Medi-Cal (the data cannot distinguish between FSFM Medi-Cal and exclusively state-funded Medi-Cal); about 14.8% (42,932) enrolled in Medi-Cal but received no POS; and about 11.1% (32,131) received POS[150] but did not enroll in Medi-Cal.[151]

The final step of the pathway displayed in Figure 4 reveals that 17.3% of all Lanterman-eligible consumers (50,173) received POS and enrolled in Medi-Cal, yet did not enroll in the HCBS Waiver. To interpret this finding, it is helpful to recall that enrollment in the HCBS Waiver requires the consumer to consent to enroll and additionally requires the RC to certify that the consumer meets the LOC required for residence in an ICF-IID. We have no data with which to estimate how many consumers decline to enroll. As discussed earlier, we suspect that relatively few, if any, Lanterman-eligible consumers would fail the LOC requirement.[152]

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[150] The data cannot distinguish between POS that are, and those that are not, eligible for federal matching funds. In the analysis that follows, we assume that all, or virtually all, POS are eligible for reimbursement through the HCBS Waiver and/or 1915(i) SPA, *see supra* Sections V.C., V.D.

[151] California does not include case management as a qualified HCBS Waiver service in its HCBS Waiver Application, but consumers who receive only case management services are covered under the Targeted Case Management Program, which includes a 50% federal match, *see* 2018 APPROVED WAIVER APPLICATION, *supra* note 11.

[152] As noted earlier with regard to Table 5, even though the LOC eligibility determination processes are quite different under the Lanterman Act and the HCBS Waiver, a common-sense reading of the two provisions makes it difficult to imagine a consumer who would quality under the former but not the latter, *see supra* Section V.E; *see also* HCBS WAIVER PRIMER AND POLICY MANUAL, *supra* note 42, at A-1. At the very least, available evidence suggests that there are very few cases in which Lanterman-eligible consumers are enrolled in the HCBS Waiver yet do not, in fact, have at least two moderate or severe support needs (qualifying conditions) in one or a combination of the following areas: self-help (e.g. dressing, personal care, etc.); social-emotional (e.g. aggression, running away, etc.); or health (e.g. tracheostomy care, apnea monitoring, etc.). In reaching this conclusion, we relied on the results of DDS' biennial audits of RCs, one goal of which is to determine whether "[the] consumer's qualifying conditions documented in the CDER [Client Development Evaluation Report] are consistent with information contained in the consumer's record," which bears directly on the LOC requirement, *see* CAL. DEP'T DEVELOPMENTAL SERVS. & DEP'T HEALTH CARE SERVS., REDWOOD COAST REGIONAL CENTER HOME AND COMMUNITY-BASED SERVICES WAIVER MONITORING REVIEW REPORT 11 (Feb. 26, 2018), https://www.dds.ca.gov/Transparency/docs/HCBSWaiver_TCM/RCRC_Waiver_2018.pdf (last visited July 6, 2019). Our review indicated that across all regional centers, less than four percent of Lanterman-eligible consumers sampled during the most recent audits had been improperly enrolled in the HCBS Waiver due to deficiencies in the LOC documentation, *see Regional Centers Biannual Home and Community-Based Services Waiver; Targeted Case Management and Federal Nursing Home Reform Reviews*, CAL. DEP'T DEVELOPMENTAL SERVS., https://dds.ca.gov/Transparency/RCWaiver_TCMReview.cfm (last updated May 8, 2019) (last visited May 10, 2019) (selecting audits under "Home and Community-Based Services Waiver Program" for a given regional center and examining the percentage of consumers enrolled in the HCBS Waiver that failed criterion 2.5.b concerning "consumer's qualifying conditions documented in the CDER are consistent with information contained in the consumer's record"). In 14 of 21 regional centers, less than five percent of the cases that were sampled contained such deficiencies, and there was no regional center in which more than 9% of sampled files were found to be deficient, *see id*. Moreover, even in cases that were red-flagged by the DDS auditors, the audit did not conclude that the consumer in question was actually ineligible for the HCBS Waiver, but merely that the documentation relevant to his/her LOC determination was incomplete or inadequate.

Using these figures as a springboard for analysis, simple back-of-the-envelope calculations suggest that California may be able to recoup a great deal more federal funding from CMS than it currently receives. To see why this is so, it is helpful to focus on two groups: (1) the 32,131 consumers who are Lanterman eligible, live in the community, and receive POS from their RCs, yet are not enrolled in Medi-Cal; and (2) the 50,173 consumers who are Lanterman eligible, live in the community, receive POS, and are enrolled in Medi-Cal, yet are not enrolled in the HCBS Waiver. Based on the available data, we suspect that a sizable fraction of both of these groups are not receiving any federal matching funds, yet likely could do so with relatively modest encouragement and assistance.

Our logic with regard to the first group of 32,131 is as follows. This group of consumers—who are Lanterman eligible, live in the community, and receive POS from their RCs *yet are not enrolled in Medi-Cal*—likely contains some consumers who cannot enroll in FSFM Medi-Cal because of their undocumented immigration status. Importantly, however, even undocumented immigrants are eligible to receive full-scope Medi-Cal, and there is no compelling reason to think that undocumented immigrants are *overrepresented* in this group. Since undocumented residents tend to have lower income and assets than other residents, one might expect them, if anything, to have more to gain from Medi-Cal enrollment. To be sure, some undocumented residents might decline to enroll in government-funded program for fear that doing so might heighten their visibility and consequently their risk of deportation. Yet the 32,131 individuals in this group have *already* chosen to make their presence known to state authorities because they are *already* receiving POS from their RCs. By this logic, it seems reasonable to assume that the proportion of undocumented residents in this group does not exceed the statewide average of 5.6%.[153] If this is the case, then approximately 1,800 members of the original 32,131 would not qualify for federal matching funds even if they did enroll in Medi-Cal. The consumers that remain, which number about 30,000, are of particular interest since they are *already* receiving POS, yet their failure to enroll in Medi-Cal has precluded the state from receiving any federal matching funds on their behalf.

Our reasoning with regard to the second group of 50,173—consisting of those who are Lanterman eligible, live in the community, receive POS, and are enrolled in Med-Cal—is more involved, because we must account not only for the undocumented immigrants in this group, but also for the (unknown) proportion of individuals who are enrolled in the 1915(i) SPA program and thus are already receiving federal matching funds. To perform the former calculation, we once again can rely on the 5.6% statewide estimate, but it would be inappropriate to deduct that percentage from the group of those that fail to enroll in the HCBS Waiver, because that is a highly self-selected group.[154] To derive a credible estimate, we must calculate 5.6% of *all*

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[153] *See supra* note 56 and accompanying text. As noted earlier, available evidence suggests that if anything, undocumented residents constitute a *smaller* proportion of RC consumers than they do of general population, so the 5.6% figure may well be an over-estimate, *see* HAYES & HILL, *supra* note 56, at 1; *see also* Metzker, *supra* note 56 (noting, "[A]vailable health interview survey data . . . show a lower disabled rate among undocumented adults").

[154] The key point is that *all* of the undocumented immigrants who make it to the fifth step will fail to enroll in the HCBS Waiver and 1915(i) SPA because federal law categorically bars them from doing so. Consider, for example, a simplified hypothetical in which 1000 consumers are Lanterman eligible, reside in the community, receive POS, and are enrolled in Medi-Cal; and a quarter of this number (250) decline to enroll in the HCBS Waiver or 1915(i) SPA programs. The question is how many among the latter group of 250 are likely to be undocumented immigrants. To

consumers who make it to the penultimate step (182,452), and take that as our estimate. This calculation (0.056 X 82,452) produces an estimate of about 10,200 consumers who cannot enroll in the HCBS Waiver or 1915(i) SPA because of their immigration status.

Our next task is to estimate the number of consumers who do not enroll in the HCBS Waiver because their services are *already* being reimbursed through the 1915(i) SPA program. Although we have no information on how many consumers are enrolled in the 1915(i) SPA, the amounts of federal reimbursements derived from the HCBS Waiver and 1915(i) SPA programs—$1.7 billion and $250 million, respectively—imply that 1915(i) SPA program is about 15% as large as the HCBS Waiver. By this logic, it seems reasonable to assume that about 15% as many consumers are enrolled in the 1915(i) SPA program as are enrolled in the HCBS Waiver, yielding an estimate of about 20,000 consumers (132,279 X 0.15) enrolled in the 1915(i) SPA.

In short, of the 50,173 consumers who are not enrolled in the HCBS Waiver despite meeting the other key criteria (Lanterman eligibility, community residence, Medi-Cal enrollment, and receipt of POS), it seems reasonable to assume that about 20,000 are already enrolled in the 1915(i) SPA, and another 10,000 are disqualified from both programs because of their immigration status. This leaves approximately 20,000 RC consumers who have satisfied the key criteria for enrolling in the HCBS Waiver and 1915(i) SPA,[155] yet have not crossed the finish line.

Adding together these two estimates—the estimated 30,000 RC consumers who are otherwise eligible yet have not enrolled in FSFM Medi-Cal, and the estimated 20,000 Medi-Cal recipients who are otherwise eligible yet have not enrolled in the HCBS Waiver or 1915(i) SPA—implies that there may be 50,000 or more RC consumers who are "low-hanging fruit," in that there is no obvious reason why they could not enroll in Medi-Cal and, in turn, Medicaid programs that would enable the state to recoup additional federal funds.

