



Using Data for Good:

Toward More Equitable Home and Community-Based Services in Medi-Cal

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Introduction

ost aging adults and people with disabilities will require assistance to remain living in their homes and communities at some point over their lifetime. For Medi-Cal enrollees, access to these types of supportive services, collectively known as "Home and Community-Based Services (HCBS)," varies across the state. But the limitations of public data impede the understanding of who is receiving which services and where, and what inequities may exist by race, age, geography, type of disability, and other factors.

This paper aims to support state staff, policymakers, and other HCBS stakeholders in ensuring the robust collection and reporting of HCBS data as the state undertakes various efforts to improve these services. It includes a summary of the complexities and challenges of the current HCBS infrastructure for data collection including an overview of the existing gaps in HCBS data, recommendations to address those challenges and gaps, and strategies for moving the recommendations forward. This paper focuses specifically on Medi-Cal HCBS and Medi-Cal-funded long-term care.

Comprehensive and intersectional data collection and reporting is essential to advance equity in all health care, including at-home care. Without data, California cannot identify disparities in access to and use of these essential services, determine how intersectional factors give rise to disparities, or develop strategies and policies to address those disparities.

Data to measure equitable access is particularly important for Medi-Cal's HCBS. Unlike coverage for care provided in institutional settings like nursing facilities, which is required under federal Medicaid law, coverage for HCBS is optional and not all those who meet the financial and functional eligibility criteria for services are entitled to receive them. Historically, this bias toward providing care in institutions arose out of discriminatory views of people with disabilities — particularly those living

in poverty — as "feeble-minded" or as "moral failures" and society's attempt to force them into isolated and confined settings.² While much progress has been made toward improving institutional settings and eliminating this bias by making HCBS more available, the historical roots of discrimination remain embedded structurally in HCBS and the long-term care infrastructure. Data are critical to measure and address structural ableism, ageism, racism, and other forms of discrimination that may be causing inequities in access to HCBS.

Medi-Cal is the primary payer of HCBS, which allow aging adults and people with disabilities to get the help they need at home or in community-based settings as an alternative to receiving care in a nursing facility. From help with bathing and dressing, to community-based day centers that provide support and activities, to intense case management, California offers a multitude of HCBS programs to people with low incomes who rely on Medi-Cal for health coverage. (See Appendix A for a full list of Medi-Cal funded HCBS programs.) Yet, despite the wide array of HCBS in California and the significant Medi-Cal funding for these services, there are little public data to demonstrate whether HCBS is equitably available and used by those who qualify for services.

Data collection and reporting across all HCBS programs are needed to realize California's commitment to equity and the long-standing goal of ensuring that aging adults and people with disabilities have access to needed services in their homes and communities under the Americans with Disabilities Act and *Olmstead*.³ Robust and transparent data are also central to evaluating both California's successes and its failures in advancing equity and promoting accountability.

Earlier this year, California took a significant step toward improving HCBS data when California's Department of Health Care Services (DHCS) committed to a Gap Analysis and Multi-Year Roadmap ("Gap Analysis") set to launch in 2022 to assess the gaps in the HCBS and Managed Long-Term

Services and Supports (MLTSS) programs and networks.4 One of the five primary objectives of the Gap Analysis is to reduce inequities in access to and availability of services, starting with identifying disparities through robust analyses of who is receiving services and where. This step, combined with California's commitment of \$4.6 billion outlined in its partially approved HCBS spending plan⁵ and other significant initiatives underway through the Master Plan for Aging⁶ and CalAIM (California Advancing and Innovating Medi-Cal), presents a historic opportunity for the state to build an equitable and robust HCBS infrastructure. To capitalize on this moment requires DHCS, in coordination with other state departments, to identify the gaps in access to, and use of, HCBS.

Leveraging California's Current Initiatives to Improve HCBS Data Collection and Reporting

California has launched multiple significant initiatives focused on improving health equity throughout the state, increasing supports for California's growing older adult population, and improving data infrastructure, transparency, and collaboration among health care entities. These initiatives include Gap Analysis and Multi-Year Roadmap, Master Plan for Aging, CalAIM (California Advancing and Innovating Medi-Cal), California Health & Human Services Agency data exchange framework, Long-Term Services and Supports Data Transparency Dashboard (part of the HCBS spending plan), Equity in Aging Advisory Committee, and federal waiver renewals, reprocurement, and managed care plan contracting. (See Appendix B for more details.)

Challenges in HCBS Data Collection and Resulting Gaps

HCBS in California is complex. Individual HCBS programs are overseen by multiple entities, eligibility is authorized by different sources, and HCBS programs are funded by different sources and provided by separate delivery systems. These variations in eligibility rules, pathways, and funding all contribute to the present challenges in data collection and reporting.

Demographic Data Are Not Consistently Collected and Reported in Medi-Cal

Millions of people receive services and supports through Medi-Cal HCBS programs and Medi-Cal covered long-term care. Like the Medi-Cal population overall, HCBS users include people of all ages, and of different races and ethnicities, sex, sexual orientation, and gender identity. They live across the state from urban to rural regions and have different types of disabilities and diverse needs. Collecting and reporting accurate and complete demographic data are challenges broadly in the Medi-Cal program, and HCBS and long-term care programs are no exception.

As illustrated in Table 1 (page 6), of all the Medi-Cal HCBS programs, the most robust demographic data are available for the In-Home Supportive Services (IHSS) program.⁸ In publicly reported IHSS data, race and ethnicity are also stratified beyond broad population categories into smaller subpopulations including 18 race and ethnicity categories and 30 language spoken categories.

While the demographic data available in the IHSS program are the most robust comparatively, limitations remain. For example, the IHSS data cannot be filtered intersectionally (i.e., by more than one demographic element), and sexual orientation and gender identity data are not reported at all.

In contrast to IHSS, publicly reported data on other HCBS programs include minimal to no demographic data. For example, the publicly available data reported by DHCS for the Assisted Living Waiver (ALW) consists only of a list of facilities with contact information (address, phone number), bed capacity at individual facilities, total number of waiver recipients, and the total number of waitlisted people in a current month. There are no demographic data reported about ALW recipients, or those waitlisted, such as race or ethnicity, gender, age, language spoken, or disability status.

