The Disability and Aging Collaborative

April 13, 2023

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Daniel Tsai
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Sent Via email on 04/12/2023

Re: LTSS Expenditures

Dear Administrator Brooks-LaSure and Deputy Administrator Tsai,

Accessing home and community-based services (HCBS) can be challenging for older adults and people with disabilities due to an institutional bias in federal Medicaid law that requires states to provide care in institutional settings while most HCBS remains optional. We commend current efforts by CMS to reduce the institutional bias by "rebalancing" funds and services away from institutional settings and towards community-based integrated settings.[1] To advance rebalancing efforts and achieve the health equity goals of the Biden-Harris Administration, the undersigned organizations urge CMS to improve its collection and reporting of Medicaid long-term services and supports (LTSS) expenditure data. The signatory organizations are members of the Disability and Aging Collaborative (DAC), a coalition of approximately 40 national organizations that work together to advance long-term services and support policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability and aging organizations.

Specifically, as members of DAC, we request that CMS collect standardized LTSS expenditure data annually from every state and across all LTSS programs. We also ask

[1] 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.

for disaggregation of expenditure data by the delivery system and demographic characteristics. This information will identify disparities in access and use of LTSS and help states and CMS deploy targeted strategies to meet the needs of older adults and people with disabilities. This letter examines opportunities to improve LTSS expenditure data and offers recommendations for enhanced data collection and reporting.[2]

Reliance on the Rebalancing Ratio Risks Masking Disparities

Although significant resources have been invested in rebalancing efforts at the federal and state levels, data limitations inhibit our understanding of how these efforts impact specific populations and whether actions are equitable. Since 1981, CMS has relied mainly on Medicaid LTSS expenditure data to evaluate rebalancing progress, focusing on the rebalancing ratio.[3] The rebalancing ratio analyzes state expenditures on HCBS as a percentage of total LTSS spending. Federal fiscal year expenditure data for 2019 demonstrates that 59% of LTSS spending went toward HCBS.[4] While this measure reveals greater national spending on HCBS as opposed to institutionalized care, it does not adequately capture states' expenditures or evaluate whether service provision was equitable. A growing number of states have opted to deliver increasingly more LTSS through managed care plans; reporting requirements for capitated managed care often lump expenditure data for both HCBS and institutional spending together, rendering expenditure data broadly unreliable to measure rebalancing. Moreover, the rebalancing ratio varies greatly by population type. In 2018, only 33% of LTSS expenditures went towards HCBS for older adults and people with physical disabilities.[5] As this example shows, sole reliance on the rebalancing ratio to evaluate rebalancing progress risks masking disparities in access, utilization, and adequacy of services.

The Need for Targeted Strategies

A higher prevalence of illness and poverty incurred by marginalized older adults and people with disabilities, combined with Medicaid's institutional bias, results in specific populations experiencing an increased risk of institutionalization. For example, compared to white older adults, Black older adults are nearly twice as likely, and Hispanic older adults are almost 1.5 times as likely, to have Alzheimer's and other dementias.[6] Today, an astonishing 53% of

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[2] For additional recommendations, please review Justice in Aging's Issue Brief, *Beyond Spending: Measuring California's Progress Towards Equitable Home and Community-Based Services*, available at https://justiceinaging.org/wp-content/uploads/2022/08/Beyond-Spending-Measuring-CAs-Progress-Towards-Equitable-HCBS.pdf.

[3] CMS, "Long-Term Services and Supports Annual Expenditures," (2012-2019), available at https://www.medicaid.gov/ medicaid/long-term-services-supports/reports-evaluations/index.html.

[4] Molly O'Malley Watts, MaryBeth Musumeci & Meghana Ammula, Medicaid Home & Community-Based Services: People Served and Spending During COVID-19, (2022), https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/.

[5] Centers for Medicare & Medicaid Services, Improving the Balance: The Evolution of Long-Term Services and Supports, FY 1981-2014.