To estimate the total additional revenue that might result from enrolling all 50,000 of these individuals in the HCBS Waiver or 1915(i) SPA, we can bring another important fact to bear. On average, each consumer enrolled in the HCBS Waiver reportedly saves the state $13,446.50 per year.[156] Incorporating this figure into our analysis suggests that the state may be leaving half

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see the answer, it is important to recognize that 5.6% of the original group of 1000 (in other words, 56 consumers) are likely to be undocumented immigrants, *all of whom will be disqualified from enrollment in federally-matched programs*. If one were instead to take 5.6% of the 250 consumers who do not enroll in federally matched programs, one would conclude that only 14 undocumented consumers among the non-enrolled (250 X 0.056) were undocumented, which would mistakenly imply that the remaining 42 undocumented consumers (from among the original 56) *did* enroll in the HCBS Waiver or 1915(i) SPA. The latter logic is flawed because *none* of the original 56 undocumented consumers would be permitted to enroll in federally matched programs; they would *all* appear among the group of 250. In short, the 5.6% estimate should be calculated based on the total number of consumers who reach the final step, not the subset of consumers that fail to enroll in the HCBS Waiver and 1915(i) SPA.

[155] As noted earlier, we assume for purposes of this discussion that all (or nearly all) of the POS that these 20,000 individuals are receiving from their RCs would qualify for federal reimbursement under the HCBS Waiver and/or 1915(i) SPA programs, *see supra* note 150 and accompanying text.

[156] California estimates that the average HCBS Waiver-enrollee uses $26,893 in services and supports per year (this number does not include case management services), *see* 2018 APPROVED WAIVER APPLICATION, *supra* note 11, at 277–78. Half of these costs are covered by the federal government. Because the Lanterman Act requires that

a billion dollars or more (50,000 X $13,446.50) on the table each year due to the under-enrollment of RC consumers in federally-matched Medicaid programs. Given the fact that over $l billion of California's annual expenditures on I/DD services is unmatched by federal dollars, this may well be a conservative estimate. [157]

Table 6: Medi-Cal (MC) Enrollment, POS Receipt & Enrollment in HCBS Waiver among Lanterman-Eligible & Community-Resident (LECR) Consumers in 2017[158]

RC	# LECR Consumers	Enrolled in Medi-Cal		Receiving POS & Medi-Cal		HCBS Waiver Enrolled	
		#	%	#	%	#	%
ACRC	20,924	17452	83.4%	15495	74.1%	12,033	57.5%
CVRC	15,809	14129	89.4%	10548	66.7%	7,425	47.0%
ELARC	10,005	8506	85.0%	7120	71.2%	4,549	45.5%
FDLRC	8,486	6870	81.0%	5625	66.3%	4,058	47.8%
FNRC	7,058	5945	84.2%	4603	65.2%	2,571	36.4%
GGRC	7,756	6620	85.4%	5763	74.3%	4,373	56.4%
HRC	11,634	9069	78.0%	6859	59.0%	4,503	38.7%
IRC	29,208	24024	82.3%	18517	63.4%	13,449	46.0%
KRC	7,862	6272	79.8%	4745	60.4%	3,502	44.5%
NBRC	7,431	6057	81.5%	5155	69.4%	4,287	57.7%
NLACRC	21,083	16622	78.8%	12908	61.2%	9,212	43.7%
RCEB	17,737	13186	74.3%	10200	57.5%	7,227	40.7%
RCOC	17,024	13625	80.0%	11002	64.6%	8,323	48.9%
RCRC	3,564	3034	85.1%	2614	73.3%	1,611	45.2%
SARC	14,575	11710	80.3%	10291	70.6%	8,010	55.0%
SCLARC	12,805	10748	83.9%	8297	64.8%	5,642	44.1%
SDRC	23,472	18121	77.2%	14270	60.8%	10,568	45.0%
SGPRC	10,806	9083	84.1%	7136	66.0%	4,814	44.5%
TCRC	11,053	9055	81.9%	8178	74.0%	6,407	58.0%
VMRC	11,803	9270	78.5%	7818	66.2%	5,250	44.5%
WRC	7,477	5986	80.1%	5308	71.0%	4,465	59.7%
Total	**277,572**	**225,384**	**81.2%**	**182,452**	**65.7%**	**132,279**	**47.7%**

As is shown in Table 6 (above), there is considerable variation across regional centers in the numbers of consumers who complete key steps of the Federal Match Eligibility Pathway, as well as in the proportions of consumers that ultimately enroll in the HCBS Waiver.

California cover these services and supports regardless of whether the consumer undergoes institutional deeming, the state saves an average of $13,446.50 for every consumer who does so.

[157] *See* STATE OF THE STATES, *supra* note 21, at 9 tbl.4 (estimating total unmatched state, county and local funds in California at $1,173,095,964 in 2015). Our own calculations, based on the 2017-18 budget, put this figure at about $1.41 billion.

[158] *See* E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't Developmental Servs., to Alison Morantz, Stanford Law Sch. (July 2, 2018, 14:46 PT) (figures presented in this table were presented as Microsoft Excel attachments to e-mails received form DDS in response to PRA requests); *see also* E-mail from Jason Scott, Assistant Chief Counsel, Cal. Dep't Developmental Servs., to Alison Morantz, Stanford Law Sch. (Oct. 16, 2018 15:54 PT) (figures presented in this table were presented as Microsoft Excel attachments to e-mails received form DDS in response to PRA requests); *see also 1915(c) Waivers by State: California (8), supra* note 3 (the figures in this table include children aged 0-3, who are eligible for services under the "CA HCBS Waiver for Californians w/DD." Individuals "ages 0 – no max age" are eligible for such services under the HCBS Waiver).

Analyzing the HCBS Waiver enrollment data separately for younger consumers (21 years old and younger) and older ones (at least 22 years of age) brings a few additional nuances to light.

First, a far greater percentage of younger consumers than older ones (54.9% versus 30.9%) lose eligibility because they do not receive any POS funds from their RC.[159] This disparity is not surprising in light of the Lanterman Act's mandate that regional centers act as payers of last resort.[160] Until they age out of public education (typically at age 22[161]), many consumers with I/DD are served exclusively by their school systems and receive no POS. Moreover, several types of POS that disproportionately affect school-age consumers—such as respite care, behavioral health therapy, occupational therapy, and habilitation/work activity programs—have been curtailed or eliminated entirely through legislative enactments and/or changing institutional norms.[162]

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[159] E-mail from Jason Scott (July 2, 2018), *supra* 158 (data were presented as Microsoft Excel attachments to e-mails received form DDS in response to PRA requests from years 2009 to 2017).

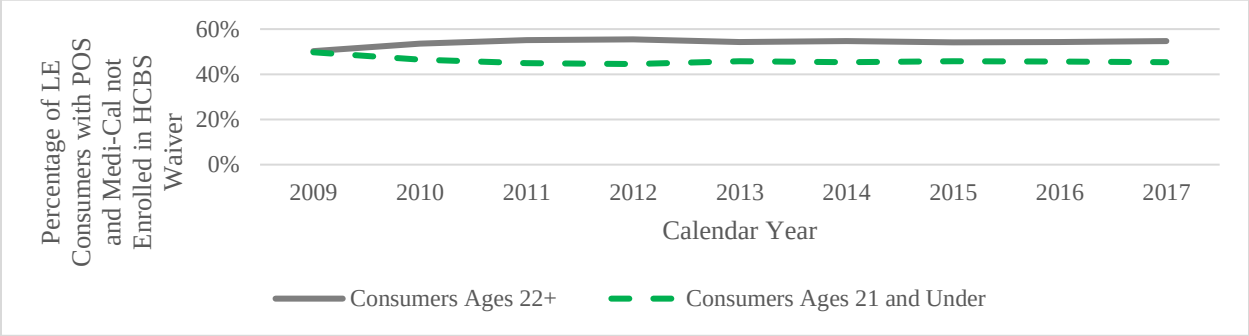
[160] LANTERMAN ENTITLEMENT REPORT, *supra* note 127, at § V.C. (discussing state's role as payor of last resort and duty to exhaust generic resources).

[161] 15TH FACT BOOK, *supra* note 35, at 42 (noting that "average per capita cost of consumers with each developmental disability category increases considerably after age 21…when Department of Education-funded services are no longer available, and out-of-home placement and day services are needed").

[162] There are at least four separate POS categories that are either underutilized by young consumers at RCs, or whose availability to minor consumers has been curtailed over time: respite care; behavioral health care (including Applied Behavior Analysis); non-behavioral therapies such as occupational therapy, physical therapy, and speech pathology; and habilitation/vocational services. During the Great Recession, the legislature imposed strict limitations on respite care, which became practically unavailable for young consumers, *see* Law of July 28, 2009, ch. 9, § 20, 2009 Cal. Legis. Serv. 4th Ex. Sess. 5168–69 (revised CAL. WELF & INST CODE § 4686.5 in 2009 but since repealed). Although these statutory restrictions have since been repealed, *see* Law of July 10, 2017, ch. 65, § 1, 2017 Cal. Legis. Serv. 1757–58 (West) (repealed CAL. WELF & INST CODE § 4686.5 in 2017), our conversations with stakeholders suggested that the provision of respite services has not been restored to previous levels. See generally Memorandum from Brian Winfield, Deputy Dir., Cal. Dep't Developmental Servs., Comm. Servs. Div., to Reg. Ctr. Exec. Dirs. 1 (Aug. 3, 2017), https://www.dds.ca.gov/SupportSvcs/docs/respiteCapRepeal8317.pdf (last visited May 8, 2019), for a summary of legislative changes. The second type of POS whose provision to younger consumers has greatly diminished is behavioral health treatment (BHT) services, especially applied behavioral analysis (ABA). A 2012 state law required "health care service plan contracts and health insurance policies to provide coverage for behavioral health treatment for individuals with autism or other pervasive developmental disorders," *see* Law of Oct. 9, 2011, ch. 650, § 1, 4, 2011 Cal. Legis. Serv. 5277 – 5279, 5281 – 5283 (West) (codified at CAL. HEALTH & SAFETY CODE § 1374.73 and CAL. INS. CODE § 10144.51); *see also* DISABILITY RIGHTS CAL., WHAT DOES SB 946 (WHICH REQUIRES PRIVATE HEALTH PLANS TO PROVIDE SOME SERVICES FOR PEOPLE WITH AUTISM) MEAN FOR ME? 1 (Nov. 2014), https://www.disabilityrightsca.org/system/files/file-attachments/F07101.pdf (last visited May 9, 2019). As a result, RCs cannot provide ABA to young consumers on Medi-Cal managed care plans unless the consumer can prove that "Medi-Cal, private insurance, or a health care service plan has denied the behavioral service and the regional center decides that an appeal would have no merit," *see id.* at 8; *see also* LANTERMAN ENTITLEMENT REPORT, *supra* note 127, at § IV.E. (noting Medi-Cal managed care plan consumers must "appeal a denial or change in BHT services directly with their [managed care plan]"). Fee-for-service consumers, however, can still receive ABA directly from RCs, *see id*. Third, statutory amendments enacted in 2009 restricted RCs' "authority to purchase…educational services for children three to 17, inclusive, years of age," *see* CAL. WELF. & INST CODE § 4648.5(a)(a)(3)(2019). Whether this amended statute relieves regional centers of the obligation to pay for supplemental supportive services ordinarily provided by public school districts—such as occupational therapy, physical therapy, and speech pathology—has become a significant point of contention. On one hand, supportive services are arguably "educational" in that they are ordinarily provided by public school districts, *see* 20 U.S.C. § 1401(26)(A) (defining "related services" so as to include "speech-language pathology...physical and occupational