Collected Versus Reported Data

For the purposes of this paper, publicly reported data are used as a proxy for what data are collected when describing data gaps. HCBS and long-term care providers are certainly collecting demographic data. For example, individual Program of All-Inclusive Care for the Elderly (PACE) sites collect race, ethnicity, language, and other demographic data on program participants, but those data are not publicly reported by DHCS.¹⁰ Nor is there a public document outlining what data DHCS requires PACE programs to collect. It is also unknown what data state departments that oversee HCBS and long-term care programs are requiring providers to report back to these departments. This issue is especially a concern for sexual orientation and gender identity data, which state law requires Medi-Cal to collect but is not publicly reported for any HCBS program.¹¹

Demographic data on residents of nursing and intermediate care facilities are collected and publicly reported, but reporting on race is limited to four categories versus the 18 categories reported for IHSS. And unlike IHSS, which reports monthly, facilities are only asked to report annually. In 2020, 113 facilities did not report any demographic or other requested data.¹² Meanwhile, no demographic data are publicly reported on who transitions out of nursing facilities through the California Community Transitions (CCT) program or who is diverted from nursing facilities through Medi-Cal managed care plans responsible for managing Long-Term Services and Supports (LTSS) programs.¹³ See Table 1 for a summary of publicly reported data by Medi-Cal HCBS program.

For accurate demographic data to be reported, those data must be reliably and uniformly collected. Many demographic elements are obtained through the Medi-Cal application process. However, it is not clear how data collected at application are linked to HCBS programs. Little is known about how consistently and thoroughly HCBS providers, Medi-Cal managed care plans, or state departments seek demographic information from HCBS recipients. Staff may be uncomfortable or untrained in soliciting sensitive information, or they may not provide enough context to HCBS users to explain why such questions are asked or their importance. This issue is apparent in the IHSS data where in Placer County valid race data are not reported for 15% of IHSS users compared to Los Angeles County, where race data are not reported for just 0.2% of IHSS users.14

Table 1. A Summary of Publicly Reported Data, by HCBS/Long-Term Care Program, 2021

	Legend: ■ Publicly reported ■ Not publicly reported						ported						
	IHSS	ALW	AIDS	НСВА	HCBS- DD	CBAS	MSSP	ССТ	СМС	MLTSS	PACE	NF	ICF- DD
Demographics													
Age							*						
Disability													
Race/Ethnicity							*						
Gender							*						
Language spoken													
SOGI													
Location													
Program Access													
Total participants													
Waitlist number	N/A				N/A	N/A		N/A	N/A	N/A	N/A	N/A	N/A
Facility/Center/Site	N/A		N/A	N/A	N/A				N/A	N/A	N/A		
Beds	N/A		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A		
Hours authorized		N/A	N/A				N/A	N/A	N/A	N/A	N/A	N/A	N/A
Transitions	N/A	N/A	N/A	N/A	N/A	N/A	N/A						
Diversions	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A				N/A	
HCBS-like services	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A				N/A	N/A

^{*} These MSSP data were available in 2019, but not 2020 or 2021

Notes: AIDS is Acquired Immunodeficiency Syndrome waiver; ALW is Assisted Living Waiver; CBAS is Community-Based Adult Services (formerly known as Adult Day Health Care) waiver; CCT is California Community Transitions; CMC is Cal MediConnect health plan; HCBA is Home and Community-Based Alternatives waiver; HCBS-DD is Home and Community-Based Services for the Developmentally Disabled waiver; ICF-DD is Intermediate Care Facility for the Developmentally Disabled; IHSS is In-Home Supportive Services; MLTSS is Managed Long-Term Services and Supports; MSSP is Multipurpose Senior Services Program waiver; N/A means it's not a relevant data point for that program; NF is nursing facility; PACE is Program of All-Inclusive Care for the Elderly; SOGI is sexual orientation and gender identity.

Source: Author analysis of HCBS and LTSS program data publicly reported on departmental government websites.

Medi-Cal HCBS Is a Complex Patchwork of Programs

Under federal Medicaid law, states have three pathways to offer HCBS: the Medicaid State Plan, Medicaid waivers, and demonstration programs (see sidebar). Over decades, California has used all three pathways, resulting in a patchwork of HCBS programs that are not all available statewide and are limited to certain populations. These variations contribute to the challenges the state faces in collecting and reporting uniform and comprehensive HCBS data that also measure access and utilization specific to each program. For example, the Multipurpose Senior Services Program (MSSP) is available only to people age 65 and over in 46 of California's 58 counties with an enrollment cap of just over 11,300 people. 15 Measuring access and utilization would look different for MSSP than IHSS, for example, which is available statewide to anyone who meets eligibility criteria, regardless of age.

HCBS and Long-Term Care Programs Are Overseen by Multiple State Departments

Medi-Cal HCBS is available to eligible recipients through numerous programs overseen by multiple and overlapping state and county government agencies and departments and is delivered through different types of providers (see Appendix A). As a result, the data that state departments require HCBS providers to collect vary, the data state departments publicly report vary, how often departments publicly report data (e.g., monthly, quarterly, annually) is not consistent, and data are difficult to locate even when departments make them publicly available. The lack of a single state department responsible for HCBS data collection, reporting, and coordination makes it harder for HCBS programs to be included in the state's broader data efforts. For example, California Health & Human Services Agency (CalHHS) is developing its data exchange framework that will govern the exchange of health information across the state.¹⁶ Unfortunately, HCBS programs have not been included among the required participants in this initiative to date.