[6] Alzheimer's Association, "Black Americans and Alzheimer's," available at https://www.alz.org/help-support/resources/black-americans-and-

individuals 65 and older in institutional long-term care have a diagnosis of dementia.[7] Additionally, research has shown that specific communities of color are admitted to nursing homes at higher rates.[8] And while nursing facility use has been declining across most populations over the last decade, the rates of nursing facility use have stayed the same or even increased for individuals under 65 with physical disabilities and serious mental illness.[9]

Because specific communities are at increased risk of institutionalization, targeted strategies are needed to ensure equitable access to HCBS. On the surface, the movement of resources away from institutionalized care and towards HCBS appears positive and aligned with rebalancing efforts. However, further review of the data suggests that nursing home closures have taken place disproportionately in Black and Latino communities.[10] CMS should make all efforts to ensure that all people have access to LTSS, especially those that live near closed facilities.

Recommendations

The following recommendations aim to improve LTSS expenditure data to better measure whether rebalancing efforts are equitable and ultimately improve the quality and accessibility of care for all older adults and people with disabilities across delivery systems.

1. Require LTSS Expenditure Data Across All States

State reporting of LTSS expenditure data varies significantly across states, with discrepancies by procedural code and completeness. For example, in their latest expenditure reports, Arkansas, California, Delaware, Illinois, and Virginia did not submit data on managed care LTSS expenditures in the fiscal year 2019.[11] We appreciate that CMS intends to use the Transformed Medicaid Statistical Information System (T-MSIS) in future expenditure reports to more

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alzheimers#:~:text=While%20older%20Black%20Americans%20are,disease%20may%20play%20a%20role; Samper-Ternet et al., "Prevalence of Health Conditions and Predictors of Mortality in Oldest Old Mexican Americans and Non-Hispanic Whites," (2012), available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3128678/.

[7] Ne'eman, A., Stein, M., & Grabowski, D., "Nursing Home Residents Younger than Age Sixty-Five Are Unique and Would Benefit from Targeted Policy Making," Health Affairs, Vol. 41, No. 10, (Oct. 2022), available at https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00548.

[8] Id.

[9] Id. For more information on disparities amongst people with IDD and people dually eligible for Medicare and Medicaid that result in higher incidences of poor health and contribute to increased risk of nursing facility placement, see CMS, "Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility or Eligibility for a Low-Income Subsidy," September 2021, available at https://www.cms.gov/files/document/2021-delis-national-disparities-stratified-report.pdf and Bradley et al., "What Do NCI Data Tell Us About Significant Racial & Ethnic Disparities Across Quality of Life & Health Domains?," availble at https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_DB_RacialEquity_final.pdf.

[10] Tyler, Denise and Fennel, Mary. "Rebalance Without the Balance: A Research Note on the Availability of Community Based Services in Areas Where Nursing Homes Have Closed," (June 2017), available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4912472/pdf/nihms753057.pdf

[11] CMS, "Medicaid Long-Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019," (Dec. 9, 2021), available at https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2019. pdf.

accurately calculate rebalancing ratios rather than state-reported expenditure data.[12] As noted in the latest LTSS expenditure report, while T-MSIS data is more comprehensive, the variability in reporting from states remains, limiting analysts' ability to conduct state-by-state comparisons.[13] For example, one 2022 CMS report based on T-MSIS data indicates that there are just 323,390 HCBS users in California and only 1,622 enrolled in the state's personal care program, In-Home Supportive Services (IHSS).[14] However, state data shows that California's enrollment in the IHSS program alone averages over 600,000 individuals monthly. Because the T-MSIS data did not capture California's IHSS claims accurately, the report inaccurately concluded that California is in the bottom five states nationally when reviewing the percentage of HCBS users compared to total LTSS users.

We urge CMS to mandate **standardized** annual reporting of LTSS expenditures and HCBS utilization data from every state and provide critical oversight to ensure the information's accuracy and timeliness. To ensure this information is captured accurately, CMS should use a standardized definition of HCBS, as defined in the American Rescue Plan Act, to enable comparisons across states over time. CMS must work with states to ensure that HCBS is coded to be accurately captured in T-MSIS. CMS should encourage states to take advantage of resources, specifically an enhanced federal match, to develop the needed infrastructure to report T-MSIS data accurately and consistently.

2. Collection, Reporting, and Disaggregation of LTSS Expenditure Data by Demographic Characteristics

A primary health equity goal of CMS is to "expand and standardize the collection and use of data, including on race, ethnicity, primary language, sexual orientation, gender identity, disability status, age, rural/urban environment, and other factors across CMS programs."[15] This goal addresses data limitations that inhibit our understanding of how rebalancing efforts impact specific populations and whether actions are equitable.