Finally, as shown in Figure 5 (below), consumers with Medi-Cal and POS who do *not* enroll in the HCBS Waiver are about equally split between older and younger consumers, although the former group slightly predominates.

Figure 5: Percentage of Lanterman-Eligible Consumers with POS and Medi-Cal Not Enrolled in HCBS Waiver, by Age Group[163]



therapy"); *see also* 20 U.S.C. § 1400(c)(5) (noting that to the maximum extent possible, education, special education, and related services should be provided to children with disabilities in a regular classroom). On the other hand, the Welfare and Institutions Code defines "services and supports for persons with developmental disabilities" to include "physical, occupational, and speech therapy, training, education," *see* Cal. Welf. & Inst. Code § 4512(b) (2019). The fact that "education" is enumerated separately from the other forms of therapy arguably implies that the latter are *not* a subset of the former. To date, administrative law judges have split on the question of whether supplemental supportive services are "educational," and as such, barred from the scope of allowable services unless an exception is granted, *compare* Claimant v. Kern Regional Center, Case No. 2013070430, at 8 (OAH 2014) (on file with authors) (holding that speech and language services and occupational therapy are not restricted educational services), *with* Claimant v. San Diego Regional Center, Case No. 2017090782, at 8 (OAH Nov. 29, 2017) (on file with authors) (holding that speech therapy is a restricted educational service but an exception is warranted in this case), *and* Claimant v. North Los Angeles County Regional Center, Case No. 2018060240, at 8–9 (OAH 2018) (on file with authors) (holding that occupational therapy and language and speech services are restricted educational services but a limited exception is warranted in this case). Finally, with reference to habilitation/vocational services, amendments to the Welfare & Institutions Code enacted in 2011 mandated that "a regional center shall not purchase day program, vocational education, work services, independent living program, or mobility training and related transportation services for a consumer who is 18 to 22 years of age… unless the individual program plan (IPP) planning team determines that the consumer's needs cannot be met in the education system or grants an exemption," *see* CAL. WELF. & INST CODE § 4648.55(a) (2019); *see also* DISABILITY RIGHTS CAL., SPECIAL EDUCATION INSTEAD OF ADULT SERVICES FOR CONSUMERS Age 18-22 3 (Aug. 2018), https://www.disabilityrightsca.org/system/files/file-attachments/F05001.pdf (last visited May 9, 2019). As a result of this provision, RCs have generally declined to provide habilitation and vocational program POS to young consumers.

[163] These data encompass the period from 2009 to 2017, *see* e-mail from Jason Scott (July 2, 2018), *supra* note 158.

VII. Participatory Re-Design

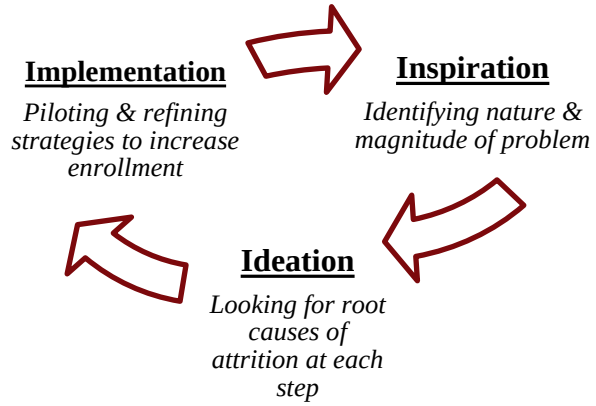
In the preceding sections, we examined in detail the six steps of the Federal Match Eligibility Pathway. We sought to quantify the amount of attrition occurring at each step and its likely fiscal impact, although the data permitted us to do so only for the HCBS Waiver, not the 1915(i) SPA program. Finally, we speculated about its possible causes.

In this section, we suggest concrete strategies that DDS could use to better understand why particular groups of consumers are not progressing through the Federal Match Eligibility Pathway and how the state might deploy that information to increase its uptake of federal funds.

A. Overview

To ensure that as many consumers as possible complete the Federal Match Eligibility Pathway, we suggest that DDS implement a participatory re-design process that treats consumers and other stakeholders as co-designers to identify areas for improvement.[164] Figure 6, below, shows the three stages of the participatory re-design process.

Figure 6: Participatory Re-Design Cycle[165]



The goal of the first stage (Inspiration) is to explore the nature and scope of the problem by identifying which consumers are not, but likely could be, enrolled in federally matched programs. The second stage (Ideation) is designed to elicit information from diverse stakeholders about the root causes of the problem, i.e., existing barriers to increasing enrollment. To avoid (real or perceived) inequities in implementation, it is critical that information be solicited from diverse groups of stakeholders (consumers, families, RCs, vendors, and providers). The third

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[164] LUCY KIMBALL, APPLYING DESIGN APPROACHES TO POLICY MAKING: DISCOVERING POLICY LAB 65 (2015) (Participatory, design is "based on the idea of involving people who would be the future users of a new system in its design . . . They become co-researchers and co-designers exploring and defining the issue and generating and prototyping new ideas").

[165] Tim Brown, *Design Thinking*, HARV. BUS. REV., June 2008, at 88–89.

stage (Implementation) involves the prototyping of potential interventions, testing of prototypes among diverse users, and incorporation of feedback to refine the interventions.

During the first stage of the process, it would be helpful for DDS to create a detailed "Federal Match Eligibility Attrition Flowchart" indicating how many consumers are completing each step of the Federal Match Eligibility Pathway. Figure 4, discussed earlier, presents this information for the state as a whole based on (incomplete) information from 2017. To improve and build on this approach, it would be helpful for each RC to create a similar flowchart, using more comprehensive data, that breaks down not only the *number* of consumers who drop out at each step, but also the (actual or likely) *reasons* why these consumers do not proceed to the next step, for both the HCBS Waiver and the 1915(i) SPA. Generating such flowcharts at the statewide and RC levels will facilitate the development of creative strategies to boost the proportion of consumers that enroll in federally-matched programs.

Table 7: Participatory Re-Design Approach to HCBS Waiver & 1915(i) SPA Enrollment[166]

Step on Pathway	**Inspiration*: Identify scope of problem***	**Ideation*: Identify Root Causes***	**Implementation*: Develop strategies to solve the problem***
Step 2: Certification of Community Residence	*How many consumers could receive HCBS Waiver/1915(i) SPA funds if they lived in community, and how many living in community comply with Final Settings Rule?*	Survey consumers & families on community living options; research barriers to community placement	Prototype strategies to increase community living and increase Final Settings Rule compliance among those living in community; prototype & refine strategies based on diverse stakeholder feedback
Step 3: Enrollment in Full-Scope, Federally-Matched Medi-Cal	*How many consumers could become eligible for HCBS Waiver/1915(i) SPA funding if they enrolled in FSFM Medi-Cal?*	Survey consumers on reasons for not enrolling in Med-Cal; interview RCs on challenges in assisting with enrollment process	Workshop with stakeholders on strategies to streamline Medi-Cal enrollment & increase take-up; prototype & refine strategies based on diverse stakeholder feedback
Step 4: Receipt of at Least One Qualifying Purchase of Service	*How many consumers could become eligible for HCBS Waiver/1915(i) SPA funding if they received one POS?*	Assess POS options in community and barriers to including them in IPP; conduct vendor focus groups in efforts to expand POS options	Workshop with stakeholders on strategies to increase availability & take up of qualifying POS options; prototype & refine strategies based on diverse stakeholder feedback
Step 5: Fulfillment of Level of Care Requirement	*How many consumers could become eligible for HCBS Waiver/1915(i) SPA funding if they met the level of care (LOC) requirement?*	Assess whether, and if so why, any consumers are not meeting LOC requirement.	Workshop with stakeholders on strategies to clarify & simplify IID LOC certification; prototype & refine strategies based on diverse stakeholder feedback
Step 6: Enrollment in 1915(i) SPA or HCBS Waiver	*How many consumers could enroll in the HCBS Waiver/ 1915(i) SPA if they gave consent &/or their service coordinator completed the necessary paperwork?*	Interview consumers, families, and service coordinators on barriers to HCBS Waiver enrollment	Workshop with stakeholders on ways to increase enrollment; prototype & refine strategies with diverse stakeholder input.

[166] *See* Brown, *supra* note 165, at 88–89.