Federal Medicaid Authority Pathways to Offer HCBS

Demonstration Waiver

- ➤ California Community Transitions
- ➤ Community-Based Adult Services
- ➤ Cal MediConnect
- Managed care plans with managed long-term services and supports
- ➤ Program of All-Inclusive Care for the Elderly

§ 1915(c)

- Assisted Living Waiver
- ► AIDS Waiver
- ► Home and Community-Based Services Alternatives Waiver
- Home and Community-Based Services for the Developmentally Disabled
- ➤ Multipurpose Senior Services Program

State Plan Amendment

- ➤ In-Home Supportive Services
- ► Home Health Care

Medi-Cal HCBS Is Paid for and Delivered Through Fee-for-Service and Managed Care

HCBS is paid for and delivered through fee-for-service or capitation arrangements that flow through either managed care plans or state or county agencies. These varied and complex arrangements present challenges for data collection and reporting — particularly when capitation payments run through managed care. As an example, every year the Centers for Medicare & Medicaid Services (CMS) collects data from states on their expenditures on institutional care versus expenditures on HCBS. California has not reported these baseline expenditure data to CMS since 2014, the year it implemented Managed Long-Term Services and Supports (MLTSS) in seven counties that account for 60% of Medi-Cal enrollees in the state.¹⁷ Without such data, it is impossible to determine the extent

to which California is rebalancing the provision of services from institutional settings to home and community-based settings.

Managed care plans have also become responsible for HCBS-like services intended to help members remain living at home including, for example, Care Plan Option (CPO) services in Cal MediConnect plans and Enhanced Care Management (ECM) (required) and Community Supports (optional) that Medi-Cal plans will start providing in January 2022 under CalAIM.¹⁸ While Cal MediConnect plans are required to report the number of CPO services the plan has provided to members, the plans are not required to report demographic data of who received CPO services, and DHCS does not publicly report the CPO data it collects. 19 On the other hand, Medi-Cal plans will be required to report some, but not all, demographic data (race, ethnicity, and primary language) of enrollees receiving ECM and Community Supports to DHCS to receive incentive payments under CalAIM.²⁰

HCBS Eligibility Rules and Pathways Vary

Financial eligibility rules for HCBS create challenges for data collection and reporting. For example, married people who need HCBS can use a federal eligibility rule called "spousal impoverishment" to maintain higher income and resources beyond the income limit for the aged and disabled program. Spousal impoverishment, however, is not automatically applied when a person applies for Medi-Cal. And because spousal impoverishment is an income counting rule, there is no associated aid code or other means for DHCS to track when spousal impoverishment rules are applied for individual eligibility determinations or whether they should have been applied. As a result, the state cannot determine who is benefiting from this eligibility rule.

Differences in how people qualify for specific HCBS programs based on need and functional status also lead to data challenges. HCBS programs differ in terms of what entity conducts the functional

assessment for eligibility and what assessment tool providers and other entities use to determine eligibility for each HCBS program. Yet data to assess for biases in eligibility determinations are largely unavailable, including data on application approval time and rates of approvals, denials, appeals, and grievances.²²

Addressing Data Gaps: Opportunities

Collecting and reporting HCBS data present state agencies, policymakers, and HCBS stakeholders with the opportunity to collaborate and build an equitable HCBS infrastructure under Medi-Cal. At a basic level, addressing the gaps in HCBS data provides the state with the opportunity to measure how well it is complying with its obligations under the Americans with Disabilities Act and *Olmstead* to provide care in the least restrictive setting and rebalancing the provision of services from institutional to HCBS settings.²³

With data, the state can also determine whether disparities exist within HCBS programs and among populations. For example, with data on the racial makeup of CBAS recipients, California could analyze whether communities of color are over- or underrepresented in the CBAS program. With age data, California could determine whether proportionately more people under 65 or over 65 are transitioned out of nursing facilities through the CCT program.

Data also allow the state to establish benchmarks to compare access and utilization between populations and programs and then develop strategies and set goals to address disparities. For example, data across long-term care programs would allow the state to examine if the populations who face barriers to accessing and using HCBS are the same populations admitted at higher rates to institutional long-term care settings.

Having HCBS access and utilization data can also assist the state in other efforts to improve the HCBS infrastructure. For example, the state is currently examining workforce capacity for HCBS programs. Having data on who is unable to access or use HCBS can inform strategies to address workforce shortages and what types of training and supports the workforce needs to adequately meet the needs of HCBS recipients.

Ultimately, with HCBS data, CalHHS, DHCS, and other state departments that oversee these services can assess whether HCBS is equitably available to aging adults and people with disabilities who need these services.

Recommendations for HCBS Data Collection and Reporting

The following recommendations serve as a starting point for DHCS to inform its Gap Analysis and to more broadly improve HCBS data collection, reporting, and transparency; enhance accountability; and advance the state's efforts to build an equitable HCBS infrastructure.

1. Establish Robust and Transparent Standards for HCBS Data Collection and Reporting

To measure access to Medi-Cal HCBS, standards must be established for data collection and reporting. Data elements should support both identifying disparities in access to and use of specific HCBS and institutional long-term care programs and more broadly measuring how well DHCS and individual HCBS programs are advancing the state's goal of providing services in the least restrictive setting.

1a. Establish a uniform set of demographic elements that must be collected and reported across all HCBS and long-term care programs, for applicants, users, and providers. Demographic elements must include, at minimum, race, ethnicity, language spoken, age, disability, immigration status, sexual orientation and gender identity, and geographic location (e.g., county and zip code). Common

definitions for each of these broad elements must be developed. Data must also be sufficiently stratified to enable assessment of disparities beyond broad population categories.

RATIONALE. Robust stratified demographic data are foundational to identifying disparities in access to and use of HCBS and long-term care programs. To ensure stakeholders can make meaningful comparisons, the demographic data collected and reported must be uniform across HCBS and long-term care programs, and where appropriate, collected and reported for applicants, recipients of services, and providers.

1b. Establish a set of core uniform access and utilization measures for all HCBS and long-term care programs.

RATIONALE. Several access and utilization measures can be implemented across all HCBS and long-term care programs to identify disparities. For example, one critical access and utilization measure is the number of applicants, stratified by demographic data, applying for HCBS or long-term care programs. Another critical measure is the processing time for applications for services, stratified by demographic data as well. Approvals, denials, and terminations for HCBS and long-term care programs as well as appeals and grievance data are also key measures for identifying disparities. Having multiple measures creates a more comprehensive picture of access and utilization that would give DHCS and other stakeholders more information to determine why disparities are arising.

