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RESEARCH TO IMPROVE THE QUALITY, IMPACT, AND VALUE OF HOME AND COMMUNITY-BASED SERVICES

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ABSTRACT

Nearly eight million Americans use Medicaid home and community-based services (HCBS) to support long-term services and supports for people with disabilities. Recent legislative changes to Medicaid will require states to make difficult choices about how best to meet these long-term services and supports needs. This paper first characterizes the unique goals of HCBS, which differ from those of traditional medical care services, and the state-federal financing and administrative structure of HCBS. Next, based on a review of the literature and input from a panel of experts in HCBS policy and research, we summarize existing evidence and knowledge gaps regarding the quality and cost implications of HCBS at the federal, state, and direct service provision levels. Based on gaps in the evidence, we propose a research agenda related to state-federal incentives, state program choices regarding HCBS financing and delivery models, and the settings and supports for direct service provision. Finally, we describe existing and novel data sources and other opportunities that could accelerate research to fill these evidence gaps and support states and others in designing, implementing, and delivering sustainable, high-quality HCBS.

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1. Introduction

The recent passage of H. R. 1 has once again brought attention to Medicaid funding as states consider how to adapt their Medicaid programs to the recent legislative changes and funding adjustments. In response to funding gaps, states will face difficult choices about how to keep required services available, whether and how to address the termination of some people formerly enrolled in Medicaid, and whether and how to curtail optional services, including many home and community-based services (HCBS). From 1982 to 2022, the percentage of Medicaid long-term services and supports (LTSS) expenditures devoted to HCBS grew from 1 to 65 percent, reflecting an extraordinary transformation in the nation's approach to meeting the ongoing service provision needs of older adults and people with disabilities. Even as HCBS has grown to encompass the majority of LTSS expenditures, considerable gaps exist in the research literature on HCBS policy and service provision (Murray et al. 2024).

Designed to help persons with LTSS needs reside in community-based settings, HCBS can include personal care services, care coordination, adult day centers, supported employment, skilled nursing care, and other services (Centers for Medicare and Medicaid Services 2025). Medicaid is the largest funder of HCBS in the nation; in 2022, it funded $129.4 billion in HCBS for 7.8 million users (Stepanczuk et al. 2024). However, despite ongoing efforts to promote the shift towards HCBS, the Medicaid program still has an 'institutional bias', as federal Medicaid law mandates coverage for nursing home services as an entitlement while most HCBS financing is covered as an optional service, with many states maintaining long waiting lists for access to HCBS (McGarry and Grabowski 2023; Caldwell and Machledt 2022). As of 2024, the Kaiser Family Foundation reports that 710,000 older adults and people with disabilities are on waiting lists to access HCBS, though due to variable approaches to waiting list management across states, not every person on a waiting list meets eligibility requirements for HCBS (Burns et al. 2024). Conversely, this statistic fails to account for eligible individuals not receiving HCBS who have not applied for services and thus are not on waiting lists. Currently there is little evidence on the most beneficial and sustainable ways to deliver HCBS to inform policymakers. Given current funding constraints, improving the evidence base regarding HCBS is timely and urgent.

This paper seeks to 1) summarize gaps in the evidence on the quality, impact and value of Medicaid-funded HCBS and 2) propose research questions that, if answered, would begin to fill

those evidence gaps. Both goals support a broader effort to achieve benefits from these services that best align the priorities of consumers and state policymakers at a given level of spending. Spending goals consider direct Medicaid expenditures, the impacts of HCBS on other payers, and the impacts on non-healthcare spending (e.g. HCBS's impacts on health and employment outcomes of people with disabilities, and family and friends involved in their care). At the same time, we interpret benefits through the prism of the unique values framework associated with HCBS.

