



LONG-TERM CARE  
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# Beyond Spending: Measuring California's Progress Towards Equitable Home and Community-Based Services

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## INTRODUCTION

Many aging adults and people with disabilities will need assistance with activities of daily living throughout their lifetimes. For many, that support is made available through the Medicaid program, known as Medi-Cal in California, as the primary payer of long-term care nationally and in the state. While most people with disabilities of all ages prefer to receive care at home rather than in an institutional setting, community care is not guaranteed and is often harder to access. This is because of structural barriers rooted in federal Medicaid law, which requires states to pay for care provided in institutional settings while making it optional for states to pay for home and community-based services (HCBS).

Much effort has been made to address this institutional bias in Medicaid over the program's nearly 60-year history. In 1999, the United States Supreme Court in *Olmstead v. L.C.* held that the unnecessary institutionalization of individuals living with disabilities violates their rights under the Americans With Disabilities Act to receive services in the least restrictive setting.<sup>1</sup> Since the *Olmstead* decision, California and states across the country have put significant resources into rebalancing the provision of long-term care away from institutional settings toward community-based integrated settings.<sup>2</sup> These efforts have taken the form, for example, of increased funding for HCBS and expansion of programs; a shift in care delivery from fee-for-service models into managed care

### Rebalancing Defined

"Rebalancing is commonly defined as achieving a more equitable balance between the share of spending and use of services and supports delivered in home and community-based settings relative to institutional care."

—Centers for Medicare &  
Medicaid Services

plans; increased coordination initiatives; and the implementation of programs to help individuals transition out of institutional settings into the community. Yet, due to limited data collection, reporting, and evaluation, California's progress towards the goal of rebalancing remains largely unknown. And whether rebalancing has been equitable—particularly with regard to age, disability, race, ethnicity, sexual orientation, gender identity, geography, and other factors—has only recently become a focus.

This paper builds on the recommendations put forth in [Using Data for Good: Toward More Equitable Home and Community-Based Services in Medi-Cal](#) and aims to support state agencies, policymakers, and interested parties in efforts to equitably rebalance the provision of services from institutions to home and community-based settings. The paper describes how rebalancing measures can advance equitable long-term care for Medi-Cal enrollees; the effects of managed care on the ability to track expenditures for long-term services and supports; why expenditure data alone is a limited measure of progress in rebalancing; and provides recommendations for adopting rebalancing measures that would advance California's goal to build a more equitable, balanced long-term care system.

Historically the ability to measure rebalancing has been impeded by limitations in California's expenditure data, but these limitations present the state with a tremendous opportunity to develop measures of rebalancing that further the state's goal of building an equitable long-term care infrastructure. New measures would allow California to identify disparities in access to and use of long-term services and supports, determine how intersectional factors give rise to disparities, and develop targeted strategies and policies to address those disparities to ensure all individuals receive the care and supports they need in the setting of their choice.

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## REBALANCING MEASURES ARE CRITICAL TO BUILDING AN EQUITABLE LONG-TERM CARE INFRASTRUCTURE

At the most foundational level, rebalancing aims to address the institutional bias embedded in federal law that mandates coverage for care provided in institutional settings while making it optional for states to cover HCBS. This institutional bias is rooted in discriminatory views of people with disabilities of all ages as less valuable to society, borne out by segregating and isolating them into confined settings.<sup>3</sup> Long-term care financing and policies have reflected and perpetuated this discrimination, favoring institutional care over HCBS, and have led to California's patchwork of HCBS programs with limited access and waitlists. Because HCBS is not universally available, there are inequities in who has access to the supports and services needed to live in the community and who has no option but to receive care in an institutional setting.<sup>4</sup> Racial discrimination and segregation in housing further compound the inequities in the long-term care infrastructure, because without accessible housing, people cannot receive HCBS.<sup>5</sup> Eradicating the discrimination ingrained in the long-term care infrastructure requires targeted rebalancing strategies and resources and an ongoing, robust evaluation of California's progress. This is particularly urgent in light of the COVID-19 pandemic that has disproportionately killed residents in institutional settings at much higher rates, especially in facilities with a greater percentage of residents of color.<sup>6</sup>

Like other states, following *Olmstead*, California drafted an [Olmstead plan](#) in 2003 and implemented a wide array of policies and initiatives to rebalance its long-term care system towards more home and community-based services.<sup>7</sup> In 2007, for example, the state launched the California Community Transitions program utilizing federal Money Follows the Person funding to support Medi-Cal enrollees transitioning out of facilities into the community when appropriate and desired.<sup>8</sup> And in 2014, the state launched the Coordinated Care Initiative demonstration as a part of California's efforts to better coordinate medical care with long-term services and supports through managed care

plans. The state also obtained enhanced federal funding for personal care services in home and community settings through the Community First Choice Option. And most recently, California has committed to making Medi-Cal managed care plans (MCPs) responsible for the institutional long-term care benefit statewide through CalAIM (California Advancing and Innovating Medi-Cal), expanding the types of HCBS-like services MCPs can offer to enrollees, and leveraging new federal funding to strengthen the Medi-Cal HCBS infrastructure.<sup>9</sup>