1c. Establish unique data access and utilization measures for each HCBS and long-term care program.

RATIONALE. Since individual HCBS programs provide different types of services that are authorized differently, establishing measures specific to each program in addition to the uniform measures described in Recommendation 1b is key to evaluating specific program access and utilization. For

example, for waivers with waitlists, measures should at a minimum include information on who is receiving services, who is on the waitlist, and the length of wait times, stratified by demographic data. Unique measures would be different for CCT, which should at a minimum include who is receiving transition services and where in the state these transitions are occurring. For CBAS and IHSS, data measures would include hours of services authorized and used.

1d. Establish data collection and reporting standards and measures for HCBS and long-term care delivered through managed care plans.

RATIONALE. Medi-Cal managed care plans have become increasingly responsible for the provision of HCBS and long-term care benefits. This trend will continue with the carve-in of the institutional longterm care benefit in managed care across the state in 2023 and as plans start providing Enhanced Care Management and Community Supports (HCBS-like services) under CalAIM in 2022. In addition to the measures outlined in Recommendations 1a, 1b, and 1c, specific data collection and reporting standards and measures are needed to measure disparities in access to and use of HCBS and HCBS-like services through managed care plans and to evaluate health plan performance. For example, plans should be required to report demographic data on who has been approved for each type of Community Supports service the plan provides.

1e. Collect and report HCBS data that allow for intersectional analysis to identify where overlapping disparities exist.

RATIONALE. Intersectional data are important to understanding disparities experienced by distinct population groups. Overlapping demographic variables such as gender, race, disability, and others can result in different experiences for different populations, and disparities can be masked when intersectional analysis is not performed. For example, the California Department of Aging reports

on the percentage of CBAS recipients that have dementia, but data on how many of those with dementia identify as Black are missing.²⁴ Without intersecting data including both disability (in this example, dementia) and race, the state cannot determine whether CBAS sites are equitably serving Black people with Alzheimer's and dementia. This is potentially crucial information because Black people are two times more likely to have Alzheimer's as a disability compared to other racial groups.²⁵

1f. Standardize frequency of data collection and reporting across all HCBS and Long-Term Services and Supports (LTSS) programs, ideally monthly.

RATIONALE. Currently, data collection and reporting time frames significantly differ between programs. For example, IHSS data are collected and reported monthly, but CBAS participant data are only required to be reported twice a year. By establishing consistent collection and reporting time frames, data would be current and consistent across programs, and DHCS could compare data across HCBS and institutional long-term care programs.

1g. Report data collection and reporting standards and all HCBS and institutional long-term care program data publicly in the LTSS Transparency Dashboard and the Master Plan for Aging (MPA) Data Dashboard.

RATIONALE. Publicly available data are key to transparency, accountability, and ultimately addressing HCBS disparities. Today, available data are spread across websites, in different formats, and maintained by different state and federal agencies and departments. DHCS should include HCBS data in the proposed LTSS Transparency Dashboard and the MPA Data Dashboard (see Appendix B). Likewise, publicizing any future required collection and reporting standards DHCS develops would increase transparency and accountability and allow stakeholders to evaluate whether gaps remain in these data collection and reporting standards.

2. Address Administrative and Infrastructure Barriers to Data Collection and Reporting

With multiple state departments responsible for HCBS data collection and reporting efforts, this set of recommendations is aimed at improving coordination of HCBS data collection and reporting across state departments as well as improving the accuracy and quality of the HCBS and institutional long-term care data DHCS collects and reports.

2a. Create a specific HCBS data task force charged with developing and implementing data standards and measures and coordinating with other state departments responsible for HCBS data collection, reporting, and oversight.

RATIONALE. The task force would ensure that data collection and reporting are standardized across programs and departments as well as prevent duplication of efforts among the departments overseeing HCBS programs. The task force would also bring consistency in the methods employed for collecting data, the types of data collected, data governance, and resolving conflicting data. The task force could also establish and share best practices across departments and help to ensure that HCBS and institutional long-term care programs are being included in other initiatives in CalHHS to equitably collect and report data, including the data exchange framework where HCBS is not currently set for inclusion. The task force would also ensure coordination with other efforts to improve the HCBS infrastructure, including efforts to measure and improve HCBS quality and efforts to increase workforce capacity as well as federal initiatives to standardize HCBS data collection.

2b. Develop and implement processes, protocols, and training to improve the completeness and accuracy of HCBS data.

RATIONALE. Comprehensive and accurate demographic data are central to identifying and addressing disparities. Those in need of HCBS have many encounters where they are asked to selfreport demographic data including with DHCS and other department staff, Medi-Cal managed care plan staff, and HCBS providers. Developing standardized training and protocols for government staff and providers on how to best approach enrollees with questions about their demographic data in a way that is respectful and how to address concerns about sharing this information would improve the accuracy and completeness of HCBS data. The HCBS data task force could coordinate across state agencies on this recommendation, since data accuracy is an issue across all health care programs in the state.

2c. Engage HCBS consumer stakeholders at every step of the process, including in efforts to develop data reporting and collection standards and measures, to improve the accuracy of data collected and reported, and to develop strategies and policies to address disparities identified in access to and use of HCBS.

RATIONALE. HCBS consumers — and in particular HCBS consumers who have been marginalized and who have experienced disparities in access to HCBS historically — have not been included in efforts to address data issues. Lived experience, however, is critical in informing better policies related to data. DHCS should draw on best practices to increase engagement and empower HCBS consumers and stakeholders for meaningful participation at all stages.

3. Use Data to Make Comparisons and Inform Strategies to Address Disparities

This final set of recommendations focuses on the steps DHCS can take to establish benchmarks to identify disparities in access to and use of HCBS that the department can then use to inform strategies and policies to address those disparities.

3a. Establish data benchmarks to compare HCBS access and utilization among populations and across HCBS programs and to set goals for improvements.

