Medicaid Long-Term Services and Supports Data

Understanding Gaps and Opportunities to Advance Research and Policy

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Executive Summary

Federal and state spending on Medicaid Long-term services and support (LTSS) exceeds $200 billion each year, but data about these services across and within states are fragmented and inconsistent, hampering evaluation. Understanding how to use existing data sources and taking steps to improve them are necessary for strengthening the evidence base and informing future LTSS policymaking.

INTRODUCTION

Medicaid finances the majority of long-term services and supports (LTSS) in the United States, accounting for approximately one-third of all Medicaid spending and a substantial portion of state budgets. Annual spending on LTSS exceeds $200 billion.[1] Following the passage of H.R. 1, the One Big Beautiful Bill Act, Medicaid programs face additional budget pressures.[2] States will need to make choices about how to stretch Medicaid dollars for long-term services and supports (LTSS). However, the evidence base guiding LTSS policy remains limited due to the absence of comprehensive, comparable longitudinal data.

States administer LTSS programs under multiple provisions of the Medicaid statute which creates a set of complex and heterogeneous rules even within a single state. Additionally, states increasingly deliver both community-based and institutional services through managed care arrangements, where it can be hard to track the services delivered or the cost for service bundles. High-quality, longitudinal data on spending, utilization, participation, and outcomes are essential for evaluating LTSS programs, but existing data sources are fragmented, inconsistent, and often difficult to interpret. This brief is based on a white paper that investigated the major LTSS data sources, assessed their limitations, and identified opportunities to strengthen the data landscape to improve the evidence base.[3]

Long-term services and supports (LTSS) include a broad range of medical, personal, and social care services that assist individuals who have difficulty caring for themselves due to age, illness, or disability. These services help people live more independently and include care delivered in institutional settings, such as nursing homes and intermediate care facilities for individuals with intellectual disabilities (ICF-IIDs), as well as care provided in home and community settings.

DATA GAPS

Medicaid's role in financing LTSS has changed over the past two decades as states have shifted from institutional care toward HCBS. This shift reflects both a legal and personal preference for community living, as affirmed in statute and court decisions, and the lower per-person cost of HCBS compared with institutional care.

However, assessing the value, accessibility, and quality of LTSS requires accurate and transparent data—something researchers and policymakers continue to struggle with. The lack of standardized reporting across LTSS programs, especially for managed LTSS (MLTSS) programs, and inconsistencies across datasets impede efforts to understand how states allocate resources and how those investments affect beneficiaries. At the same time, H.R. 1 increases the urgency for evidence to guide state program decisions.

TABLE 1. Characteristics of State Reports Capturing LTSS Expenditures and Beneficiaries

	CMS-64	CMS-372
Purpose	• Document expenditures for the purpose of obtaining federal matching funds	• Report expenditures, beneficiaries served, and services provided for the purpose of program monitoring and quality assurance
Content	• State-quarter-level expenditures reported by approximately 90 broad service categories across all Medicaid covered services	• Expenditures and beneficiaries served at the state-waiver-program-year-level and state-waiver-program-year-service-level (approximately 150 detailed service categories across all services)
Strengths	• Validity of the data • Timeliness of the data	• Only formal report including the number of beneficiaries served • The number of beneficiaries served is usually specific to a target Medicaid population • Service types used to categorize spending are highly specific
Limitations	• Only broad categories of services are captured • Lacking any information on the number and characteristics of beneficiaries served • Method of reporting adjustments to prior quarter payments creates challenges	• Lag time in reporting of approximately 18 months after the end of the reporting period • Limited to 1915(c) waivers

HCBS Authorities and Program Variation

States deliver HCBS through a patchwork of authorities, including multiple state plan options (e.g., 1915(i)) and waiver programs (e.g., 1915(c)). Because most HCBS benefits are optional, and states can target services to specific populations under some authorities, LTSS offerings vary widely, across states and over time. This variability complicates efforts to consistently measure spending, the number of people served, and the quality of services.