Rebalancing measures and goals are critical for ensuring that government policies aimed at rebalancing have their intended effect. However, today, little is known about whether past or current policies are advancing rebalancing, and whether rebalancing efforts reduce inequities in access to HCBS or perpetuate them. For example, research analyzing national nursing home closure patterns demonstrates that rebalancing efforts have led to an increase in facility closures with a correlating increase of assisted living and community adult day center openings—seemingly indicative of positive progress towards rebalancing.<sup>10</sup> However, these nursing facility closures have occurred disproportionately in low-income and predominantly Black and Hispanic communities; at the same time, assisted living and community adult day centers that replaced nursing homes opened in predominantly white communities.<sup>11</sup> In California, research has similarly shown a disproportionate increase of skilled-nursing facilities and home-health services in higher-income areas and a disproportionate decrease in *all* long-term care services options in lower-income areas.<sup>12</sup> As California makes investments in HCBS and implements policies to advance rebalancing, it is important to measure the extent to which the state’s new policies ameliorate inequities, rather than cause disparities, in access to HCBS.

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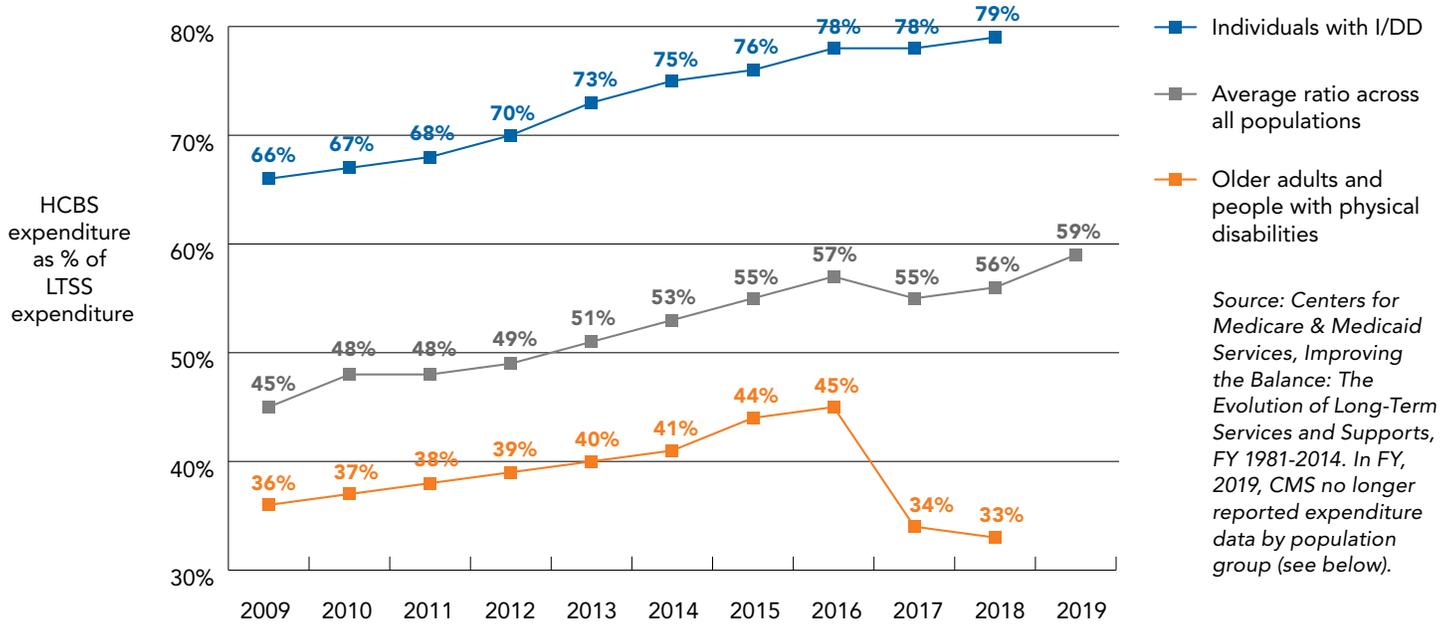
## CHALLENGES IN MEASURING REBALANCING: A HISTORICAL REVIEW OF EXPENDITURE DATA AND REBALANCING RATIOS