Table 7, above, describes how the participatory re-design approach could be used to increase HCBS Waiver and/or 1915(i) SPA enrollment. For each step, the goal would be to quantify the level of attrition occurring among different groups of consumers; identify its root cases; prototype concrete interventions to overcome it; and improve these interventions with stakeholder feedback. It would be vital to include all key stakeholders–such as consumers and their families, service coordinators, and vendors–at each stage to increase the odds of success.

B. An Illustration

To make the preceding discussion more concrete, it is helpful to zero in on a single step of the Federal Match Eligibility Pathway and envision the sorts of insights that a participatory re-design process might produce. Since FSFM Medi-Cal enrollment functions as such a critical gatekeeper for eligibility for both the HCBS Waiver and 1915(i) SPA programs, we focus on this step (Step 3) of the Federal Match Eligibility Pathway for illustrative purposes.

Table 6, discussed above, reveals that RCs differ in the percentage of consumers who are Lanterman Act eligible and reside in the community, yet are not enrolled in Medi-Cal.[167] The wide variation across RCs suggests that the level of FSFM Medi-Cal uptake is very likely amenable to policy intervention. This does not mean that increasing FSFM Medi-Cal enrollment is equally difficult, or poses the same set of challenges, in all regions. As is clear from Figure 3A and Figure 3B, the difficulty of navigating different pathways to FSFM Medi-Cal eligibility varies widely by consumer demographics (especially age, income, and immigration status) that can differ significantly across RCs. Nevertheless, as is equally clear from Figure 3A and Figure 3B, many consumers whose demographic characteristics initially preclude them from FSFM Medi-Cal enrollment, with the salient except of undocumented immigrants, can become eligible by utilizing special procedures.

The following strategies, although tentative and preliminary, exemplify the types of concrete proposals that might be considered, piloted and refined though a participatory re-design process.

(1) *Publicizing Benefits of IHSS Eligibility*

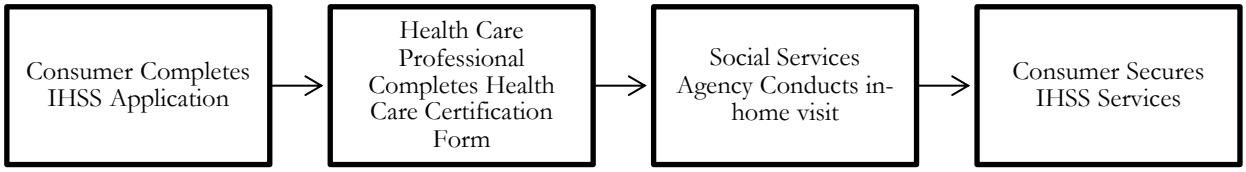
Our conversations with stakeholders suggest that some consumers and family members perceive the paperwork associated with Medi-Cal as unduly burdensome, without conferring any financial advantages. As a result, unless RC personnel insist that families complete Medi-Cal paperwork as a prerequisite to receiving RC services–which most service coordinators, understandably, are reluctant to do–it may be difficult to secure families' active cooperation in the Medi-Cal enrollment process. Such cooperation may be particularly difficult to obtain among relatively affluent families whose children are covered by private insurance.

[167] As noted earlier, our data cannot distinguish between consumers enrolled in FSFM Medi-Cal and consumers enrolled in Medi-Cal funded exclusively through the state's General Fund, *see supra* note 56 and accompanying text.

One way to increase families' motivation to collaborate in the Medi-Cal enrollment process could be to highlight the financial benefits of enrollment in In-Home Supportive Services (IHSS), for which Medi-Cal enrollment is a prerequisite. IHSS funds up to 283 hours per month of personal care services (bathing, toileting, dressing, feeding, etc.), related services (meal preparation, planning and cleanup, laundry and food shopping), paramedical services if prescribed by a doctor (injections, catheters, tube feeding, suctioning), and protective supervision (24-hour monitoring and supervision to prevent injury) to qualifying consumers.[168] It is available to residents with disabilities who receive Medi-Cal, live at home or in a non-licensed, non-institutional setting, and submit completed Health Care Certification forms.[169] In order to access RC supportive services, consumers must demonstrate that they cannot receive the same services through IHSS.[170]

As shown in Figure 7, below, the IHSS enrollment process is itself somewhat burdensome. In addition to completing the initial paperwork, the consumer must arrange for a social service agency representative to conduct a home visit.

Figure 7: IHSS Eligibility Process Chart[171]



To mitigate some of the logistical burden imposed on families and ensure that they receive all of the IHSS support to which they are entitled, RCs can submit alternative documentation justifying the need for IHSS hours,[172] or even arrange for a service coordinator to be present during the IHSS home visit.

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[168] *See In-Home Supportive Services (IHSS): The Details*, DISABILITY BENEFITS 101, https://ca.db101.org/ca/programs/health_coverage/medi_cal/ihss/program2b.htm (last visited Jan. 18, 2019).

[169] CAL. HEALTH & HUMAN SERVS. AGENCY, APPLICATION FOR SOCIAL SERVICES 1, http://www.cdss.ca.gov/cdssweb/entres/forms/English/SOC295.pdf (last visited Jan. 18, 2019) (IHSS application); *see also* CAL. HEALTH & HUMAN SERVS. AGENCY, IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM: HEALTH CARE CERTIFICATION FORM, http://www.cdss.ca.gov/cdssweb/entres/forms/English/SOC873.pdf (last visited Jan. 18, 2019).

[170] *See* LANTERMAN ENTITLEMENT REPORT, *supra* note 127, at § V.C.; *see also* CAL. WELF. & INST. CODE § 4689.05 (2019); *see also id.* § 4659(c) ("[N]otwithstanding any other law or regulation, regional centers shall not purchase any service that would otherwise be available from . . . In-Home Supportive Services . . . when a consumer or a family meets the criteria of this coverage but chooses not to pursue that coverage").

[171] CAL. DEP'T SOC. SERVS., OVERVIEW OF THE IHSS PROGRAM 2 (2017), http://www.cdss.ca.gov/Portals/9/Documents/IHSS%20Overview%20FINAL-2.9.17.pdf?ver=2017-03-08-150254-537 (last visited Jan. 19, 2019).

[172] IHSS regulations specify that county social services departments "shall accept alternative documentation in place of" a health care certification, which is meant to "[i]ndicate that the applicant is unable to independently perform one or more activities of daily living; [i]ndicate that without services to assist the applicant with activities of daily living, the applicant is at risk of placement in out-of-home care; [p]rovide a description of any condition or functional limitation…[and b]e signed by a LHCP-HCC [Licensed Health Care Professional for the purposes of signing the Health Care Certification]," *see* CAL. DEP'T SOC. SERVS., MANUAL LETTER NO. SS-16-02, IN-HOME

RCs could also do more to make families aware of the significant financial benefits that come with IHSS enrollment. Although IHSS pay rates are typically only slightly higher than minimum wage, no specialized training is required to become a provider.[173] Therefore, some consumers (or their caregivers) can arrange for immediate family members, friends, or extended family to be compensated for care that they already provide. It should be noted that special restrictions apply to parents who provide care to their minor children, making IHSS enrollment somewhat more complex in such situations.[174] Nonetheless, for consumers with significant needs, family members who provide extensive support can potentially parlay IHSS enrollment into several thousand dollars of extra income per month.[175]

A systematic campaign to more effectively "market" the benefits of IHSS to families, characterizing it as a valuable benefit of Medi-Cal enrollment, could induce more families—even those who carry private insurance—to pursue Medi-Cal enrollment.[176]

SUPPORTIVE SERVICES 61.1a – 61.1c (Oct. 1, 2016), http://www.cdss.ca.gov/ord/entres/getinfo/pdf/mlSS1602.pdf (last visited May 28, 2019). One type of acceptable alternative documentation is a consumer's "Individual Program Plan, which is an agreement developed by the planning team for a developmentally disabled individual who receives Regional Center Services, that outlines the individual's goals and objectives, and specifies the services and supports he/she will need to achieve them," *see id.* We are aware of at least two instances in which RCs (Harbor RC and Westside RC) submitted independent needs assessments, conducted by RC personnel, to IHSS describing in detail the need for particular types of support, *see, e.g.*, HARBOR REG'L CTR., NURSING ASSESSMENT FOR [NAME REDACTED] (Jan. 21, 2009) (on file with authors); *see also, e.g.*, WESTSIDE REG'L CTR., WHOLE PERSON ASSESSMENT FOR [NAME REDACTED] (July 18, 2003) (on file with authors).

[173] Undocumented persons and persons with felony convictions are ineligible.

[174] *See In Home Supportive Services (IHSS) Alert: IHSS parent providers of minor children*, DISABILITY RIGHTS CAL., https://www.disabilityrightsca.org/post/in-home-supportive-services-ihss-alert-ihss-parent-providers-of-minor-children (last visited Jan. 18, 2019) (stating to qualify as an IHSS provider, the parent of a minor child must have "left full-time employment or [be] prevented from obtaining full-time employment because no other suitable provider is available and the inability of the parent to perform supportive services may result in inappropriate placement or inadequate care," where "full-time employment" is defined as at least 40 hours per week). Moreover, regardless of who provides the support, special eligibility requirements apply to minor children, *see In-Home Supportive Services (IHSS) Program*, CAL. DEP'T SOC. SERVS., https://www.cdss.ca.gov/IHSS-for-Children (last visited January 18, 2019) (listing various eligibility restrictions that apply to minor children).