HCBS can be differentiated from many other types of healthcare in that the program prioritizes both medical and non-medical outcomes within its expressed goals. HCBS are intended to advance unique goals within the health care system, such as personal autonomy and community participation. In 2014, the Centers for Medicare & Medicaid Services (CMS) established new regulations that delineate the difference between institutional care and HCBS to formalize the unique nature of the latter. These regulations, which came into full effect in 2023, require HCBS to meet minimum standards, including being delivered in settings that are integrated in and support "full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS." Additional requirements regarding community integration, such as "individual initiative, autonomy, and independence in making life choices," speak to the broader range of considerations relevant in defining HCBS program goals (U.S. Department of Health and Human Services 2014). While these requirements are operationalized differently across age groups, populations, and contexts, they reflect a broader scope of program goals than are typical in standard medical care provision. While other types of service provisions need to account for factors such as privacy and autonomy, HCBS considers these primary *outcomes*. In seeking to articulate a research agenda to define value in HCBS programs, a comprehensive identification of research opportunities must consider the unique context of HCBS highlighted in the regulations above.

The remainder of the paper is organized as follows. Section 2 describes the methods used to review what is known about HCBS, to highlight gaps in knowledge, and opportunities to fill research gaps that may increase the value of HCBS. Section 3 characterizes what is known

regarding HCBS quality, spending, and the effects of program organization and policies, highlighting gaps in the evidence. Section 4 proposes priorities for future research that address both quality and cost considerations through this prism, Section 5 notes barriers that may impede research progress, and Section 6 concludes.

2. Methods

We use several sources to identify evidence gaps and opportunities for future work. First, we recruited a panel of experts on HCBS. These 12 individuals have research, policy, or advocacy expertise on HCBS, for aging populations, people with Intellectual and Developmental Disability (I/DD), or both. The panel shared research priorities for HCBS during two virtual meetings. We also convened a two-day in-person meeting in April 2025, hosted by the University of Pennsylvania's Leonard Davis Institute, for the project team (Harvard University and University of Pennsylvania faculty members and staff), the expert panel, and seven invited speakers. The convening included panels on state Medicaid policy, financing strategies, and data hurdles related to HCBS. This discussion, with diverse expertise and viewpoints, allowed us to contrast and prioritize a wide range of gaps in the HCBS literature and research opportunities.

In addition to the expert panel, we conducted an extensive literature review regarding HCBS spending, contained in a separate working paper (White et al. 2025) and relied on published reviews (Z. Wang et al. 2024; Kim 2025; Bucy et al. 2023) of the evidence on HCBS quality and outcomes, augmented with other relevant literature on costs and benefits of HCBS.

3. Organization of HCBS financing and delivery

Medicaid HCBS policy and financing operate within a multi-level context, a product of the complex distribution of responsibility within Medicaid as a whole. In *Figure 1*, we describe the policy context of Medicaid's HCBS financing and service delivery through a three-tiered approach, emphasizing: a) the relationship between financing and civil rights enforcement interactions between federal and state policymakers, b) program administration choices of state policymakers, and c) direct service provision interactions between persons receiving HCBS and providers.

Federal-State Incentive Structure

At the uppermost tier is the **Federal-State Incentive Structure,** the relationship between the federal government and state Medicaid policymakers. State decision-making is shaped by an incentive structure established by a complex system of different HCBS financing authorities.

Olmstead v. L.C. Enforcement and Federal HCBS Policy Design

Although some state plan HCBS financing authorities have always existed, the 1915(c) waiver – which today accounts for approximately half of Medicaid HCBS spending (Colello and Saraswathula 2025) – was established by the Omnibus Budget Reconciliation Act of 1981 to permit states to pay for a broader range of nonmedical services in community-based settings (Miller 1992). The 1915(c) waiver also permits states to cap enrollment and maintain a waiting list for services (Colello and Saraswathula 2025), an option not available for HCBS financed through state plan services (mandated or optional community-based services, not financed by a waiver, that states offer to all eligible Medicaid enrollees). As a result, 1915(c) waivers permitted states to offer a higher-intensity benefit, often targeted toward high-acuity populations that require a level of service that could not be extended to all persons with LTSS needs due to cost.