RATIONALE. Benchmarks are needed to effectively compare HCBS access and utilization data and identify disparities across populations. Different types of benchmarks can be used for comparisons. To measure differences between populations, the more advantaged population could be used as a benchmark. For example, if rates of IHSS hours authorized are higher among White IHSS users, the state could use White IHSS users as the benchmark. Historical data comparing the same population over a period of time could also be used as benchmarks, as could national or state data outside of California.

3b. Conduct statistical analyses to identify meaningful differences in HCBS data.

RATIONALE. Raw data alone can be useful, but statistical analysis is needed to determine if there are meaningful differences between data. For example, raw data may demonstrate that White older adults are enrolled in CBAS at higher rates than Black older adults. This could point to a disparity in access to CBAS between White and Black older adults. Yet statistical analysis may find that the proportion of White older adults is higher than the proportion of Black older adults in the state, and when comparing proportions, there may be no statistically significant difference in CBAS enrollment. Statistical analysis supports evidence-based policymaking to address disparities.

Moving the Recommendations Forward

DHCS is well-positioned to implement these recommendations as part of the state's Gap Analysis and the initiatives in its HCBS spending plan. There is general recognition of the need to analyze disparities in access to and use of HCBS services, and multiple initiatives are addressing this need by providing resources to invest in California's data infrastructure. To advance these recommendations. DHCS can leverage and coordinate with initiatives underway in the state. As DHCS conducts its Gap Analysis work, it should identify where these recommendations intersect with other initiatives, including the LTSS Data Transparency Dashboard, CalAIM, the CalHHS data exchange framework, the Master Plan for Aging, and with waiver renewals and managed care plan contracting (see Appendix B). There are opportunities to leverage existing stakeholder processes underway in these various initiatives to obtain feedback and to ensure stakeholder engagement in data collection and reporting efforts.

Some of the recommendations in this paper can be implemented on a faster timeline than others, as a few recommendations are more complex. Nonetheless, efforts to improve the quality and scope of data collection and reporting can begin even if some pieces will need time to develop. Most of the recommendations could be implemented in collaboration statewide by CalHHS, DHCS, and other state agencies including the California Department of Aging (CDA), California Department of Public Health (CDPH), California Department of Social Services (CDSS), and California Department of Developmental Services (CDDS). Each of these departments has important roles to play in data collection and reporting. However, dedicated resources are essential, including adequate funding for development and implementation. While the Gap Analysis is funded, more resources will be needed to fully fund the recommendations in

this paper. Public funding of this work is essential and in addition to leveraging initiatives cited in Appendix B, philanthropic funding in support of data collection and reporting efforts could accelerate progress.

Moreover, collection and reporting of accurate data are just the first steps. Developing and implementing policies and interventions to address disparities in access to and use of HCBS will require ongoing and substantial resources and stakeholder engagement.

Conclusion

Uniform and comprehensive data collection is not an easy task. However, for California to further its goals of increasing equity and eliminating disparities, the state must create a path to measure inequities. Collecting and reporting data are the first steps to reaching this goal. By building up data infrastructure, increasing transparency around collected data, and mandating the robust collection of demographic data, California can establish itself as a leader in advancing health equity. Numerous initiatives already in play provide momentum for the recommendations in this paper, and California is well-positioned to realize this future.

Appendix A. Medi-Cal HCBS Programs

	SERVICES	ELIGIBILITY	AVAILABILITY	OVERSIGHT	PROVIDERS			
State Plan Services must be available statewide to all Medi-Cal enrollees who meet eligibility criteria.								
Home Health ²⁷	Intermittent skilled nursing care; in-home medical care services; physical, occupational, or speech therapies; home health aide services; medical supplies; medical equipment; and medical appliances.	Need skilled nursing facility level of care	Statewide	DHCS CDSS	Home care organizations			
In-Home Supportive Services ²⁸	Personal care services to allow enrollees to remain safely in the home rather than in an institution; services may include meal preparation, personal care services, laundry, housecleaning, shopping, accompaniment to medical appointments, and 24-hour protective supervision for those with mental or cognitive impairments.	Have medical, cognitive, or behavioral condi- tions or other disabilities and need assistance with activities of daily living	Statewide	DHCS CDSS County public authorities	Independent contractors, including caregivers hired directly by Medi-Cal recipients			
HCBS Waiver Individuals must meet nursing facility level of care to be eligible for federal 1915(c) waiver services. Waivers can be limited geographically and by population and can cap enrollment.								
Assisted Living Waiver ²⁹	Personal care services, care coordination, housekeeping, intermittent skilled nursing care, and care coordination for transitions from a nursing facility to an assisted living facility.	Age 21 or over; need nursing facil- ity level of care; willing and able to safely reside in an assisted living facility or in publicly subsi- dized housing	15 counties, limited to 5,744 slots	DHCS Care Coordination Agencies	Residential care facilities for the elderly, adult residential care facilities, home care organiza- tions			
AIDS Waiver ³⁰	Case management, house-hold services such as grocery shopping and meal preparation, transportation, and minor home adaptations such as ramp installation and grab bars.	All ages; diagnosis of HIV or AIDS or both, with current symptoms or disabilities related to HIV disease or treatment; can live safely at home; need nursing facil- ity level of care	26 counties, ³¹ limited to 1,500 slots	CDPH DHCS	Waiver agencies (can be a home health agency, outpatient hospi- tal department, county health department, or commu- nity-based organization that meets certain requirements)			