[175] As of this writing, IHSS rates are around $12 in most counties, *see County IHSS Wage Rates*, CAL. DEP'T SOC. SERVS., https://www.cdss.ca.gov/inforesources/IHSS/County-IHSS-Wage-Rates (last visited Jan. 24, 2019) (click "County Individual Provider Wage Rates" to see the IHSS rate in MS Excel format). However, a law that went into effect in 2016 entitles IHSS care providers to earn overtime (time and a half) for all hours over 40 per week, as long as they do not exceed 66 total hours per week for all recipients, *see* CAL. DEP'T SOC. SERVS., IMPORTANT INFORMATION FOR THE IN-HOME SUPPORTIVE SERVICES PROVIDER 2, https://www.cdss.ca.gov/cdssweb/entres/forms/English/TEMP3001.pdf (last visited Jan. 24, 2019). Moreover, IHSS income earned by providers for care they provide to individuals living in their home is excluded from gross income, *See In Home Support Services (IHSS)*, STATE OF CAL. FRANCHISE TAX BD., https://www.ftb.ca.gov/aboutFTB/newsroom/IHSS.shtml (last visited January 24, 2019). Thus as long as an individual with I/DD is authorized to receive at least 264 hours of care per month, his or her family member can earn approximately $3,800 per month in after-tax income for providing approximately 66 hours per week of in-home care.

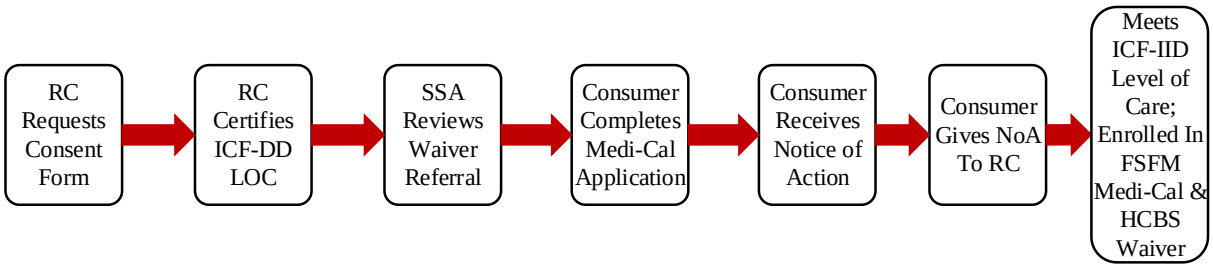
[176] Consumers might also be informed that in cases where there is potential concern about a consumer's quality of care, IHSS' Quality Assurance procedures require unannounced visits conducted by CDSS officials, *see What In-Home Supportive Services Recipients Should Know About Home Visits*, DISABILITY RIGHTS CAL. (July 2, 2018), https://www.disabilityrightsca.org/publications/what-in-home-supportive-services-recipients-should-know-about-home-visits (last visited Apr. 11, 2019). Although these visits are not announced in advance, they are not random

(2) *Increasing Use of Institutional Deeming*

Another way to enroll more consumers in FSFM Medi-Cal and the HCBS Waiver would be to strengthen more affluent families' motivation to undergo institutional deeming. The institutional deeming process allows Lanterman-eligible consumers who reside in the community and have at least one qualifying POS (i.e., those who have completed steps 1, 2, and 4) to complete the three remaining steps of the Federal Match Eligibility Pathway simultaneously.[177] In effect, institutional deeming allows a CDSS to ignore parental income (or a portion of spousal income) in assessing a consumer's financial eligibility for FSFM Medi-Cal, as long as the consumer does not hold significant assets or income in his/her own name.

Yet as shown in Figure 8, below, institutional deeming is a cumbersome process. Interested consumers must complete a great deal of paperwork at the outset, and must complete more forms (and undergo a reevaluation) every year to preserve their eligibility. Moreover, in some counties, families are required to submit their tax returns with their applications, even though family income has no bearing on their eligibility determination.

Figure 8: The Institutional Deeming Approach to Achieving Medi-Cal Eligibility[178]



Because under state law, a consumers' entitlement to the services and supports contained in the IPP is *not* contingent on the state's capacity to obtain federal matching funds, middle- and upper-income families may feel little incentive to undergo the institutional deeming process.

Here again, an important goal should be to educate more affluent families on the full range of benefits that accrue to Medi-Cal recipients. Although special restrictions apply to minors (particularly if their parents are the ones applying to become providers), the availability of IHSS might nevertheless provide some inducement even to relatively well-off families who spend

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because the visits must be prompted by an "articulable program integrity concern" or "some concern about the receipt or quality of recipient's services, recipient's wellbeing, or other program integrity concerns," *see id.*

[177] LANTERMAN REG'L CTR., OBTAINING MEDI-CAL COVERAGE FOR YOUR CHILD THROUGH INSTITUTIONAL DEEMING 1 (2010), https://lanterman.org/uploads/lntrmn_med_waiver_eng_final_aug2010.pdf (last visited Jan. 19, 2019) (noting requirements for institutional deeming).

[178] DISABILITY RIGHTS CAL., THE MEDI-CAL DEVELOPMENTAL DISABILITY WAIVER 13-6-13-7 (Dec. 1, 2012), https://www.disabilityrightsca.org/system/files?file=file-attachments/506301Ch13.pdf (last visited Jan. 19, 2019).

significant hours each month supporting family members with I/DD.[179] Moreover, even for families that carry private insurance, access to Medi-Cal as a secondary insurer can prove financially advantageous. Not only does Medi-Cal sometimes cover costs that are not covered by private insurance plans,[180] but physicians are statutorily banned from "balance billing" Medi-Cal recipients for the difference between Medi-Cal's rates and the rates charged to private-pay clients.[181] Yet another benefit of institutional deeming for more affluent families is waiver of the Family Cost Participation Program (FCPP) fee[182] and the Annual Family Program fee.[183] As of April 1, 2019, the FCPP requires parents who earn more than four times the federal poverty level to pay 10% of the cost of respite, day care, and camping services received from RCs, and requires parents earning more than ten times the FPL to pay the entire cost.[184] Being freed from such cost-sharing responsibilities could be a significant motivation for some families.[185] The state also could appeal to families' sense of civic duty by stressing that FSFM Medi-Cal enrollment strengthens the I/DD System as a whole by saving state resources.[186] In short, even

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[179] *See supra* Section VII.B.(2); *see also* DISABILITY RIGHTS CAL., *IHHS Alert*, *supra* note 174.

[180] Conversation with Nurse Advocate, Blue Shield Cal. (Sept. 14, 2018) (Blue Shield, like many other private insurers, does not cover medical transport from an individual's residence to a hospital for non-emergency care. For example, a developmentally disabled individual with diabetes who required medical transport to a hospital for regular dialysis treatments would rarely, if ever, receive reimbursement through private insurance. Non-emergency medical transport from an individual's residence to a hospital is, however, a benefit that can be covered by Medi-Cal).

[181] *See Reminders Regarding Third-Party Liability Billing*, CAL. DEP'T HEALTH CARE SERVS., http://files.medi-cal.ca.gov/pubsdoco/newsroom/newsroom_22055_01.asp (last visited Jan. 19, 2019) (noting that for a Medi-Cal provider to "attempt to obtain payment from Medi-Cal recipients [above the authorized copayment amount] for the cost of Medi-Cal covered health care services" is a violation of state law); *see also* Elizabeth Davis, *Balance Billing - What It Is and How It Works*, VERYWELL HEALTH (May 2, 2018), https://www.verywellhealth.com/balance-billing-what-it-is-how-it-works-1738460 (last visited Jan. 18, 2019) (explaining that balance billing is generally illegal if the patient is a Medicaid recipient using a health care provider that either accepts Medicaid assignment, or has an agreement with Medicaid).

[182] *See* CAL. DEP'T DEVELOPMENTAL SERVS., FAMILY COST PARTICIPATION PROGRAM GUIDE, https://www.dds.ca.gov/FCPP/Docs/BestTranslations_Pamphlet.pdf (last visited July 5, 2019) (detailing the FCPP fee); *see also* FRANK D. LANTERMAN REG'L CTR., *supra* note 177, at 1 (noting that if a child receives Medi-Cal through institutional deeming, his/her family will be exempted from having to pay the FCPP fee).

[183] *See Annual Family Program Fee*, CAL. DEP'T DEVELOPMENTAL SERVS. (June 5, 2019), https://www.dds.ca.gov/AnnualFamilyProgram/ (last visited July 5, 2019) (detailing the AFP fee); *see also* Harbor Reg'l Ctr., A Guide to the Annual Family Program Fee (Sept. 2015), http://www.harborrc.org/files/uploads/G00145.pdf (last visited July 5, 2019) (noting that if a child receives Medi-Cal through institutional deeming, his/her family will be exempted from having to pay the AFP fee).

[184] *See* FAMILY COST PARTICIPATION PROGRAM GUIDE, *supra* note 182, at 4.

[185] As a practical matter, the FCPP has become less pertinent since 2009, because Great-Recession-era budgetary cuts to programs such as camping and social recreation have yet to be reinstated, *see* LANTERMAN PRIMER, *supra* note 52, at § IV.B; *see also* LANTERMAN ENTITLEMENT REPORT, *supra* note 127, at § VI.B.1. The prospect of being exempted from FCPP-imposed cost-sharing responsibilities would become a far more significant financial inducement if these programs were fully reinstated.

[186] Technically, institutional deeming comes with two other benefits, assignment to a service coordinator with a slightly lower caseload and review of the IPP on an annual rather than triennial basis, *see* CAL. WELF. & INST. CODE § 4640.6(c)(3) (2019). However, these are unlikely to be perceived as significant benefits. Many RCs are already out of compliance with service coordinator caseload requirements, and even if they were in compliance, institutional deeming would only reduce the caseload by four consumers. Since any RC consumer can convene an emergency IPP within 30 days, regardless of whether (s)he has been institutionally deemed, it not clear that IPP review on an

for families with significant means, marketing the many benefits of institutional deeming could provide a sufficient inducement to complete the process.