The subsequent expansion of HCBS had many motivations, including the growing shift toward deinstitutionalization in disability service provision, increasing interest among older adults in aging in place, and concerns about the "medical-model orientation of Medicaid-financed long-term care" (Miller 1992). In 1999, the Supreme Court ruled in *Olmstead v. L.C.* that the integration mandate of the Americans with Disabilities Act (ADA) meant that the "unjustified segregation" of people with disabilities constituted discrimination, creating an affirmative obligation for states to offer services in the most integrated setting (U.S. Department of Justice Civil Rights Division, n.d.). Subsequent litigation and enforcement actions by the Department of Justice and the Department of Health and Human Services Office of Civil Rights have been important tools for reinforcing consumer preferences and promoting the shift toward HCBS and away from institutional care.

Even as *Olmstead v. L.C.* has offered federal policymakers a "stick" to encourage states to shift from institutionalization to HCBS, the federal government has also established numerous "carrots" to incentivize state HCBS expansion. Beginning with the Money Follows the Person program established by the Deficit Reduction Act of 2005 (Vardaman 2016), Congress also created multiple programs that offered states a financial incentive for further expanding HCBS in

the form of an enhanced Federal Medicaid Assistance Percentage (FMAP), or higher Medicaid funding rates from the federal government. However, rigorous evaluations of the causal effect of these financing incentives have only recently begun to emerge (Ne'eman 2025).

One 2023 study finds that the Community First Choice State Plan Option (CFC), a financing authority created by the Affordable Care Act offering states a six-percentage-point enhanced FMAP for certain HCBS expenditures, had little effect on total (state and federal) HCBS expenditures. Instead, states appear to have shifted existing expenditures into the more favorable financing authority established by CFC, essentially 're-financing' existing services to draw down more federal funds without changing service access (Oyeka and Arora 2023). Another related study uses workforce data from the American Community Survey (ACS) as a proxy for both HCBS and institutional care utilization, and finds that CFC had no impact on the number of workers in either HCBS or institutional care. In contrast to CFC, this latter study finds another program designed to incentivize HCBS expansion – the Balancing Incentive Program – substantially increased the size of the HCBS workforce. Structural differences between the incentive structure established by CFC and BIP may have led to different results. While CFC was primarily adopted by states with mature HCBS programs, BIP was limited to states with lower levels of HCBS spending. In addition, BIP incorporated performance targets for expanding HCBS as a percentage of total LTSS expenditures, with states that had yet to meet their performance targets upon entering the program increasing their HCBS workforce twice as much as other states participating in BIP (Ne'eman 2025).

Additional research may help improve the design of federal policies to promote HCBS expansion, thereby improving the cost-effectiveness of future HCBS investments. Recent legislative efforts to promote HCBS expansion, such as Section 9817 of the American Rescue Plan Act, which provided states with a temporary enhanced FMAP for HCBS, have adopted an approach like CFC. The research cited above suggests that attaching performance targets or targeting resources to low-access states, in the fashion of BIP, may be more effective at stretching federal dollars to expand HCBS access. At the same time, researchers have yet to rigorously evaluate the causal effects of more than two decades of enforcement activities under *Olmstead v. L.C.* Evaluating the impact of the many *Olmstead v. L.C.* settlement agreements concluded by civil rights enforcement authorities could yield important insights into how federal policymakers should approach HCBS policy. As federal policymakers consider how best to

facilitate the expansion of HCBS to meet legal requirements, our expert panel noted the importance of research on how best to align federal and state incentives to make effective use of limited resources.

Financial Integration Across Payers

Access to Medicaid HCBS is associated with improved outcomes and lower costs for other payers, such as shifting Medicare-financed post-acute care from institutional towards home health (Wang, Werner, et al. 2024). In such contexts, organizations that can act to prevent poor care outcomes often do not directly benefit from investments. Our panel highlighted the need for additional research on the impact of financial alignment across Medicare and Medicaid (e.g., Medicare-Medicaid Plans, Dual Eligible Special Needs Plans [D-SNPs], etc.) in shifting incentives regarding HCBS provision. Our experts noted the possibility that integration might increase incentives for health plans to provide HCBS by giving them access to cost savings in Medicare. The growth of fully integrated and highly integrated D-SNPs (Fully Integrated D-SNP [FIDE] and Highly Integrated D-SNPs [HIDE SNPs]), which increase integration of Medicaid LTSS with Medicare benefits, makes understanding this policy context more urgent, particularly given the growing alignment between D-SNPs and Medicaid MLTSS (Medicaid and CHIP Payment and Access Commission 2023).