Since 1981, analysts have primarily relied on Medicaid long-term services and supports (LTSS) expenditure data to measure a state’s progress in rebalancing.<sup>13</sup> State Medicaid systems using fee-for-service models reimburse providers for specific covered services and submit reimbursement information to the Centers for Medicare & Medicaid Services (CMS).<sup>14</sup> CMS analyzes state expenditures, calculating the rebalancing ratio, or percentage, of HCBS and institutional long-term care spending out of total LTSS expenditures and publishes results in annual LTSS expenditure reports. In the latest report from federal fiscal year 2019, expenditure data shows that nationally, 59% of total LTSS expenditures were for HCBS and 41% were for institutional care.<sup>15</sup> A decade earlier (fiscal year 2009), 45% of total LTSS expenditures were for HCBS and 55% were for institutional care—a notable shift in spending towards HCBS as demonstrated in Figure 1.

However, these spending patterns vary widely from state to state and between different population groups. For example, as seen in Figure 1, national HCBS spending only exceeds 50% of total LTSS expenditures for the developmentally disabled population, increasing steadily over the last decade from 69% in 2009 to 79% in 2018. Other populations have not achieved the same level of rebalancing. Spending for HCBS for older adults and people with physical disabilities has remained far below 50% of total LTSS expenditures and in fact has declined from 36% in 2009 to 33% in 2018. Put another way, in 2018 two-thirds (67%) of national LTSS spending for older adults and people with physical disabilities went towards care provided in institutional settings. This HCBS spending differential by population is attributable to three factors: 1) the high needs and accompanying higher costs of care for people with developmental disabilities; 2) states implementing specific strategies and programs—to the

credit of significant advocacy by disabled people, their families, and advocates—to expand access to HCBS for this population; and 3) states transitioning HCBS into managed care for older adults and people with physical disabilities masking spending on these services for this population as discussed in more detail below.<sup>16</sup>

**FIGURE 1**  
Percent of Total National LTSS Expenditures for HCBS, by Population Group & Year



## CALIFORNIA'S LTSS EXPENDITURE DATA IS NOT AN ACCURATE MEASURE OF REBALANCING

These LTSS expenditure reports do not adequately account for the transition in many states over the last decade away from fee-for-service Medicaid models and toward managed care systems that use capitation reimbursement models.<sup>17</sup> Under capitation models, the state pays the plan a fixed rate per covered member for all services offered under that plan, including HCBS and institutional care.<sup>18</sup> States base rates on complex actuarial formulas that use several factors, including historical claims, cost, and population-focused utilization data.<sup>19</sup>

LTSS expenditure data in managed LTSS states has become broadly unreliable as a source for calculating their rebalancing ratios.

Many states that transitioned to capitated reimbursement models have not reported expenditure data that is accurately apportioned between HCBS, institutional services, and other health care.<sup>20</sup> Consequently, LTSS expenditure data in managed LTSS states has become broadly unreliable as a source for calculating their rebalancing ratios—especially for older adults and people with physical disabilities. For this reason, Arkansas, California, Delaware, Illinois, and Virginia did not submit data on managed care LTSS expenditures for fiscal year 2019.<sup>21</sup> And for the first time in fiscal year 2019, CMS no longer included spending breakouts and rebalancing ratios for sub-populations, including older adults and people with physical disabilities, people with autism spectrum disorder, people with intellectual and developmental disabilities, and people with behavioral health conditions, on the basis that states submitted unreliable data that could lead to misleading results.<sup>22</sup>

Because California delivers a high proportion of LTSS through managed care, and detailed managed care information had not been made available to ensure accurate reporting of institutional and HCBS expenditures

through that delivery system, CMS ceased including California in its annual LTSS expenditure reports in 2015.<sup>23</sup> In efforts to verify that LTSS expenditure data is not available in California, Justice in Aging reviewed publicly available LTSS Medi-Cal spending data for California for years 2014 through 2019 and discovered the same limitations in the data outlined in the CMS LTSS expenditure reports. Specifically, the capitated rates paid to managed care plans masked the amount of LTSS expenditures for both institutional expenditures through managed care plans and expenditures for the Community-Based Adult Services (CBAS) program—the only HCBS benefit delivered nearly exclusively through managed care.<sup>24</sup> Justice in Aging also confirmed these findings and the limitations with LTSS expenditure data with the Department of Health Care Services (DHCS)—the state’s Medicaid agency.<sup>25</sup>

“The state’s shift to managed care and capitation reimbursement may currently be an impediment to measuring rebalancing, but it also serves as an opportunity to move to a more effective way to define and measure rebalancing.”