If showcasing these benefits proves insufficient, DDS could consider taking more proactive steps to increase the prevalence of institutional deeming. To reduce the time cost for families, for example, DDS could train RC personnel to assist families in completing the initial paperwork, or use the data already collected to auto-populate portions of the IHSS Application upon receipt of the Medi-Cal Notice of Action. To reduce the emotional/social costs cost, the legislature could prohibit CDSSs from demanding that families submit full income tax returns with their institutional deeming applications[187], and work to eliminate psychological barriers such as the perceived stigma of a family member receiving "welfare" or being deemed appropriate for institutional care. The state might even try a "peer to peer" system whereby families that have already completed the process are finally rewarded for helping other families enroll.[188] Some of

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annual basis confers any additional advantage; in fact, some families may view it as a burden, *see* CAL. WELF. & INST. CODE § 4646.5(b) (2019) (granting right to emergency IPP within 30 days).

[187] As discussed earlier, institutional deeming is supposed to be a method of last resort for enrolling in FSFM Medi-Cal in cases where the consumer does not qualify for other eligibility categories. To assess families' eligibility for other, means-tested programs, the CDSS must have the capacity to analyze information on each applicant's assets and level of income. Yet it is not necessary for applicants to submit a full income tax return to accomplish this goal. Applicants could instead be asked to attest to the amount of income they received in the prior month, and the accuracy of this self-attested amount could be cross-checked against the information contained in California's Healthcare Eligibility, Enrollment and Retention System (CalHEERS) database, which is already used to verify a consumer's income tax data from federal sources, *see generally* CAL. DEP'T HEALTH CARE SERVS, CALIFORNIA HEALTHCARE ELIGIBILITY, ENROLLMENT AND RETENTION SYSTEM (CALHEERS) ONLINE SINGLE STREAMLINED APPLICATION 15, https://www.dhcs.ca.gov/formsandpubs/laws/Documents/SPA%2013-022%20California%20Healthcare%20Eligibility,%20Enrollment%20and%20Retention%20System%20DRAFT%20ADA.pdf (last visited July 8, 2019) (requiring consumer's consent for the state to verify income tax data for Medi-Cal enrollment). In Colorado and Washington, for example, self-attestation reportedly has "enabled higher volumes of real-time eligibility determinations, and state audits have found the systems to be operating well as intended," *see* JANE WISHNER ET AL., URBAN INST., MEDICAID REAL-TIME ELIGIBILITY DETERMINATIONS AND AUTOMATED RENEWALS: LESSONS FOR MEDI-CAL FROM COLORADO AND WASHINGTON v–vi (Aug. 2018), https://www.urban.org/sites/default/files/publication/98904/medicaid_real-time_eligibility_determinations_and_automated_renewals_2.pdf (last visited July 8, 2019). Since CalHEERS already enables real-time eligibility determinations, there is no compelling reason why scrutiny of tax returns should be a required step in the institutional deeming process, *see id.* at 35–36 (noting that CalHEERS is used for MAGI Medi-Cal eligibility determinations, and CalHEERS includes real-time verification of income tax data, immigration status, and identity); *see also* Letter from Sandra Williams, Cal. Dep't Health Care Servs., to All Cty. Welf. Dirs. et al. (May 15, 2019), https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/ACWDL/2019/19-14.pdf (last visited July 8, 2019) (noting recent updates to the CalHEERS system). In theory, California could verify a consumer's income *after* (s)he is institutionally deemed, thereby provisionally enrolling the consumer in FSFM Medi-Cal and the HCBS Waiver, *see* WISHNER ET AL., *supra* note 187, at 41 tbl.2 (noting that unlike Colorado and Washington, California does not currently allow for the verification of self-attested income post-determination).

[188] The notion of compensating third parties to assist residents with the process of enrolling in Medi-Cal and other health insurance plans is not entirely unprecedented. As part of the rollout of "Covered California" in the wake of the passage of the Affordable Care Act, the state adopted an Assister and Navigator Program whereby non-governmental entities could be compensated for helping residents with the health insurance enrollment process, *see* ALAMEDA CTY. SOC. SERVS. AGENCY, HEALTH REFORM 101 – CALIFORNIA'S HEALTH EXCHANGE AKA "COVERED CALIFORNIA" 2, http://achealthcare.org/wp-content/uploads/2013/03/HCR-on-Exchange.pdf (last visited July 8, 2019) (section on "What is the Assister and Navigator Program?"). "Assister entities" were "compensated by the [Health] Exchange for successfully enrolling and renewing individuals in Exchange plans during the initial

these strategies could be piloted in one or two regional centers to determine their efficacy before being implemented on a broader scale.[189]

(3) ***Promoting the Use of CalABLE Accounts***

Another potential intervention to increase consumer enrollment in HCBS Waiver or 1915(i) SPA is for RCs to encourage the use of CalABLE Accounts among consumers whose personal assets disqualify them from FSFM Medi-Cal. As discussed earlier, some consumers may be ineligible for Medi-Cal because their assets exceed the SSI asset limit.[190] CalABLE accounts offer a way for even consumers with significant assets to circumvent these barriers. The CalABLE program, which was created by the Legislature in 2015 and went into effect on December 18, 2018,[191] allows persons with I/DD to establish and own "protected" accounts for qualified disability expenses not otherwise covered by healthcare or RCs, such as housing or funeral and burial expenses.[192] Assets stored in such accounts are "protected" in that they are not taken into account when determining a person's eligibility for SSI. Contributions are currently limited to $15,000 per year, with a lifetime cap of $100,000.[193] For many adults with I/DD, the establishment of CalABLE accounts could provide a pathway to SSI benefits, which in turn could facilitate enrollment in Medi-Cal either through SSI-linked Medi-Cal, or through the A&D FPL Medi-Cal program (assuming countable individual income is below 100% of the FPL).

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enrollment period from October 2013 through March 2014 ($58/successful application and $25/successful renewal)," while "navigator entities" were paid "through a block grant" for assisting with outreach to specific groups, *see id.* Before participating in the program, however, both types of entities "[had to] apply to be certified, as only trained enrolled and certified individuals will generate compensation for their certified entities," *see id.*

[189] In theory, the state could deputize RC personnel, instead of CDSS personnel, to make decisions regarding Institutional Deeming. Doing so, however, would raise several practical difficulties. First, deputizing RC personnel to perform these assessments might require an amendment to the state plan authorizing the provision of services under the HCBS Waiver, *see* 2018 APPROVED WAIVER APPLICATION, *supra* note 11**.** Secondly, since many RC staff are already struggling with high caseloads, tasking them with this added responsibility, and providing them with the training necessary to carry it out, would likely require additional resources, *see* LANTERMAN PRIMER, *supra* note 52, at § IV.B. (noting that average RC staff caseloads have dramatically increased over the last decade). Finally, RC personnel might have (or at least be perceived by CMS as having) a conflict of interest, since their own responsibilities could be affected, at least indirectly, by how many consumers (and which ones) are enrolled in Medi-Cal and/or the HCBS Waiver.

[190] See *supra* Figure 3(A), Figure 3(B).

[191] *See About the California Achieving a Better Life Experience (CalABLE) Program*, CAL. STATE TREASURER, http://www.treasurer.ca.gov/able (last visited Jan. 18, 2019) (noting that "the CalABLE Savings Plan opened to the public on December 18, 2018).

[192] CAL. WELF. & INST. CODE § 4875 (2017) (providing that "Qualified disability expenses" are any expenses related to the eligible individual's disability, including education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses).

[193] *See* CAL. STATE TREASURER, FACT SHEET 5 (2019), https://www.treasurer.ca.gov/able/resources/factsheets/factsheet-extensive-en-us.pdf (last visited Jan. 18, 2019) (noting that for CalABLE accounts, "[t]he "maximum yearly contribution limit is currently $15,000" and "[t]he maximum lifetime limit is currently $100,000").

For instance, an adult consumer whose parents deposited $50,000 into an ordinary bank account would have to spend down most of those savings before becoming eligible for SSI. But if the same consumer shifted that $50,000 (over the course of several years) into a CalABLE account, (s)he could become eligible for SSI and, in turn, FSFM Medi-Cal.

In light of the substantial benefits of CalABLE enrollment, both for RC consumers and for the state as a whole, RC case managers should receive training on CalABLE accounts and recommend it to any consumers who are disqualified from SSI eligibility because they hold excessive assets in their own names.

(4) *Assisting Consumers with SSI Appeals*

Since SSI recipients qualify automatically for FSFM Medi-Cal, a fourth potential method to increasing enrollment in FSFM Medi-Cal would be to assist consumers with SSI appeals.[194] To receive SSI, a claimant must prove to the Social Security Administration (SSA) that (s)he meets the SSA's definition of disability for his/her specific condition.

Table 8, below, compares the Lanterman Act definition of disability with the SSA definitions that apply to the two most common specific I/DD diagnoses in California, intellectual disability and autism.[195] These two conditions jointly comprise about 56% of all consumers served by RCs.[196] Notably, the SSA provides separate definitions for minors (under age 18) and adults, while the Lanterman Act provides a single definition for consumers of all ages.

Table 8: Comparison of SSA and Lanterman Definitions of "Disability"

	Age	SSA Definitions	Lanterman Act Definition[197]
Intellectual Disability	18+	"significantly subaverage general intellectual functioning, significant deficits in current adaptive functioning, and manifestation…before age 22. Signs may include, but are not limited to, poor conceptual, social, or practical skills evident in your adaptive functioning"[198]	" 'Developmental disability' means a disability that originates before an individual attains 18 years of age;

[194] Through a Public Records Act request, we requested data on consumers who receive SSI, but DDS replied that they do not currently collect this data.