National Medicaid Policy Considerations

Further research needs to consider how the bigger-picture direction of federal Medicaid policy will impact HCBS provision, even if lawmakers are not considering HCBS-specific policy decisions. For example, changes to provider taxes and federal work requirements might affect state budgets or eligible individuals, which could, in turn, affect the HCBS services provided by a state (Schubel et al. 2025). There is a need for research to understand how federal-level decisions affect state-level decisions regarding HCBS.

State Program Administration

Below the federal-state incentive structure is **State Program Administration**. States possess a variety of options for the design and implementation of their HCBS programs, including the particular combination of services to offer different groups of HCBS consumers, whether and

how to maintain a waiting list (and for which populations), decisions regarding rate-setting and service definitions, and a range of choices regarding evolving systems change taking place within the spectrum of HCBS. State LTSS program administration is frequently subdivided into different agencies. Most commonly, Aging and Physical Disability (APD) service agencies support older adults and persons with physical disabilities acquired after age 22, and state Intellectual and Developmental Disability (I/DD) service agencies help people with significant disabilities that manifest before age 22.

There are several significant challenges in the extant literature on state program administration choices regarding HCBS. First, the work is primarily descriptive in nature, rather than causal. Thus, most extant literature offers limited insights for policymakers hoping to identify potential benefits or harms of alternative program choices. Second, even where more rigorous causal inference methods have been applied to the study of state program administration choices, findings are often limited to a specific subpopulation (Bucy et al. 2023). For instance, studies focused on older adults may not generalize to persons under age 65. Because of the separate program administration structure, researchers often exclude persons with I/DD altogether. Because state service systems are frequently targeted at sub-populations, research on one population will not necessarily accurately capture the effect of HCBS on other intended program recipients.

Our panel discussed the opportunities and challenges that emerge from serving broad and diverse populations within HCBS. In recent years, federal and state policymakers have increasingly adopted a common framework for "aging and disability" services, establishing programs such as the Aging and Disability Resource Centers to streamline access to HCBS. There are significant advantages of permitting older adults and people with disabilities to access a common administrative infrastructure for service provision, preventing silos that preclude people from accessing helpful supports.

At the same time, challenges have emerged due to the different values framework embedded within the aging and disabled population. Service needs for older adults at typical retirement ages differ from those of younger adults with disabilities. Some HCBS program goals, such as access to competitive integrated employment, are less relevant for older adults than for younger groups of people with disabilities. Conversely, the large number of older adult LTSS users can

mean that they receive more attention from policymakers than younger recipients (Ne'eman et al. 2022).

Another area of conflict arises from differing opinions on congregate care. While disability service provision is largely shifting towards non-congregate service models, many providers argue in favor of some forms of congregate service provision (such as adult day centers and assisted living facilities) for older adults. Others raise concern that these models may unnecessarily segregate older adults from the broader community, arguing that a similar shift towards non-congregate approaches to care should proceed in aging as well (Medicaid and CHIP Payment and Access Commission 2022). Our panel highlighted the continued relevance of these debates. Despite these challenges, our expert panel identified emerging research priorities for the design of state HCBS programs.

Managed Long Term Services and Supports

States have greatly expanded their use of managed LTSS (MLTSS) – the contracting out of Medicaid LTSS benefits to private health plans – with such arrangements growing from 8 to 26 states over the 2004-2023 period (Yocom et al. 2020; Wysocki et al. 2020). A limited literature is emerging on the impact of these transitions. For example, a recent study used the Health and Retirement Survey to find that MLTSS adoption increased HCBS utilization, reduced reliance on unpaid care (care provided by family and friends), and did not impact nursing home utilization; however, there was also suggestive evidence of reductions in the intensity of HCBS utilization (Bhaumik et al. 2025).