	SERVICES	ELIGIBILITY	AVAILABILITY	OVERSIGHT	PROVIDERS
Home and Community- Based Services Alternatives Waiver ³²	Services include a care team that coordinates and arranges for other medical care, behavioral health services, and other home and community-based supports; home modifications and habilitation services.	All ages; meet specific levels of care, including nursing facility, intermediate care facility, and acute and subacute hospital care	Statewide, limited to 8,000 slots	DHCS	Waiver agencies (local nongov- ernmental organizations)
Home and Community-Based Services for the Developmentally Disabled ³³	Services provided by regional centers such as community living arrangement services; homemaker/chore services; home health aide; occupational and physical therapy; optometric/optician services; speech, hearing, and language services; financial management; communication aides; environmental accessibility adaptations; housing access services; behavioral intervention services; specialized medical equipment and supplies. This is the largest California HCBS waiver program.	All ages; regional center consumers with a developmental disability diagnosis	Statewide	CDDS DHCS	Regional centers
Multipurpose Senior Services Program (MSSP) ³⁴	Health care and social services to assist people to remain in their homes, including case management and needs assessments, counseling, personal care, transportation, meal services, and minor home repair and maintenance services.	Ages 65 and over; need nursing facil- ity level of care	46 counties, limited to 11,370 slots	CDA DHCS	Contracted agencies (local government and private nonprofit organizations)

	SERVICES	ELIGIBILITY	AVAILABILITY	OVERSIGHT	PROVIDERS			
Medicaid Demonstration Medicaid demonstrations can be limited geographically and by population.								
California Community Transitions (CCT) ³⁵ Federal Demonstration: Money Follows the Person	Support for those who choose to transition out of long-term care institutional settings and back to the community; enhanced funding for supplemental services not typically offered under the state plan or other waivers, such as payment for security deposits and other costs to setting up a household.	All ages; resided in a nursing facil- ity or hospital for any amount of time*	40 counties	DHCS	Contracted CCT lead organiza- tions (local government and private nonprofit organizations)			
Community-Based Adult Services (CBAS) ³⁶ (formerly known as Adult Day Health Care) Federal Demonstration: § 1115	Nursing services; mental health services; occupational, speech, and physical therapies; behavioral health services; nutritional counseling; meals; social services; and transportation. Services are provided on-site at CBAS centers and recipients must enroll in a Medi-Cal managed care plan to receive CBAS services.	Age 18 and over; medical, cogni- tive, behavioral conditions or disabilities; need nursing facility level of care	27 counties	CDA DHCS Medi-Cal managed care plans	Adult day health centers, CBAS centers			
Cal MediConnect ³⁷ Federal Demonstration: § 1115 [†]	Integrated Medicare/Medi-Cal plan implemented in 2014 providing hospital, medical, and prescription drug benefits, and long-term care in a single plan; includes increased care coordination, and enhanced vision and transportation benefits.	Age 21 and over; enrolled in both Medicare and Medi-Cal (dually eligible enrollees)	7 counties	DHCS DMHC	Cal MediConnect plans can offer Care Plan Option services, which are HCBS-like services, through contracts with providers such as independent living centers, Area Agencies on Aging, and other nonprofit providers.			
Medi-Cal Managed Care Plans with Managed Long-Term Services and Supports (MLTSS) ³⁸ Federal Demonstration: § 1115‡	Specific long-term care services through Medicaid managed care plans that are financially responsible for those services. In California, MLTSS include institutional long-term care benefits, Community-Based Adult Services, and (for a limited time) MSSP.§	Qualify for the specific MLTSS service [#]	7 counties	DHCS DMHC	Plans contract with nursing facilities and coordinate with waiver providers.			

	SERVICES	ELIGIBILITY	AVAILABILITY	OVERSIGHT	PROVIDERS
Program for All-Inclusive Care for the Elderly (PACE) ³⁹ Federal Demonstration: PACE Demonstration	Comprehensive preventive, primary, acute, and long-term care services so recipients can remain in their homes. Services are provided on-site at PACE centers and care is exclusively provided by PACE providers. Transportation is provided to and from PACE sites.	Age 55 and over; live in a PACE program service area, need nursing facility level of care and able to live safely in the community. The majority of PACE recipients are enrolled in both Medicare and Medi-Cal (dually eligible enrollees).	15 counties	DHCS DMHC	Nonprofit PACE centers**

^{*} SB 214 (Cal. 2020); and "The California Community Transitions (CCT) Program: A Way for a Nursing Home Resident to Return to the Community," Disability Rights California, April 1, 2021. SB 214 expanded eligibility from residing over 60 days in a nursing facility to also include anyone residing in a nursing facility for any amount of time under 90 days. SB 214 is effective until January 1, 2024.

Notes: AIDS is Acquired Immunodeficiency Syndrome waiver; ALW is Assisted Living Waiver; CBAS is Community-Based Adult Services (formerly known as Adult Day Health Care) waiver; CCT is California Community Transitions; CDA is California Department of Aging; CDPH is California Department of Public Health; CDSS is California Department of Social Services; CMC is Cal MediConnect health plan; DHCS is California Department of Health Care Services; DMHC is California Department of Managed Health Care; HCBA is Home and Community-Based Alternatives waiver; HCBS-DD is Home and Community-Based Services for the Developmentally Disabled waiver; IHSS is In-Home Supportive Services; MLTSS is Managed Long-Term Services and Supports; MSSP is Multipurpose Senior Services Program waiver; PACE is Program of All-Inclusive Care for the Elderly.

Source: Author analysis of HCBS and LTSS program data publicly reported on departmental government websites.

[†] California Advancing & Innovating Medi-Cal (CalAIM) Proposal (PDF), California Dept. of Health Care Services (DHCS), January 2021. Cal MediConnect will discontinue January 1, 2023.

[‡] Medicaid Section 1115 Demonstration Five-Year Renewal and Amendment Request: CalAIM Demonstration (PDF), DHCS, June 2021. CalAIM will use § 1915(b) authority for MLTSS plans starting in 2023 and will expand statewide.

[§] MSSP will be carved out of managed care and return to a fee-for service waiver benefit under CalAIM on January 1, 2022. See CalAIM Proposal.

[#] Some people are excluded from Medi-Cal managed care plan enrollment, such as PACE enrollees. For a full list of exclusions, see Coordinated Care Initiative Participating Populations for Cal MediConnect (PDF), DHCS, last updated June 2020. In January 2022, previously excluded population groups will be required to join managed care in CCI counties, see CalAIM Proposal, Appendix F.

^{**} For-profit demonstration now permitted. See 42 C.F.R. § 460.30; and 84 FR 25610 "Medicare and Medicaid Programs; Programs of All-Inclusive Care for the Elderly (PACE)," August 2019.