[195] *See* LANTERMAN PRIMER, *supra* note 52, at 22 fig.3 (listing intellectual disability, autism, "fifth category," cerebral palsy, and epilepsy as the top five unduplicated disability categories in California, excluding the catchall "other" category). We did not find an analog for "Fifth Category" (described by DDS as either "a disability 'closely related to' intellectual disability OR 'requiring treatment similar to' intellectual disability") in the Social Security Administration's disability definitions, *see* DISABILITY RIGHTS CAL., "FIFTH CATEGORY" REGIONAL CENTER ELIGIBILITY (Jan. 2016), https://www.disabilityrightsca.org/system/files/file-attachments/551001_0.pdf (last visited May 8, 2019).

[196] LANTERMAN PRIMER, *supra* note 52, at § III.F. fig.3 (illustrating that in 2016–17, autism comprised 23% and Intellectual Disability comprised 33% of the I/DD consumer population).

[197] CAL. WELF. & INST. CODE §§ 4512(a), (l) (2017).

[198] 20 C.F.R. § Pt. 404, Subpt. P, App. 1, Listing 12.05 (defining "intellectual disorder," which includes "intellectual disability, intellectual developmental disorder, or historically used terms such as 'mental retardation'"); *see*

	Under 18	Both "1. Significantly subaverage general intellectual functioning evident in your cognitive inability to function at a level required to participate in standardized testing of intellectual functioning; and 2. Significant deficits in adaptive functioning currently manifested by your dependence upon others for personal needs (for example, toileting, eating, dressing, or bathing) in excess of age-appropriate dependence."[199] OR "2. Significantly subaverage general intellectual functioning evidenced by a or b: a. A full scale (or comparable) IQ Score of 70 or below on an individually administered standardized test of general intelligence; or b. A full scale (or comparable) IQ score of 71-75 accompanied by a verbal or performance IQ score (or comparable part score) of 70 or below on an individually administered standardized test of general intelligence; and 2. Significant deficits in adaptive functioning currently manifested by extreme limitation of one, or marked limitation of two, of the following areas of mental function: a. Understand, remember, or apply information…b. Interact with others…c. Concentrate, persist, or maintain pace…d. Adapt or manage oneself."[200]	continues, or can be expected to continue, indefinitely; and constitutes a substantial disability for that individual . . . [T]his term shall include intellectual disability, cerebral palsy, epilepsy, and autism . . . [and] disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability, but shall not include other handicapping conditions that are solely physical in nature . . . "Substantial disability" means the existence of significant functional limitations in three or more of the following areas of major life activity . . . (A) Self–care,(B) Receptive and expressive language,(C) Learning,(D) Mobility, (E) Self–direction,(F) Capacity for independent living, (G) Economic self–sufficiency."
Autism Spectrum Disorder	18+	"Medical Documentation of both of the following: 1. Qualitative deficits in verbal communication, nonverbal communication, and social interaction; and 2. Significantly restricted, repetitive patterns of behavior, interests, or activities."[201] AND "Extreme limitation of one, or marked limitation of two, of the following areas of mental functioning…1. Understand, remember, or apply information…2. Interact with others…3. Concentrate, persist, or maintain pace…4. Adapt or manage oneself."[202]	
	Under 18	"for children age 3 to attainment of age 18…Medical documentation of both of the following: 1. Qualitative deficits in verbal communication, nonverbal communication, and social interaction; and 2. Significantly restricted, repetitive patterns of behavior, interests, or activities."[203] AND "Extreme limitation of one, or marked limitation of two, of the following areas of mental functioning…1. Understand, remember, or apply information…2. Interact with others…3. Concentrate, persist, or maintain pace…4. Adapt or manage oneself."[204]	

Taken at face value, the severity criteria required under the Lanterman Act seem no less stringent than those required by the SSA. For example, an adult with autism must have "significant

also Soc. Sec. Admin., *Revised Medical Criteria for Evaluating Mental Disorders*, 81 F.R. 66138–01, 2016 WL 5341732 (Sept. 26, 2016) (effective Jan. 17, 2017).

[199] 20 C.F.R. § Pt. 404, Subpt. P, App. 1, Listing 112.05.A.

[200] *Id.* at Listing 112.05.B.

[201] *Id.* at Listing 12.10.A.

[202] *Id.* at Listing 12.10.B.

[203] *Id.* at Listing 112,10.A.

[204] *Id.* at Listing 112.10.B.

functional limitations" in at least three "areas of major life activity" to qualify for services under the Lanterman Act, while the same individual need only have "[e]xtreme limitation of one, or marked limitation of two…areas of mental functioning" under the SSA definition. It is difficult to envision a consumer who has "significant functional limitations" in at least three areas of major life activity yet lacks "marked limitations" in at least two areas of mental functioning. The Lanterman Act and SSA definitions differ in another salient regard: the SSA explicitly defines each condition, whereas the Lanterman Act does not. Yet since the diagnostic criteria are relatively well established, this difference does not seem likely to be material in most cases.[205]

Overall, then, many consumers whose SSI claims are initially denied are likely to have strong cases on appeal.[206] Although there is a private bar for establishing Social Security eligibility,[207] many consumers and family members may be unwilling (or unable) to hire their own attorneys, especially if they already have access to private health insurance. To facilitate FSFM Medi-Cal enrollment, RCs might consider assisting consumers with SSI appeals, or DDS might consider authorizing client rights advocates (CRAs) to do so. At the very least, RCs could explicitly direct consumers to local clinics or legal aid organizations that might assist with the appeal process.

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[205] While definitions for intellectual disability and autism under the SSA and Lanterman Act differ, both the SSA's definitions and the diagnosis process under the Lanterman Act heavily rely on the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). The SSA's definitions for intellectual disability and autism closely track the American Psychiatric Association (APA)'s definitions for these conditions in the DSM-V, which is developed by physicians and commonly used by physicians when making diagnoses, *compare Neurodevelopmental Disorders*, *in* DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (5th ed. 2013), https://dsm.psychiatryonline.org/doi/abs/10.1176/appi.books.9780890425596.dsm01 (last visited June 5, 2019) (entry for "Intellectual Disability"), *and Neurodevelopmental Disorders*, *in* DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (5th ed. 2013), https://dsm.psychiatryonline.org/doi/abs/10.1176/appi.books.9780890425596.dsm01 (last visited June 5, 2019) (entry for "Autism Spectrum Disorder 299.00 (F84.0)"), *with* 20 C.F.R. § Pt. 404, Subpt. P, App. 1, Listing 12.05, 112.05.B., *and* 20 C.F.R. § Pt. 404, Subpt. P, App. 1, Listing 12.10.B., 112.10.B. While the Lanterman Act definitions for these conditions do not as closely resemble the DSM-V's definitions, the process of determining a consumer's eligibility for regional center services heavily relies on physician expertise and the regional center's collection of consumer diagnostic information based on the DSM-V, *see* RIGHTS UNDER THE LANTERMAN ACT – CHAPTER 2: DEVELOPMENTAL DISABILITIES, *supra* note 134, at 2-3–2-5; *see also* CAL. DEP'T DEVELOPMENTAL SERVS., CDER FIELD MANUAL 17 (Sept. 2015), https://www.dds.ca.gov/CDER/docs/CDERManual_DiagnosticElement.pdf (last visited June 6, 2019) (noting "[d]iagnoses of mental disorders should be made by those persons qualified to utilize the DSM5 set of codes").

[206] An adverse determination can be appealed first to a local administrative law judge, then to the national Appeals Council, and finally to federal court, *see* CAL. WELF. & INST. CODE § 4706(a) (2017); *see also* Gulbransen v. Far Northern Regional Center, No. CIV S–11–1231 JAM DAD PS, 2011 U.S. Dist. WL 2462994, at *3 (E.D. Cal. Jun. 17, 2011).

[207] *See, e.g.*, *Referral Service*, NAT'L ORG. SOC. SEC. CLAIMANTS' REPRESENTATIVES, https://www.nosscr.org/referral-service (last visited January 18, 2019) (detailing online and phone referral service). Attorneys involved in appeals before the Social Security Administration are subject to fee caps: "Section 206 of the Social Security Act limits the fee we authorize under a fee agreement to 25 percent of [the client's] past-due (retroactive) benefits or a maximum dollar amount we set, whichever is less. As of 2018, the maximum is $6000," *see* Soc. Sec. Admin., OMB No. 0960-0810, Instructions for Completing Form SSA-1693 3 (Dec. 2018), https://www.ssa.gov/forms/ssa-1693.pdf (last visited Apr. 30, 2019).

(5) *Helping Adult Consumers Enroll in FSFM Medi-Cal*

A final intervention that could increase FSFM Medi-Cal enrollment would be for RCs (or other stakeholders) to proactively help adult consumers navigate circuitous regulatory pathways to FSFM Medi-Cal enrollment. Since 81.7% of Lanterman-eligible consumers living in the community are already enrolled in FSFM Medi-Cal, the number who are eligible but have not yet enrolled may be relatively small. Moreover, it may include some undocumented residents who are categorically disqualified. Nevertheless, an appreciable number of potentially Medi-Cal-eligible consumers may not have enrolled because some potential pathways to enrollment were not fully explored.