The detailed characteristics of MLTSS programs vary dramatically across and even within states; causal effects likely vary considerably from state to state. For example, different states have adopted distinct approaches in how they determine capitated rates, risk-adjusted payments, quality measures, and other program choices crucial to shaping health plan behavior (Stockdale et al. 2024). Treating MLTSS as a unitary intervention without accounting for this policy variation could mislead state policymakers about what works and what does not. Our expert panel emphasized the importance of building out more detailed information regarding what lies 'under the hood' of state MLTSS programs, to account for the effect of specific design choices in evaluation of MLTSS's causal effects.

Value-Based Payments

Following a growing tradition of value-based payments (VBP) for medical care, in which care providers are paid more for meeting benchmarks related to spending or quality, some states have incorporated VBP within HCBS programs. For example, in 2025, Connecticut is paying up to 2 percent of expenditures to HCBS service providers with below-benchmark rates of avoidable hospitalizations, with plans to expand VBP measures to include hospital discharge to the community and person-centered goals (Connecticut Department of Social Services 2025). Since 2023, Missouri's Department of Mental Health has used VBP to reward HCBS providers serving the I/DD population across eight domains ranging from remote supports to direct service provider apprenticeships. To start, most payments encourage participation and reporting (Missouri Department of Mental Health, n.d.). Despite a rich set of state activities, and a report highlighting various opportunities for VBP in HCBS (Bennett et al. 2018), we lack rigorous evidence of the effectiveness and value of VBP in the HCBS context. HCBS VBP is under-researched for a few key reasons. First, there is scant research on all aspects of HCBS, despite these services having a large impact on both users and state budgets. Second, the COVID-19 pandemic greatly exacerbated a growing HCBS workforce crisis, making it difficult for the VBP incentive structure to work as intended. Our expert panel highlighted VBP as a priority area for future program evaluation to inform state policymaking.

Self-Directed Services

Nearly all states permit self-directed services in at least one waiver or state plan service (Mohamed et al. 2025). Under self-directed services, HCBS consumers or their authorized representatives can decide who they hire. States have a variety of choices to make in designing self-directed services programs, such as whether to offer 'budget authority' (enabling consumers to negotiate wage rates or spend allocated funds on non-staff costs within the constraint of an individual budget).

In contrast to many other areas of HCBS, self-direction has been subject to rigorous evaluation through a randomized controlled trial that took place from 1998 to 2003 in three states: the Cash and Counseling Demonstration. Studies of Cash and Counseling found that self-direction significantly reduced unmet needs in daily living, household activities, transportation, and routine health, without any increase in adverse outcomes or injuries (Carlson et al. 2007).

The demonstration increased satisfaction with paid caregivers and overall care arrangements for both care recipients (Carlson et al. 2007; Schore et al. 2007) and caregivers (Foster et al. 2007). Life satisfaction also improved among care recipients, with differences ranging from 8 to 23 percentage points across states and age groups (Carlson et al. 2007). Randomization into the treatment group yielded eight percent higher total spending, but this was partially offset by cost savings from reduced nursing home placement and is partially attributable to increases in access to authorized care due to prior workforce shortages (Dale and Brown 2007).

Although studies of Cash and Counseling represent one of the most significant program evaluation efforts in HCBS to date, our expert panel noted that additional research is needed to inform state policy design choices regarding self-direction under present-day conditions. Relevant health and labor policies have changed dramatically since the Cash and Counseling Demonstration.

Regulatory changes to labor law promulgated by the Obama Administration in 2013 (and subject to a proposed rollback under the second Trump Administration) also created a dilemma for many states. The 2013 changes both extended overtime protections to home care workers and established a 'joint employment' relationship for state governments (in which a worker is considered employed by both the state and the HCBS consumer, and thus the state takes on responsibility for overtime pay for workers employed by multiple consumers) within many states' self-directed HCBS programs (U.S. Department of Labor 2025). This required state Medicaid agencies to make choices regarding whether to permit workers delivering self-directed services to work more than 40 hours a week and under which circumstances, prompting a variety of responses from state governments seeking to balance cost containment with the desire of many HCBS consumers to maintain existing provider relationships and minimize the number of persons assisting them with intimate activities of daily living (Doty et al. 2019).