As a first step, CMS should work with states to improve the self-reporting of Medicaid applicants' demographic information. The CMS Data Quality Atlas, for example, found most states' race and ethnicity data to be "concerning" or "unusable."[16] Data quality concerns specific to applicants' race and ethnicity information are caused, in part, by low rates of self-reporting. Medicaid applicants may fear, for example, that reporting demographic information could result

[12] Id.
[13] Id.
[14] CMS, "Medicaid Beneficiaries Who Use Long-Term Services and Supports: 2019," (July 2022), available at https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-user-brief-2019.pdf.
[15] CMS, "CMS Strategic Plan Pillar: Health Equity," (2022), available at https://www.cms.gov/files/document/health-equity-fact-sheet.pdf
[16] DQ ATLAS, "Race and Ethnicity," (2019), available at https://www.medicaid.gov/dq-atlas/landing/topics/single/map?topic=g3m16&tafVersionId=23

in denial of Medicaid eligibility. Additionally, insufficient understanding of race and ethnicity questions contributes to inaccurate reporting of demographic information.[17]

To improve the collection and reporting of self-reported demographic information, CMS should revise Medicaid model applications to include evidence-based best practices to inform applicants about why they are being asked to report their demographic information and how it will be used. Medicaid applications must also assure applicants that their demographic information will not impact their eligibility determination.[18] To improve the accuracy of self-reported data, CMS should also implement evidence-based best practices, such as targeted training for Medicaid enrollment workers, to assist applicants in more accurately selecting the demographic categories that align with their identities.[19] These recommendations will improve the accuracy and quality of demographic information within existing datasets, like T-MSIS.

CMS should use the T-MSIS dataset to advance the administration's health equity goals of expanding the use of demographic data. Because the T-MSIS dataset includes demographic information and expenditure data, states can use this dataset to evaluate the impact of their rebalancing efforts on specific populations, identify access and quality disparities, and develop targeted strategies to ensure equitable access to services for those at increased risk of institutionalization.[20] We encourage CMS to use T-MSIS data to evaluate rebalancing progress within and across states and to stratify this information by demographic factors, including age, disability, race, ethnicity, primary language, sex, sex characteristics, sexual orientation, gender identity, and rural/urban environment. As the combination of these demographic identities can compound inequities, we urge CMS to evaluate rebalancing progress on populations with intersectional identities (for example, the impact of rebalancing efforts on LGBTQ+ people with disabilities and Black older women). As previously noted, CMS should provide technical assistance to ensure the accuracy of this administrative data.

3. Stratify LTSS Expenditure Data by Delivery System

Many states do not differentiate LTSS spending by delivery type, making LTSS expenditures data unreliable for calculating rebalancing ratios.[21] This data limitation inhibits meaningful comparisons of how well different delivery models, such as MLTSS, meet the needs of care recipients. This is particularly alarming considering a recent report from GAO that uncovered

[17] MACPAC, "Improving Medicaid Race and Ethnicity Data Collection and Reporting: Review of recommendation and draft chapter for March report," (2023), available at https://www.macpac.gov/publication/medicaid-race-and-ethnicity-data-collection-and-reporting-review-of-draft-chapter-and-recommendations-for-the-march-report/.
[18] Id.
[19] Id.
[20] CMS, Transformed Medicaid Statistical Information System (T-MSIS), available at https://www.medicaid.gov/medicaid/ data-systems/macbis/transformed-medicaid-statistical-information-system-t-msis/index.html
[21] CMS, "Medicaid Long-Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019," (Dec. 9, 2021) at 5, available at https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2019. pdf.

significant access and quality problems in MLTSS programs.[22] Stratifying LTSS expenditure information by the delivery system – specifically managed care, fee-for-service, and PACE – will help states to evaluate the quality of care by the delivery system and make adjustments, as needed, to evaluate models and identify the most effective, efficient, and impactful approaches.

4. Ensure the Accuracy of the Data

CMS must conduct rigorous quality reviews to ensure the accuracy of the data included and analyzed in its reports.[23] Quality reviews should be done not only for overall HCBS and institutional expenditures but also for the accuracy and completeness of all fields in the HCBS taxonomy. The CMS Data Quality Atlas currently does not track the quality of HCBS data.[24] We recommend that HCBS be added and updated annually so that the quality of data and reporting is known and progress can be tracked over time.