As illustrated earlier in Table 2, Figure 3A and Figure 3B, there are numerous potential pathways to FSFM Medi-Cal eligibility for citizens and green card holders. Yet individuals who are eligible for the more complicated SSA-linked programs—e.g., SSI 1619(d), A&D FPL, ABD-MN, and 250% WDP—may not receive the Medi-Cal benefits to which they are entitled because the CDSS fails to recognize and certify their eligibility under these programs. As noted earlier, consumers who do not quality in the first instance for MAGI-linked, SSI-linked, Pickle-type, or Alternative SSA Medicaid Programs may be able to utilize institutional deeming, cafeteria plans, and/or CalABLE accounts to meet the applicable income requirements.[208]

DDS and regional centers could pilot different programs to increase Medi-Cal enrollment among eligible consumers. These might include the provision of extra service coordinator training, assistance from Clients Rights Advocates, peer-to-peer programs, or referrals to legal service organizations.[209]

(6) *Mitigating Adverse Effects of Medi-Cal Recoupment Provisions*

As discussed earlier,[210] Medicaid recoupment provisions can have the unintended consequence of penalizing certain consumers for enrolling in Medi-Cal. Although these provisions may come into play less often in the educational context since the passage of the Affordable Care Act, they can still impose financial penalties on RC consumers who settle tort claims, and reduce the estates of individuals who receive FSFM Medi-Cal benefits before their death. It is possible that some RC consumers, especially those with private health insurance, have *already* been deterred from enrolling in FSFM Medi-Cal for fear that one of these provisions could harm their family's financial interests. Yet the vast majority of RC consumers are likely unaware of these risks. Although RCs have an ethical obligation to inform consumers that Medi-Cal enrollment carries risks as well as benefits, clearer messaging on this issue could have unintended consequence of lowering rates of Medi-Cal enrollment.

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[208] *See supra* Section V.C. (discussing multiple pathways to FSFM Medi-Cal enrollment and methods to reduce barriers to FSFM Medi-Cal eligibility).

[209] The CalHEERS system could facilitate this process by confirming self-attested income in an at least partly automated fashion, *see supra* note 187 and accompanying text; *see also* JANE WISHNER ET AL., *supra* note 187, at vii (noting that CalHEERS could be used for enrollment in multiple benefit programs beyond Medi-Cal in California).

[210] *See id.* (discussing Medicaid recoupment provisions).

To mitigate the risk that consumers are financially harmed enrolling in Medi-Cal, as well as the risk that informing consumers of this risk will lower Medi-Cal enrollment (and in turn federal matching dollars), the state could take proactive steps to shield RC consumers from Medi-Cal recoupment provisions. For example, the state could exempt at least some RC consumers from the scope of these provisions, or agree to indemnify certain RC consumers for the financial harm they cause.[211]

[211] *See supra* section V.C. (discussing Medicaid recoupment provisions). Waiving the Medicaid recoupment provisions under certain circumstances, or for certain types of consumers, is not unprecedented. For example, in 2002, the state granted a waiver of claims due to IHSS receipt under its Estate Recovery program, *see* Letter from Richard Brantingham, Acting Chief, Medi-Cal Eligibility Branch, Cal. Dep't Health Servs., to All Cty. Welf. Dirs. et al. 3 (June 18, 2002), https://www.dhcs.ca.gov/services/medi-cal/eligibility/Documents/c02-35.pdf (last visited June 5, 2019); *see also* CAL. CODE REGS. tit. 22, § 50963 (2019) (outlining "Substantial Hardship Criteria" for a hardship waiver under the California Estate Recovery program).

VIII. Enhancing Long-Term Stability of the Regional Center System

Although in the short term increasing drawdown of Medicaid matching funds might reduce the fiscal burden on the state, it is not difficult to imagine scenarios in which, over the long term, it could undermine the stability of the system as a whole. For example, if the state responded by reducing General Fund expenditures, DDS's budget could become more vulnerable to any future cutbacks in Medicaid funding. If such cutbacks were to occur in the midst of a broad economic downturn, the legislature might be reluctant to make up the budgetary shortfall. In light of these political realities, it is critical to ensure that recouping more federal matching funds does not compromise the I/DD system's capacity to withstand systemic risk.

Additionally, although not the focus of this report,[212] the scarcity of affordable housing has become a significant barrier to supporting Lanterman Act beneficiaries. Federal regulations prohibit HCBS Waiver and 1915(i) SPA funding from being used to cover room or board.[213] Yet in many areas of the state, the income that RC consumers receive from other social service programs (such as SSI[214] and Social Security Disability) is insufficient to cover market-rate housing, and subsidized or low-income housing is extremely scarce.[215] Unless federal regulations are revised to permit HCBS Waiver and 1915(i) SPA funds to cover rental costs, which seems unlikely as of this writing, the deficient stock of affordable housing will put community-based options such as Supported Living Services (SLS) and Independent Living Services (ILS) out of reach for many RC consumers.

Using any cost savings realized from the increased uptake of federal matching funds to expand the stock of affordable housing could ameliorate both problems at once. For example, DDS could place at least two-thirds of such funds into a dedicated housing fund for RC consumers who otherwise could not afford to live in proximity to their families.[216] Utilizing the additional

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[212] We discuss this issue at length in a separate report, *see* LANTERMAN PRIMER, *supra* note 52, at § V.H.

[213] *See* CTR. MEDICAID & CHIP SERVS., CTRS. MEDICAID & MEDICARE SERVS., PREVENTING UNALLOWABLE COSTS IN HCBS PAYMENT RATES 6, https://www.medicaid.gov/medicaid/hcbs/downloads/training/preventing-unallowable-costs.pdf (last visited Jan. 18, 2019) (noting that "unallowable costs" for HCBS Waiver programs include "room and board"); *See also State Agencies Claimed Unallowable and Unsupported Medicaid Reimbursements for Services Under the Home and Community-Based Services Waiver Program*, OFFICE OF THE INSPECTOR GEN., https://oig.hhs.gov/oas/reports/region7/71603212.asp (last visited Jan. 19, 2019); *See also* Social Security Act § 1915(i), 42 U.S.C. § 1396n(a) (2019) (noting that State plan amendment for the provision of medical assistance for home and community-based services cannot include cost of "room and board").

[214] *See supra* Section V.(C) (discussing Supplemental Security Income).

[215] *See* TECH. ASSISTANCE COLLABORATIVE & CONSORTIUM FOR CITIZENS WITH DISABILITIES, PRICED OUT IN 2014: THE HOUSING CRISIS FOR PEOPLE WITH DISABILITIES ii (2014), [hereinafter PRICED OUT IN 2014], http://www.tacinc.org/media/52012/Priced%20Out%20in%202014.pdf (last visited Jan. 18, 2019).

[216] It is possible that placing federal matching funds directly into a dedicated state-run housing fund could be construed as violating Medicaid regulations. Therefore, the legislature may need to pre-commit to "match" each dollar of additional federal revenue with a dollar of additional General Funds, or devise another, more indirect, method to channel increased federal revenues into a special dedicated housing fund.

revenue in this manner would dampen the legislature's incentives to reduce outlays from the General Fund. Moreover, since housing expenses are expressly disallowed by Medicaid, such an approach would help overcome a major barrier to full community integration, while strengthening the resilience and equity of the system as a whole.

Importantly, this would not be the first time the state has sought creative ways to mitigate the housing shortage faced by RC consumers. In a recent report, the Legislative Analyst's Office assessed a legislative proposal to use land obtained from the closure of Developmental Centers to increase affordable housing for consumers living in the community.[217] The report highlighted the 1981 Harbor Village Project, in which DDS entered into a long-term lease with a private developer to develop mixed-income housing within Fairview Developmental Center grounds.[218] DDS expects Harbor Village to generate approximately $1.9 million per year in surplus revenue after FY 2020-21.[219] In accordance with legislation passed in 2015, all surplus revenue will flow into the Department of Developmental Services Trust Fund, which DDS may use to "provid[e] housing and transitional services for people with developmental disabilities."[220] Other models, such as Buy-it-Once,[221] rely on the participation of nonprofit entities. If the state opts to create a dedicated housing fund with increased federal revenues, we recommend that it investigate a broad range of models, including ones being tried in other regulatory settings or in other states.

In short, parlaying an increase in federal matching funds into expanded housing options for RC consumers could reduce one of the greatest existing barriers to community integration, while making the regional center system as a whole less vulnerable to fiscal challenges that may arise in the decades to come.

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[217] *See* MAC TAYLOR, CAL. LEGISLATIVE ANALYST'S OFFICE, SEQUESTERING SAVINGS FROM THE CLOSURE OF DEVELOPMENTAL CENTERS 1-2 (2018), http://www.lao.ca.gov/reports/2018/3735/sequestering-savings-013118.pdf (last visited Jan. 18, 2019).

[218] *Id.* at 12.

[219] *Id.*

[220] CAL. GOV'T CODE § 14670.36(c) (2017).

[221] *See* CAL. WELF. & INST. CODE § 4688.6(a) (2017) (noting "[T]he department may receive and 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 available for occupancy 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").

IX. Conclusion

This report aims to identify ways in which the RC system could enhance its capacity to draw down federal monies. We focus on two specific mechanisms for doing so: increasing enrollment in the HCBS Waiver, and increasing enrollment in the 1915(i) SPA. After analyzing in detail the Federal Match Eligibility Pathway whereby consumers progress from Lanterman Act eligibility to enrollment in one of these two federally-matched programs, we attempt to quantify the degree of attrition at each step of the process.

Our analysis suggests that there is considerable room for improvement in the state's enrollment of consumers in the HCBS Waiver and 1915(i) SPA programs: California likely could claim hundreds of millions, and perhaps half a billion or more, of additional federal dollars by increasing enrollment in these two programs alone.

We propose that the state undertake a participatory re-design process whereby stakeholders quantify the level of attrition at each stage of the enrollment process; identify its root causes among different groups of consumers; and collaboratively develop strategies to increase enrollment. Using FSFM Medi-Cal enrollment as an illustration, we discuss several concrete proposals that such a participatory re-design process might yield.

Increasing California's enrollment in federal waiver programs, however, carries important risks. Although it could strengthen the economy by lowering the share of the regional center system's cost that is borne by the state, it could also increase the state's vulnerability to future Medicaid cuts. For this reason, we suggest that instead of seeing the increased drawdown of federal matching funds as an opportunity to reduce its contributions from the General Fund, the state should invest more in programs that increase the stock of affordable housing dedicated to individuals with I/DD.

To learn more about our activities, please visit us at

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