Until recently, there were no rigorous studies of the causal effects of the 2013 changes to labor law on self-directed services, which might have impacted cost and quality in either direction. Recent research (Miller and Coe 2025) has studied how the labor law changes (which took effect in 2015) changed the direct care workforce along two dimensions, turnover and overtime. In states more affected by the Home Care Final Rule, relative to comparison industries, workers in home health care experienced lower turnover rates and had a higher percentage of stable jobs. This analysis did not examine how such changes may affect the quality or

satisfaction with direct care for people receiving HCBS, although existing surveys like the Health and Retirement Survey, the Medicare Current Beneficiary Survey, or related surveys offer potential ways to learn more about the effects of these policies on people with LTSS needs.

Several panel members also noted that additional research is needed on reducing administrative burden to make it easier for more HCBS consumers and families to participate in self-direction if they are interested in doing so, placing particular emphasis on the role of fiscal intermediaries contracted with by state governments to support self-directed services. States have a variety of options available for contracting for fiscal intermediary services, some of which involve balancing the cost advantage from the selection of a single provider with quality benefits from permitting consumers to select their own fiscal intermediary. Further research is needed to understand how particular methods of care either promote or restrict autonomy, either directly or through unintentional means.

Fiscal intermediaries may also obstruct supportive decision making due to financial incentive structures. For example, if a provider is penalized for the number of falls a patient has, the patient may be directed into a congregate care setting even if that patient prefers to accept the risk of falls in the home setting. Such changes inadvertently reduce patient autonomy. More research is needed to determine whether specific delivery approaches to HCBS are supportive of independent decision-making than others, due to underlying incentive structures, and the implications for all stakeholders involved in receiving or supporting HCBS. Future work should examine how a range of service providers, including states, contracted intermediaries, and family members, both preserve and limit patient decision-making when financial incentives are introduced.

Separate from the role of fiscal intermediaries, panel members also expressed concern that the financial incentives of self-directed care might become misaligned when the needs of an HCBS consumer differ from those of a paid family caregiver. This might be especially prominent for individuals facing dementia, other forms of cognitive impairment, or who otherwise need support with decision-making.

Finally, several panel members noted that states are increasingly wrestling with the question of the compensation of family members under self-directed program models. Although recent work leveraging the Cash and Counseling demonstration documents strong quality benefits and some cost offsets when permitting family members to be hired to provide self-directed care (Guo

et al. 2015), some state rules prevent or limit payments to family caregivers, particularly legally responsible relatives. This restriction is motivated in large part by the desire to limit state financial responsibility for care that would otherwise be provided without compensation within the family unit. However, reliance on uncompensated family care may contribute to unmet need, reduced care quality, and reduce employment among family members. Revisiting such policies and their impact across a broader set of domains is timely given that many states lifted restrictions that prohibited compensating family caregivers during the COVID-19 public health emergency, prompting discussion regarding the potential for continuing such flexibility (Burns et al. 2025). Additional research is needed to understand how states should approach the design of self-directed services programs to best balance these priorities.

Considering how often policy discussions involve claims of fraud and abuse (or fears that it could occur), panelists also expressed concern over the lack of research on fraud and abuse, especially when comparing agency-directed versus self-directed services. In addition to concerns about moral hazard induced by publicly funded HCBS, Medicaid fraud and abuse have long been a concern of federal policy makers, especially in the personal care space. In response, states have introduced programs, like electronic visit verification, in which direct service providers use digital means to confirm details of services delivered (e.g. location of care, start time, end time, etc.), to address the fear of fraud in self-directed services. Although the federal government has issued reports on improper use of personal care funds (Committee on Oversight and Government Reform 2011; Lollar and Kayala, n.d.), there has been little systematic independent research on this topic in recent time period. Some panel members expressed a need to clearly define the type of services that do and do not represent fraud or waste, as well as potential harms and unintended consequences of fraud prevention. For example, processes like electronic visit verification may limit fraud but also limit appropriate access to services in settings where access is already challenging, like rural areas with unreliable broadband in which digital applications for electronic visit verification work poorly, preventing service providers from being reimbursed for services. This is one of many examples shared by panel members. Further research efforts could help elucidate both the prevalence of fraud and the relative magnitude and impact of such waste relative to the added health and social benefits enabled by HCBS. Such data would help states establish appropriate guardrails and oversight systems.