Appendix B. Opportunities to Advance HCBS Data Recommendations in Current Initiatives

Gap Analysis and Multi-Year Roadmap

The Department of Health Care Services (DHCS) is conducting a Gap Analysis and Multi-Year Roadmap ("Gap Analysis") of its Home and Community-Based Services (HCBS) and Managed Long-Term Services and Supports (MLTSS) programs and networks. One objective is to determine who is and who is not receiving HCBS services, to identify and address inequities.⁴⁰ The Gap Analysis aims to analyze current populations receiving HCBS and identify gaps in access, determine unmet needs, assess community resources and gaps in referrals, and examine eligibility and intake processes so there is "no wrong door" to accessing HCBS. The Gap Analysis will include recommendations for the state to implement. Many of the findings and recommendations in this paper can inform the Gap Analysis.

How are HCBS data relevant? As this paper demonstrates, the Gap Analysis cannot produce a comprehensive analysis of inequities in the system if the data to do this work are not collected or reported. As a whole, this paper's findings and recommendations can inform the work of the Gap Analysis.

Long-Term Services and Supports Data Transparency Dashboard

As part of the state's HCBS spending plan (supported by the federal American Rescue Plan Act), DHCS is proposing \$4 million to fund a Long-Term Services and Supports (LTSS) Data Transparency Dashboard linking nursing home and HCBS utilization, quality, demographic, and cost data.⁴¹

How are HCBS data relevant? This dashboard is an important step toward data transparency because it includes many of the data points currently unavailable, such as LTSS utilization and cost data. This paper's findings and recommendations can inform decisions on the data collected for and included in

this dashboard, such as consistent reporting time frames and comparative data.

CalAIM

CalAIM (California Advancing and Innovating Medi-Cal) is a framework to transform Medi-Cal's health care delivery structure and increase equity in the Medi-Cal system. 42 Among other initiatives, three strategies will be introduced: population health management, Enhanced Care Management, and Community Supports. Together these initiatives aim to increase data collection and data exchange between organizations supporting the same enrollee, identify high-need enrollees, and provide support services including HCBS and LTSS to address medical and behavioral health needs as well as needs related to the social determinants of health. CalAIM also includes mandatory managed care enrollment for populations not previously part of Medi-Cal managed care and the carve-in of institutional long-term care into managed care plans.

How are HCBS data relevant? The increasing responsibility of Medi-Cal plans for HCBS, institutional long-term care, and Community Supports necessitates increasing plans' data collection and reporting to track disparities in access to and utilization of these services. Community Supports are similar to services offered by HCBS programs and can include housing transition services, housing deposits, respite services, personal care services, sobering centers, meals, and more that plans can offer in lieu of covered Medi-Cal services. Community Supports differ from HCBS programs because a plan can elect to offer Community Supports, and these services cannot be duplicative of other HCBS and long-term care services an enrollee might be receiving. As CalAIM mandates increased managed care enrollment and the carve-in of some LTSS into Medi-Cal managed care plans, reporting demographic data of recipients of HCBS and Community Supports as well as LTSS

expenditures data will be key to evaluating whether the equity goals of CalAIM are achieved.

Data Exchange Framework

CalHHS is creating a mandatory statewide data exchange framework — a single data-sharing agreement and common set of policies and procedures that will govern health information exchange — to be used by almost all health care entities in the state, including health insurance companies, hospitals, medical providers, government agencies, and skilled nursing facilities.⁴³

How are HCBS data relevant? While HCBS is not currently included in this framework, the development of common policies and procedures for data exchange is aligned with some of this paper's recommendations for uniform data collection standards.

Master Plan for Aging

The Master Plan for Aging (MPA) is a framework for the state to prepare for the growth of the older adult population. One of its enumerated goals is to promote healthy aging and increase services and supports to promote aging at home and in the community. Part of this work includes the creation of a data dashboard to track the MPA's progress. The data dashboard includes data on the availability of HCBS services and supports to older adults by county and identifies counties with gaps in long-term services and supports. ⁴⁴ For example, the data dashboard highlights the lack of PACE centers in San Luis Obispo in 2020. ⁴⁵

How are HCBS data relevant? This dashboard provides limited demographic information on institutional long-term care (LTC) residents in California, but overall, there is no intersectional data on HCBS or LTC in the dashboard. The MPA data dashboard could incorporate existing demographic data on LTC residents and coordinate with the upcoming LTSS Data Transparency Dashboard to incorporate additional HCBS utilization and demographic data to provide a more complete picture of the availability of LTSS in California.

Equity in Aging Advisory Committee

This committee is responsible for advising the California Department of Aging (CDA) in its work on the MPA (including ensuring equity principles are included as the MPA progresses) and in its role overseeing HCBS programs like MSSP and CBAS.⁴⁶

How are HCBS data relevant? This committee could address gaps in HCBS data in its work and partnership with the CDA.

Waiver Renewals, Reprocurement, and Contracting

California is renewing several HCBS waivers, entering into new contracts with managed care organizations that wish to operate Medi-Cal plans, and entering into and renewing contracts with integrated Medicare and Medicaid plans.

How are HCBS data relevant? The contracting process gives California an opportunity to incorporate specific and uniform data collection and reporting requirements for Medi-Cal managed care plans and to strengthen Medi-Cal's data infrastructure.