In 2014, the last year in which CMS included California in its expenditure reports and calculated a rebalancing ratio, the state expended 64% on HCBS and 36% on institutional care across programs and populations and ranked 8th in the country in terms of its spending on HCBS.<sup>26</sup> For comparison, Oregon was ranked first in 2014, spending 79% of LTSS expenditures on HCBS, and Mississippi was ranked last, with 27% of expenditures going towards HCBS. While California cannot provide a current rebalancing ratio based on LTSS expenditures, the lack of a rebalancing ratio offers California an opportunity. As a measure of rebalancing, expenditure data has always been inadequate. It serves as a foundational and relatively rudimentary measure of a state’s increase or decrease in spending towards HCBS compared to institutional care. And while increased spending on HCBS can indicate growth in HCBS availability, it does not measure the number of individuals accessing services, quality of services provided, equitable access to services, or the adequacy of services in meeting consumer needs.<sup>27</sup> The state’s shift to managed care and capitation reimbursement may currently be an impediment to measuring rebalancing, but it also serves as an opportunity to move to a more effective way to define and measure rebalancing.

## REBALANCING, REIMAGINED

The time to reimagine rebalancing is now. CMS recently defined rebalancing as “achieving a more equitable balancing between the share of spending *and* use of services and supports delivered in home and community-based settings relating to institutional care” (emphasis added).<sup>28</sup> This is a welcome shift from the historical dependence on expenditures as the sole federal rebalancing measure, as service utilization is an integral part of measuring the provision of particular services. Yet, to ensure that rebalancing can be accurately measured and used to identify disparities in access, utilization, and the adequacy of particular services in supporting integrated community living—particularly with the move of more services and programs into managed care—California must adopt a new framework that reflects the degree to which the state is accomplishing the goals of *Olmstead* by equitably providing nursing-home-level services in the community.

“California must adopt a new framework that reflects the degree to which the state is accomplishing the goals of *Olmstead* by equitably providing nursing-home-level services in the community.”

California has already begun taking encouraging steps toward evaluating the state’s rebalancing efforts. For example, in 2021, California committed to assessing the adequacy and availability of LTSS by conducting a Gap Analysis study and developing and publishing an LTSS Dashboard as part of the “LTSS Data Transparency Initiative” and the state’s Master Plan for Aging.<sup>29</sup> The first version of the LTSS Dashboard is to be published sometime in 2022 with the goal of providing more data publicly and tracking and measuring the state’s progress in providing LTSS.<sup>30</sup> Further, DHCS indicated that the state would not rely on expenditure data, but instead integrate stratified utilization and demographic data in the new LTSS Dashboard and report cost data. Among

other measures, California also plans to track the total number of institutional care and HCBS program users out of the total Medi-Cal population, the count of particular waiver users, the number of users of multiple programs and waivers, and the number of HCBS users who also had a nursing facility stay. The state indicates that the data will be stratified by demographic groups, with a commitment to make reporting more robust in the future.<sup>31</sup>

Federally, CMS recently published a “Home and Community-Based Services Quality Measure Set” that sets forth data collection measures that states can use to measure the quality, equity, and rebalancing of their long-term care systems.<sup>32</sup> California could leverage this new tool to add qualitative measures to its current quantitative measurement framework. These quality measure sets, together with the demographic and utilization data the state plans to collect and report on in the LTSS Dashboard, can create a powerful framework to evaluate and address inequities in the state’s long-term care system while making a meaningful difference in the quality of life for low-income older adults and people with disabilities.

## RECOMMENDATIONS FOR MEASURING EQUITABLE REBALANCING UTILIZING LTSS EXPENDITURE DATA

With the implementation of CalAIM and the development of its LTSS Dashboard, California can lead the way nationally in creating an equity-centered, rebalanced long-term care system. The following recommendations serve to inform and build on efforts already underway to develop the LTSS dashboard and offer additional rebalancing measures and strategies to assess disparities and address inequities in California’s long-term care system. **Guided by a thorough and intentional data collection effort, California can move the needle towards an equitably rebalanced system.**

### UTILIZE T-MSIS DATA TO PUBLICLY REPORT LTSS UTILIZATION DATA WITH DEMOGRAPHICS FOR ALL MEDI-CAL ENROLLEES

California’s reporting of LTSS utilization could rely on the data the state submits to CMS through the Transformed Medicaid Statistical Information System (T-MSIS). States can aggregate and analyze already submitted claims data for all Medicaid encounters through T-MSIS, including eligibility details, demographic information, service utilization, expenditure data, and managed care claims data.<sup>33</sup> Because the data, including claims details such as admission and discharge dates, diagnostic information, waiver or program participation, and cost or reimbursement data, is identified per user it is not duplicative.<sup>34</sup> Using the T-MSIS data, California could calculate its rebalancing ratio, overall and for targeted population subgroups, since the T-MSIS includes cost data. In fact, in its latest 2019 report on LTSS expenditures, CMS indicated that it would rely on T-MSIS data as the more accurate source for calculating rebalancing ratios for population subgroups.<sup>35</sup>