Growth of Managed LTSS

The proliferation of capitated delivery models in managed long-term services and supports (MLTSS), has introduced new challenges for tracking expenditures. In many states, a large percentage of managed care claims have missing or implausible payment records. As a result, states with large MLTSS or other capitated options like the Program of All-Inclusive Care for the Elderly (PACE) programs often have less reliable or incomplete spending data. This means the states leading innovation, from which we might learn the most, often have the least reliable data.

MAJOR DATA SOURCES FOR LTSS SPENDING AND PARTICIPATION

Researchers typically rely on three categories of data to study LTSS. These include periodic state reports submitted to the Centers for Medicare and Medicaid Services (CMS) (CMS-64 and CMS 372); administrative data from the Medicaid Statistical Information System (MSIS) (through 2015)

and the newer Transformed Medicaid Statistical Information System (T-MSIS) (2016 to date); and state surveys.

Each has strengths, but none offers a complete picture.

State financial report data are available through summaries on the CMS website, in reports produced by CMS contractors, or through filing a Freedom of Information Act request.[4,5]

The Medicaid Analytic Extract (MAX) (for MSIS) and Transformed Analytic File (TAF) (for TMSIS) are administrative datasets that provide the most comprehensive beneficiary-level spending data. They allow policymakers and researchers to see the specific mix of services LTSS users are receiving and the associated costs nationwide.

These datasets also permit detailed analyses of who uses HCBS, and within some states or settings with high quality data, the types of specific services provided. Access to MAX and TAF files requires approval from the CMS Privacy Board and a data use agreement (DUA), a lengthy and often costly process.

In addition to administrative datasets, several national surveys of states provide valuable information. The KFF Annual HCBS Survey offers long-term trend data on spending, beneficiaries, and state policies for major HCBS programs.[6] These data provide rich program-level insights and longitudinal trends. As in any survey, gaps remain, including incomplete coverage across HCBS authorities, missing years, and potential double-counting of beneficiaries served via more than one authority.

TABLE 2. Characteristics of Administrative Data Capturing LTSS Expenditures and Beneficiaries

	Administrative Medicaid Data: MAX and TAF
Purpose	• Collect standardized person-level data on Medicaid beneficiaries and services for the purpose of program administration and oversight as well as research
Content	• Calendar year, beneficiary-level files containing information on Medicaid enrollment, service utilization (both fee-for-service claims and encounter records), and payments from Medicaid agencies to care providers or managed care organizations
Strengths	• Only national or nearly national data source at the beneficiary level • Supports analyses of the mix of services, and associated costs, provided to LTSS users • Access to data quality information and growing community of research reports aid users of these data
Limitations	• Substantial variation in data quality across states • Missingness of records and data elements • Inconsistencies in data coding across states • Lag time of approximately two years after the end of the calendar year

Other survey-based data sources include the State of the States in Intellectual and Developmental Disabilities from the Kansas University Center on Developmental Disabilities and the University of Minnesota Institute on Community Integration's Residential Information Systems Project (RISP).[7,8]

ALIGNMENT AND DISCREPANCIES ACROSS DATA SOURCES

Comparisons between TAF-based analyses and state-reported CMS-64/CMS-372 spending data show substantial discrepancies. (Figure 1)

TAF underestimates total LTSS, institutional, and HCBS spending compared to state reports. For example, 2019–2020 TAF estimates were 11–18% lower than state-reported expenditures. (Figure 2)

When looking at service-specific categories, TAF overestimates home health spending by up to threefold and underestimates personal care spending by 40–60%.

At the state level, TAF often underestimates total LTSS, institutional LTSS, and HCBS spending compared to the state reports. However, this does not hold for every state; some states reported lower expenditures than those calculated in TAF. For example, in 79 out of 96 state-years, TAF analyses showed lower total LTSS expenditures than the state reports. Institutional LTSS and HCBS expenditures follow a similar pattern.

However, relationships between TAF-calculated and state-reported rebalancing ratios—the percentage of LTSS spending devoted to HCBS— and service category spending are less predictable. In 45 out of 96 state-years, TAF calculated a higher rebalancing ratio than the state reported.