5. Present Information in a Beneficiary-Friendly Format

Once enhanced LTSS expenditure data becomes available, this data must be presented in a timely, user-friendly, and accessible format for the public. We encourage CMS to consult with advocates and researchers about best practices to ensure the widespread availability and use of the data. For now, the T-MSIS Analytic Files from T-MSIS are only available after a significant lag and can be prohibitively expensive for many researchers and policy analysts to access. We also encourage CMS to review innovative efforts at the state level and consider ways to encourage other states to adopt promising practices. For example, California's new LTSS dashboard will report LTSS utilization data stratified by demographic information.[25]

6. Beyond Expenditure Data

Standardized reporting across states is critical to evaluate HCBS quality. Although the introduction of the "Home and Community-Based Services Quality Measure Set" represents a promising step forward in understanding the quality of services delivered, the voluntary nature of

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[22] GAO, "Medicaid Long-Term Services and Supports: Access and Quality Problems in Managed Care Demand Improved Oversight," (November 2020), available at https://www.gao.gov/assets/720/710680.pdf.

[23] Kyle J. Caswell, Timothy A. Waidmann & Keqin Wei, Measuring Medicaid Service Utilization among Dual Medicare-Medicaid Enrollees Using Fee-for-Service and Encounter Claims, (2021), https://www.urban.org/sites/default/files/publication/104788/measuring-medicaid-service-utilization-among-dual-medicare-medicaid-enrollees-using-fee-for-service-and-encounter-claims-t-msis-analytic-files-data-quality_0.pdf.

[24] Medicaid.gov, DQ Atlas, available at https://www.medicaid.gov/dq-atlas/welcome.

[25] 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/; See also Minnesota Department of Human Services, "LTSS demographic dashboard," available at https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/public-planning-performance-reporting/performance-reports/demographic-dashboard/.

these measures creates significant variation across states and makes HCBS quality comparisons difficult. To allow for robust analysis of the HCBS quality across states, CMS should mandate standardized reporting of the Home and Community-Based Services Quality Measure Set, while recognizing the challenges presented by current state reporting of a variety of HCBS quality measure sets (e.g., CAHPS HCBS; NCI; NCI-AD; POM). As previously indicated, states will require technical assistance and resources from CMS to accurately report this information.

Additionally, while T-MSIS captures information on healthcare utilization, it does not include information on enrollees' psychological, social, and environmental needs. For example, CMS now requires health risk assessments for Medicare Advantage D-SNP plans to include screenings for housing, food, and transportation. Collecting and reporting this information in coordination with claims data could help better determine how well D-SNPs meet the social needs of people dually eligible for Medicare and Medicaid.[26] Beyond collecting an individual's need for resources, measures must also evaluate the extent to which beneficiaries are successfully connected to resources that ultimately resolve their health related social needs. Coordinated reporting of claims data and information on beneficiaries' social determinants of health could positively assist analysts in better identifying how well delivery models meet the needs of beneficiaries.

Conclusion

The undersigned organizations appreciate the commitment on behalf of CMS toward rebalancing efforts. We look forward to working with the agency to improve LTSS expenditure reporting data as a critical first step in evaluating state-based rebalancing progress, identifying disparities in access, and developing more tailored services that meet the needs of older adults and people with disabilities. For questions regarding this letter, please contact Amber Christ, Managing Director of Health Advocacy at Justice in Aging, at achrist@justiceinaging.org.

Sincerely,

AARP

Allies for Independence

American Association on Health and Disability

ANCOR (The American Network of Community Options and Resources)

Autistic Self Advocacy Network

[26] Brown-Podgorski, Brittany and Eric Robert, "Integrating Medicare and Medicaid Data to Improve Care Quality and Advance Health Equity Among Dual-Eligible Beneficiaries," (November 2022), available at https://www.healthaffairs.org/do/10.1377/hpb20221011.325614/.

Caring Across Generations

Justice in Aging

Lakeshore Foundation

National Association for Home Care & Hospice

National Council on Independent Living

National Disability Rights Network

National Health Law Program

National Committee to Preserve Social Security and Medicare

New Disabled South

The Arc of the United States

National Association on Councils of Developmental Disabilities

Service Employees International Union

National Academy of Elder Law Attorneys

National Council on Aging

United Spinal Association

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