More importantly, California could use the T-MSIS data to conduct its own access and quality analysis by linking HCBS utilization with institutional encounters, stratified by subpopulations, including age, diagnosis, race, ethnicity, geography, and cost. T-MSIS is a large and complex dataset and dedicated resources are needed for DHCS to review, analyze, and report findings on LTSS, specifically. CMS provides 90% federal matching to states for “the design, development, installation, or enhancement” of the T-MSIS system.<sup>36</sup> This enhanced federal funding with dedicated state resources could provide the support DHCS needs to leverage the T-MSIS data. In sum, utilizing the T-MSIS data could significantly improve the state’s ability to identify access and quality disparities, measure its rebalancing progress for specific populations, and ultimately develop targeted strategies and interventions to deliver culturally-competent and high-quality care and supports to the highly diverse population in need of HCBS and institutional care.

## PUBLICLY REPORT BOTH CURRENT AND HISTORICAL LTSS UTILIZATION DATA

DHCS indicated that its new LTSS Dashboard would include LTSS utilization data going back to 2021. The Dashboard could also include historical data retrospectively for a minimum of ten years. Historical data could allow the state to assess historical trends, the effect of rebalancing-focused policy changes, and the impact policy changes may have had on addressing disparities in access to HCBS. Further, retrospective data could capture the impact of the COVID-19 pandemic on the long-term care infrastructure, particularly in light of the tragic loss of life in nursing facilities and the significant corresponding increase in federal and state funding poured into institutional and HCBS care as part of the pandemic response.

DHCS has indicated that it will publish updated versions of the LTSS Dashboard to incorporate new metrics in the years 2022 through 2025. The LTSS Dashboard could also be updated annually at a minimum, on an ongoing basis to demonstrate baseline rebalancing progress and allow tracking of new initiatives such as CalAIM on their equitable access to long-term care services.<sup>37</sup> Further, the LTSS Dashboard could be assessed periodically to determine whether to update metrics or other aspects of the Dashboard.

## COLLECT AND REPORT MEDI-CAL MANAGED CARE UTILIZATION AND COST DATA STRATIFIED BY DEMOGRAPHIC CATEGORIES FOR NEW HCBS-LIKE BENEFITS

As noted previously, California has been unable to track its rebalancing efforts through expenditure data since at least 2015 due to its reliance on managed care to deliver LTSS. The role of managed care plans in reapportioning institutional care and HCBS is only growing with the implementation of CalAIM, including the pending carve-in of institutional long-term care statewide in January 2023, and the rollout of Enhanced Case Management and Community Supports under managed care that began in January 2022.<sup>38</sup> The goals for carving LTSS into managed care include: expanding HCBS, promoting community inclusion, improving quality, and increasing efficiency.<sup>39</sup> These HCBS-like benefits are intended to address social determinants of health and help individuals avoid unnecessary hospitalizations and remain at home and connected to their communities—and can serve as a means of rebalancing.<sup>40</sup> Without data, however, it is impossible to determine the extent to which Medi-Cal managed care plans are meeting these goals and advancing the state’s broader rebalancing efforts. Collecting and reporting detailed HCBS utilization data with robust demographic data for Medi-Cal managed care, including Community Supports and Enhanced Case Management, is critical to measuring the state’s progress on rebalancing. Demographic data could be disaggregated and reported intersectionally so that the state can track disparities within subpopulations and among distinct population groups with intersecting identities, as outlined in [Using Data for Good: Toward More Equitable Home and Community-Based Services in Medi-Cal](#).<sup>41</sup>

“Collecting and reporting detailed HCBS utilization data with **robust demographic data for Medi-Cal managed care**, including Community Supports and Enhanced Case Management is **critical to measuring the state’s progress on rebalancing**.”

## ANALYZE LTSS UTILIZATION DATA TO SET BENCHMARKS AND ANNUAL GOALS FOR EQUITABLE REBALANCING

California could set annual equitable rebalancing goals and use collected data to ensure that the state is meeting these goals. Recognizing that “increasing the collection of standardized demographic and language data across health care systems is a crucial first step towards improving population health,” CMS set priorities and guidelines for

achieving health equity and eliminating disparities in its recently published “Framework for Equity.”<sup>42</sup> As discussed above, California’s progress on rebalancing is unknown, and no demographic data is currently publicly available to determine disparities in access and utilization of services. California can model its rebalancing strategy on CMS’s Framework by setting equity-oriented goals informed by assessments of programs for unintended consequences and disparities in quality, access, and outcomes for its long-term care system.