Endnotes

- 1. This paper uses the term "aging adults" to recognize that Home and Community-Based Services (HCBS) supports an aging population with functional needs, and these needs are not limited to the commonly accepted "older adult" threshold of age 65. HCBS is also available to children under 18, but that population is not a focus of this paper.
- Emily Shea Tanis, The Cost of Doing Business: Institutional Bias and Community-Based Services and Supports (PDF), Georgetown Journal on Poverty Law and Policy 27, no. 2 (Winter 2020): 291–304; and Sidney D. Watson, From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History (PDF), Georgia State Univ. Law Review 26, no. 3 (Mar. 2012): 937–69.
- 3. 42 U.S.C. § 12101, Americans with Disabilities Act, US Dept. of Justice, accessed October 25, 2021; and *Olmstead v. L.C.*, 527 U.S. 581 (1999).
- MFP Supplemental Funding Proposal Gap Analysis and Multiyear Roadmap (PDF), Dept. of Health Care Services (DHCS).
- Pending Centers for Medicare & Medicaid Services approval, Initial HCBS Spending Plan Projection (PDF), DHCS, last updated September 17, 2021.
- "Master Plan for Aging," California's Dept. of Aging (CDA), accessed September 18, 2021.
- 7. California Advancing and Innovating Medi-Cal (CalAIM) Proposal (PDF), DHCS, January 2021.
- 8. Author analysis of Monthly IHSS Program Data (2019– September 2021), CDSS.
- 9. "Assisted Living Waiver," DHCS, last modified September 15, 2021.
- 10. Custom data request, CalPACE, received October 24, 2021.
- AB 959 (Cal. 2015) requires DHCS, California Dept. of Public Health (CDPH), California Dept. of Social Services (CDSS), and CDA to collect sexual orientation and gender identity data.
- "2020 Reporting Form Long-Term Care Facilities"; and "2020 Long-Term Care Facilities Utilization Data (October 2021)," California Health & Human Services Agency (CalHHS).
- 13. Kristie Liao and Victoria Peebles, *Money Follows the Person:*State Transitions as of December 31, 2019 (PDF), CMS, 4;
 California's Dept. of Developmental Services (DDS) maintains a Regional Center Oversight Dashboard that tracks the percentage of Regional Center consumers who reside in the community versus in institutional settings over time. The dashboard does not include transitions between community and institutional settings. See, "2020 Performance Data Dashboard", DDS, last modified January 8, 2020.
- Author analysis of Monthly IHSS Program Data (September 2021), CDSS.

- "Multipurpose Senior Services Program," DHCS, last modified October 7, 2021.
- "Data Exchange Framework," CalHHS, accessed September 20, 2021.
- 17. Long-term care and the MSSP program were moved into managed care plans in the Coordinated Care Initiative (CCI) demonstration. For more detail on the CCI, see Amber Christ, Advocates Guide to California's Coordinated Care Initiative (PDF), Justice in Aging, December 2017; and author analysis of County Certified Eligibles - May 2021, DHCS, August 2021.
- CalAIM Proposal, DHCS; and "Enhanced Care Management, Community Supports, and Incentive Payments," DHCS, last modified October 29, 2021.
- 19. Public Records Act request, DHCS, received December 2018.
- Milestones and Measures for CalAIM Incentive Payments
 — Program Year 1 / Calendar Year 2022 (EXCEL DOWNLOAD),
 DHCS; and Proposed Submission Template for CalAIM Incentive Payments Measures Payment 1: Needs
 Assessment Measures (EXCEL DOWNLOAD), DHCS, accessed on November 3, 2021.
- Patient Protection and Affordable Care Act of 2010 (PDF),
 Pub. L. No. 111-148, § 2404, 124 Stat. 119 (2010).
- The data CDSS report for IHSS are a good model for reporting application and denial data. Monthly IHSS Program Data, CDSS.
- 23. Under Olmstead, states are required to provide long-term services and supports to people, both those at risk of institutionalization and those residing in institutions, in the community setting if the person does not oppose living in the community, a professional has deemed community living to be appropriate, and provision of such services can be reasonably accommodated by the state.
- 24. "Participant Characteristics," CDA, accessed September 20, 2021. Twenty-one percent of CBAS participants have dementia as of December 2020. Dementia includes Alzheimer's diagnosis.
- 25. "2020 Alzheimer's Disease Facts and Figures," Alzheimer's Assn., accessed September 20, 2021.
- HCBS Spending Plan, DHCS; and "GOAL TWO for 2030: Health Reimagined," CDPH, accessed September 20, 2021.
- 27. 42 C.F.R. § 440.220(a)(3); and Amber Christ and Georgia Burke, A Primer on Dual-Eligible Californians: How People Enrolled in Both Medicare and Medi-Cal Receive Their Care, California Health Care Foundation (CHCF), September 2020, 20.
- 28. "In-Home Supportive Services (IHSS) Program," CDSS, accessed October 26, 2021; and Claire Ramsey, *In-Home Supportive Services (IHSS): A Guide for Advocates*, Justice in Aging, June 2019.

- "Assisted Living Waiver," DHCS; and Jennifer Ryan and Julie Stone, Medi-Cal Explained Fact Sheet: Medicaid Waivers in California, CHCF, October 2019.
- 30. "AIDS Medi-Cal Waiver Program," DHCS, last modified October 12, 2021.
- 31. Medi-Cal Waiver Program Providers (PDF), CDPH, last modified June 2018.
- 32. "Home & Community-Based Alternatives Waiver," DHCS, last modified October 15, 2021; and Medi-Cal Explained, CHCF, 4.
- 33. "California Waiver Factsheet," CMS, accessed November 5, 2021; and *Dual-Eligible Californians*, CHCF, Appendix A.
- 34. "Multipurpose Senior Services Program," DHCS; and Medi-Cal Explained, CHCF, 4.
- 35. "Consolidated Appropriations Act of 2021: California Community Transitions Project," DHCS, last modified August 13, 2021.
- "Community-Based Adult Services," DHCS, last modified March 23, 2021.
- 37. Christ, Advocates Guide, 8; and Cal. Welf. & Inst. Code § 14132.275.
- 38. Christ, Advocates Guide, 8.
- "Program of All Inclusive Care for the Elderly," DHCS, last modified March 23, 2021; and "Program of All-Inclusive Care for the Elderly (PACE)," CMS, last modified October 18, 2021.
- 40. Gap Analysis, DHCS.
- 41. HCBS Spending Plan, DHCS.
- 42. CalAIM Proposal, DHCS.
- 43. "Data Exchange Framework," CalHHS.
- 44. GOAL TWO, CDPH.
- 45. GOAL TWO.
- 46. Equity in Aging Advisory Committee (PDF), CDA, accessed October 26, 2021.