FIGURE 1. National TAF-Calculated and State-Reported LTSS, Institutional, and HCBS Expenditures, 2019-2020
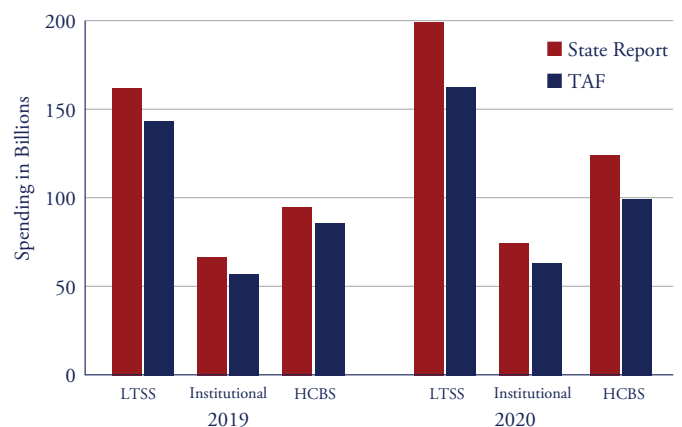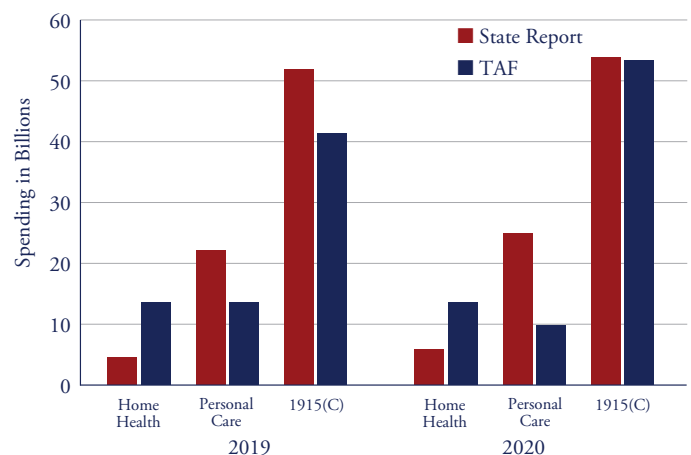

FIGURE 2. National TAF-Calculated and State-Reported Home Health, Personal Care, and 1915(C) Waiver Expenditures, 2019-2020

Source, Figure 1 & 2: Arp et. al. *Medicaid LTSS Spending.*

CHOOSING A DATA SOURCE FOR RESEARCH

Each data source has its own advantages and limitations, but some are more standardized or comprehensive than others. The most appropriate data source for describing LTSS and HCBS depends crucially on the research purpose.

To characterize broad trends in HCBS and LTSS spending over a relatively long period, the best available source is the series of annual contractor-generated reports published on the Medicaid website from Mathematica and Truven.[5] For periods from 2016 and forward, TAF is the best available source for tracking HCBS beneficiaries across large geographic areas, especially for identifying unique individuals.

POLICY RECOMMENDATIONS FOR IMPROVING DATA INFRASTRUCTURE

Comprehensive, accurate data are essential to helping states invest in the high-value, high-quality, accessible, and financially sustainable LTSS services. The following recommendations outline steps to improve LTSS data reliability and availability and to strengthen research in this area:

Federal Priorities:
- Increase transparency in CMS-64/CMS-372 processing.
- Enhance TAF data quality, documentation, and accessibility.
- Release details on prior-period adjustments.

State Opportunities:
- Invest in improved administrative data submissions.
- Partner with researchers for state-level analyses.

Research Community:
- Combine data sources and share code/methodologies.
- Apply smoothing and imputation where necessary.
- Use caution when interpreting service-level estimates.
- Prioritize state-specific analyses in collaboration with state partners.

CONCLUSION

Improving transparency, consistency, and quality across data sources is essential for advancing evidence-based LTSS policy and ensuring that resources support accessible, high-quality services for beneficiaries.

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