In setting rebalancing goals, California could also refer to the recently-published CMS Measure Set, which analyzes various data collection tools and surveys and suggests using different tools for different HCBS assessments. California could also look to the experiences of other states’ expenditure-free goal-setting structures. For example, Minnesota’s LTSS goals to improve access, quality, and sustainability of LTSS, guided by collected qualitative and quantitative data and accountability measures, help the state take data-driven actions and track their effect on stated goals.<sup>43</sup> Washington State’s acuity assessment tools used to determine how many nursing-home level care individuals use institutional and community services can also be a helpful rebalancing measure.<sup>44</sup> By stratifying these measures with demographic data, California can set equity-focused rebalancing goals that assess the success of implemented policies and guide future state policy decisions.

## BEYOND LTSS UTILIZATION AND COST DATA: LEVERAGE QUALITATIVE DATA

Like expenditure data, LTSS utilization data is limited and merely shows the number of individuals using specific LTSS services. Building a robust data resource that links utilization stratified by demographic groups along with other quality measures can identify discrepancies in quality and access and would provide a richer, equity-centered assessment of the state’s current rebalancing status.

To start, California could create a baseline rebalancing measure by stratifying demographic data with the number of care hours provided in nursing homes compared to HCBS service hours provided to individuals evaluated as requiring nursing home-level care. Additionally, California could track managed care plans’ rebalancing success and hold plans accountable by using CMS’s “Home and Community-Based Services Quality Measure Set” to ensure HCBS sufficiency in preventing institutionalization.<sup>45</sup> Measures of access to and sufficiency of HCBS in the CMS HCBS measure set include:

- The number of long, medium, and short-term admissions to facilities from community settings among people enrolled in managed care versus those enrolled in fee-for-service Medi-Cal, stratified by age and other demographic criteria.<sup>46</sup>
- The proportion of facility admissions that successfully transferred to the community within 100 days of admission.<sup>47</sup>
- The proportion of long-term facility stays that result in a successful transition to the community.<sup>48</sup>
- National Core Indicator Surveys for both Aging and Disabilities and for Intellectual and Developmental Disabilities to evaluate the sufficiency of person-centered care.<sup>49</sup>

Finally, the state could incorporate lessons from its recent review of Regional Centers to ensure equitable access to services for individuals with intellectual and developmental disabilities. In 2017, the state launched a qualitative analysis of the progress Regional Centers were making serving this population and addressing disparities by using expenditure and experiential data measuring consumer experience to identify areas of difference among demographic groups.<sup>50</sup> While much work remains to address disparities in access to Regional Center services, the state’s progress and challenges in this area could inform equitable rebalancing across the Medi-Cal long-term care infrastructure and for all populations.

# CONCLUSION

California is undertaking significant changes once again to its Medi-Cal program that present enormous opportunity to make real progress towards realizing the mandate in Olmstead. The implementation of CalAIM and other initiatives provide opportunities to deliver the kind of coordinated care that policymakers have envisioned for the past 30 years. Together with the state's new data collection and evaluation efforts, California can make real progress towards ensuring all people with disabilities have access to the care and supports they need in the least restrictive and most integrated setting. California has led the way in innovation in Medicaid and now has the opportunity to set the standard nationally for embedding principles of equity in its data collection, reporting, and its means of measuring and evaluating rebalancing. The time is now to go beyond expenditure data and meaningfully move the needle on equitable rebalancing.

# ADDITIONAL RESOURCES

## National Resources

- [CMS Framework for Health Equity 2022-2023](#) (April, 2022). CMS Office of Minority Health developed a 10-year plan for embedding equity into all CMS programs, including Medicare, Medicaid, and CHIP, broken down into five priority groups: data collection and analysis, programmatic disparities analysis, organizational and workforce capacity building, advancement of language access and cultural competency, and increasing access to health services and coverage.
- [CMS LTSS Expenditure Reports](#). Publication of annual state reports on LTSS expenditures, from 1981 to 2019, including institutional and HCBS spending and beneficiary reports.
- CMS [HCBS Quality Measure Set](#) (July 21, 2022). CMS-developed standardized measures for assessing HCBS quality and outcomes. Each measure includes information on whether it can be used to assess access, rebalancing, and community integration and settings requirements under the HCBS settings rule.
- CMS [Long-Term Services and Supports Rebalancing Toolkit](#) (Nov., 2020). To support states' efforts to rebalance their LTSS from institutional to home-and-community-based settings, CMS created a toolkit that includes resources, tools, and best-practices strategies to support state programs aimed at shifting away from institutional placement towards community living. This toolkit includes a history of HCBS programmatic development and rebalancing progress, demographic trends, ideas for HCBS program improvement, and Medicaid flexibilities that states can leverage to support rebalancing efforts.
- [National Core Indicator Surveys](#). Human Rights Services Institute and National Association of State Directors of Developmental Disabilities Services, together with participating state developmental disabilities and social services agencies, issue person-centered surveys to LTSS consumers and their families that can be used by state agencies to measure and track performance, quality, and outcomes of state LTSS programs. The NCI-I/DD survey for individuals with intellectual and developmental disabilities, and the NCI-AD survey, assess programs serving older adults and individuals with physical disabilities. California is a participating state in the NCI-I/DD but does not administer the NCI-AD survey.
- [Transformed Medicaid Statistical Information System](#). The CMS website publishes background information on the T-MSIS, state compliance and data quality evaluations, and [T-MSIS analytic files](#), which publish data from various data sources, including the CMS-64 state reports and T-MSIS claims data.
- [T-MSIS Technical Instructions](#) (last updated August 2021). CMS guidelines to states on reporting requirements and data quality measures for T-MSIS claims data submissions.
- [CMS Measures of State Long-Term Services and Supports System Rebalancing](#) (Nov., 2019). A comprehensive review of quality measures that states can use to evaluate and improve HCBS and support their LTSS rebalancing efforts.
- [“Implementing Health Reform: Improved Data Collection and the Monitoring of Health Disparities”](#) (2014). *Annu. Rev. Public Health.* 35: 123-38, 125. (Arguing that granular subpopulation demographic data is imperative for identifying disparities.)
- [Medicaid and LTSS Primer](#) (Dec 15, 2015). Kaiser Family Foundation's review of LTSS, how are they paid for, who uses them, and how are they evaluated and developed.
- [“Reforming Long-Term Care with Lessons from the COVID-19 Pandemic”](#) (February, 2021). Urban

Institute's summary of roundtable participant recommendations, based on lessons learned from COVID-19 deaths in congregate living facilities. Recommendations include strengthening HCBS infrastructure, investing in a robust caregiver workforce, improving LTSS financing, and improvement to LTSS delivery and continuum of care.

## State Resources

### California

- [California Regional Center Disparities Report](#) (2022). Public Counsel's publication analyzes continuing disparities in service expenditure and utilization at California's Regional Centers, despite California's financial investment in disparity reduction at the Centers.

### Minnesota

- [HEDA: Conducting a Health Equity Analysis. A guide for local health departments](#) (July, 2022). Minnesota's Department of Health published guidelines for conducting equity-centered community health assessments. This framework recommends using community engagement, qualitative and quantitative data collection, and analyzing policy and systemic factors to identify health inequities and health outcomes between population groups.
- [Health Equity Demographic and Socio-economic Data Portal](#) Applying the HEDA framework, Minnesota has a dedicated health equity data portal, which publishes demographic data together with data on social determinants of health by county, including education, unemployment, income, and incidents of particular health conditions.
- ["Status of Long-Term Services and Supports: Aging and Adult Services, Disability Services, Behavioral Health, Nursing Facility Rates and Policy"](#) (August, 2019). Biennial Legislative Report by Minnesota Department of Human Services, using data-informed evaluation of Minnesota's long-term care system and its rebalancing efforts. The report, provides an assessment of the current status of the state's LTSS system, identifies needs and sets goals and recommendations for future changes and investments to improve and further rebalance the state's long-term care system.

### Oregon

- [Oregon Long-Term Support Services System Collaboration Framework](#). Coordinated Care Organizations and local AAA organizations work together to provide community-based long-term care in a coordinated effort to prevent institutionalization and address health inequities.
- McConnel, John et. Al. ["Oregon's Emphasis on Equity Shows Signs of Early Success Among Black and American Indian Medicaid Enrollees"](#) (2018). Health Affairs 37, No. 3. available at <https://pubmed.ncbi.nlm.nih.gov/29505371/> (analyzing Oregon's move to locally provided care through coordinated care organizations on health inequities, finding that the use of CCOs together with health equity policies led to a reduction in access to care but not emergency care use).

# ENDNOTES

- 1 *Olmstead v. L.C.*, 527 U.S. 581, 583 (1999).
- 2 Little Hoover Commission, “Long Term Strategy in Long-Term Care,” (April, 2011) available at <https://lhc.ca.gov/sites/lhc.ca.gov/files/Reports/205/Report205.pdf>; Community Living Policy Center, “Care Can’t Wait: How Do Inadequate Home- and Community-Based Services Affect Community Living and Health Outcomes?,” (2021), available at <https://heller.brandeis.edu/community-living-policy/images/pdfpublications/care-cant-wait.pdf>.
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were more likely to close, and at even higher rates in states with lower Medicaid reimbursements levels, and “high Medicaid occupancy was associated with almost a three-fold higher closure probability for facilities with low Medicaid reimbursement rates, but less than a two-fold higher closure probability for facilities with high Medicaid reimbursement rates.” At 1103).

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- 21 Id.
- 22 In 2019, CMS removed LTSS targeted population subgroups reporting from the total expenditure and percentage of LTSS expenditures for HCBS calculations. Id. at 42.

- 23 In 2015 and currently, institutional long-term care is a Medi-Cal managed care benefit in 27 of California's 58 counties. Community-based adult services (CBAS) is a Medi-Cal managed care benefit in all 58 counties. Under CalAIM, institutional long-term care will become a managed care benefit in all 58 counties effective January 1, 2023. See, DHCS, "CalAIM Long-Term Care Carve-In," last visited Aug. 22, 2022, available at <https://www.dhcs.ca.gov/provgovpart/Pages/Long-Term-Care-Carve-In-Transition.aspx>. See also, CMS, Mathematica and Truven Health Analytics, "Medicaid Expenditures for Long-Term Services and Supports (LTSS) in 2015," at 11 (April 14, 2017) (explaining why California is not included in the 2015 Medicaid LTSS Expenditure Report), available at <https://www.medicaid.gov/sites/default/files/2019-12/ltssexpendituresffy2015final.pdf>. See also,
- 24 Justice in Aging analyzed California annual data from institutional care facilities' revenue disclosure reports published on the California Health and Human Services Open Data Portal. We added all Gross Routine Medi-Cal Revenues annually, for years 2014-2019. We then compared annual long-term care expenditures reported on the CMS-64. Because revenue expenditures were over-inclusive and CMS-64 were underinclusive, the difference between revenues and expenditures was as much as \$2 billion. For revenue data, see CHHS, "Long-Term Care Facility Integrated Disclosure and Medi-Cal Cost Report Data & Pivot Tables," (2014-2019) available at <https://data.chhs.ca.gov/dataset/long-term-care-facility-disclosure-report-data>; For state-reported expenditure data see CMS, "Expenditure Reports From MBES/CBES," (2014-2020) available at <https://www.medicaid.gov/medicaid/financial-management/state-expenditure-reporting-for-medicaid-chip/expenditure-reports-mbescbes/index.html>.
- 25 Justice in Aging submitted a Public Record Act request on April 19, 2022 to DHCS for (a) California's disaggregated expenditure data for both HCBS and institutional services that were prepared or submitted by the state for its federally-required CMS-64 reports (b) any other publication, study, analysis or other documentation that disaggregates LTSS expenditure by HCBS and institutional services, including demographic and (c) All LTSS Claims Data files submitted by California to the Transformed Medicaid Statistical Information Systems (T-MSIS) for all available years from 2019 to the present, indicating age, race, and ethnicity of claimants. On May 5, 2022, DHCS communicated that by May 13, 2022, the Department will determine whether our requested documents could be produced. On June 14, 2022, after not receiving a response to the May 13, 2022 communication, Justice in Aging provided a follow-up letter explaining the purpose of the request, and simplifying it to only HCBS and institutional expenditure data. DHCS to date did not produce any records in response to our request. DHCS confirmed in a meeting with Justice in Aging on July 14, 2022, that no other evaluation or reports on rebalancing exist.
- 26 CMS, Mathematica and Truven Health Analytics, "Medicaid Expenditures for Long-Term Services and Supports (LTSS) in 2014," (April 15, 2016) at Table C, available at <https://www.medicaid.gov/sites/default/files/2019-12/ltssexpenditures-2014.pdf>.
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- 28 CMS, "Home and Community-Based Services Quality Measure Set," (July 21, 2022) at 8, available at <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf>.
- 29 DHCS, "California's Request for Money Follows the Person Supplemental Funding," available at <https://bit.ly/3AaIXTb> and "Attachment A Money Follows the Person Supplemental Funding Proposal," available at <https://www.dhcs.ca.gov/services/ltc/Documents/Money-Follows-the-Person-Supplemental-Funding-Proposal.pdf>; DHCS Dashboard Initiative available at <https://www.dhcs.ca.gov/provgovpart/Pages/DHCSDashboardInitiative.aspx>; and Master Plan for Aging available at <https://mpa.aging.ca.gov/>.
- 30 DHCS Webinar Presentation of the LTSS Dashboard Initiative. June 15, 2022.
- 31 Id.
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- 36 42 CFR §433.110-112.
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- 38 DHCS, CalAIM Enhanced Care Management, Community Supports, and Incentive Payment Program Initiatives, available at <https://www.dhcs.ca.gov/enhancedcaremanagementandinlieuofservices>.
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- 45 CMS, “Home and Community-Based Services Quality Measure Set,” (July 21, 2022) at 15, available at <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf>.
- 46 CMS, “Medicaid Managed Care Long-Term Services and Supports (MLTSS) Measures Technical Specifications and Resource Manual,” (2022) at 37 available at <https://www.medicaid.gov/media/3396>.
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