Quality Measurement

In both Fee-For-Service (FFS) and MLTSS contexts, questions regarding how to measure HCBS quality arise. The sheer volume and variation in quality measures (a recent evidence map sponsored by the Agency for Healthcare Research and Quality identified 29 different quality measure sets used across HCBS literature) (Z. Wang et al. 2024) creates a significant challenge. State Medicaid programs and other payers use a wide variety of outcomes, including National Core Indicators (NCI), the HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS), and Healthcare Effectiveness Data and Information Set (HEDIS) measures, among others (Z. Wang et al. 2024; Hartman and Lukanen 2016; Bucy et al. 2023). Surveys, such as the NCI Aging and Disability survey (National Core Indicators- Intellectual and Developmental Disabilities 2025a; National Core Indicators- Aging and Disabilities 2025), have already contributed to important findings, as in one recent analysis revealing racial and ethnic disparities in access to HCBS (Fabius et al. 2024). Because these measures are not always collected consistently nor universally, panel members called for an effort to level-set definitions of quality for HCBS service users, families, agencies, providers, and state policy makers. Recognizing that different stakeholders may prioritize different types of quality measures, efforts to define or prioritize a subset of measures that are harmonized, feasible to collect, and assess both person-centered goals and program needs could help advance the evidence on HCBS. Researchers could also work directly with measure stewards to update and improve existing measures to better meet immediate needs. In addition, panel members highlight that there is little qualitative or quantitative information on quality improvement or oversight efforts that do or do not explicitly work to include community members using HCBS in advisory roles. Efforts to understand the effect of incorporating community members in such roles could contribute to evidence on how to support effective HCBS in ways that are financially sustainable.

Measure development has historically prioritized tracking quality in HCBS contexts, as states frequently embed financial incentives for quality improvement into MLTSS contracts through ‘quality withholds’ that require health plans to earn back a portion of their capitated payments in exchange for meeting preset quality measures. In 2022, CMS issued a “Dear Colleague” letter articulating an HCBS Quality Measure Set for use by state Medicaid agencies, including several specifically oriented for MLTSS contexts (Tsai 2022). In 2024, CMS updated the measure set, including adding FFS versions of MLTSS measures to permit comparisons across delivery

systems (Tsai 2024). Also in 2024, CMS issued regulations requiring states to report on the HCBS Quality Measure Set every other year beginning in 2028, including reporting measures stratified by race, ethnicity, sex, age, rural/urban status, disability and language (U.S. Department of Health and Human Services 2024). The existing version of the Quality Measure Set includes both claims-based measures and survey-based measures.

Our expert panel discussed several important factors related to quality measurement, many of which relate to the unique nature of HCBS' multifaceted goals. Because HCBS seeks to promote unique goals such as autonomy and community inclusion, as well as more traditional dimensions of health care quality (such as mortality and the mitigation of functional impairment), our expert panel emphasized the importance of including survey instruments that capture measures not easily identified in administrative claims data. For example, the HCBS Quality Measure Set laid out by CMS includes questions from the NCI regarding the percentage of HCBS recipients who report they are able to see or talk to friends and family when they want to, who report they can choose or change their support staff, can stay home when others leave, feel their personal space is respected in their home, and other experiential components of HCBS receipt. At the same time, panel members noted the importance of implementing such measures alongside less subjective claims-based measures. As part of the Quality Measure Set, CMS promulgated and has served as measure steward for measures relating to reducing admission to institutional facilities from the community, minimizing institutional length of stay, and successfully transitioning persons to the community after institutional stays (Tsai 2024). Panel members praised these innovations and pushed for the continued inclusion and expansion of underused measures, such as those looking at mental health outcomes within the I/DD community, to ensure that the holistic needs of HCBS users are being met.

Panel members noted a tension between the desire to track quality regarding autonomy and community inclusion and the subjective nature of the survey-based measures relied on to measure these concepts. Because administrative claims-based measures may be more likely to shift provider and health plan behavior than survey-based measures, an alternative way of prioritizing measures of autonomy and experience was proposed. Panel members suggested that research could identify types of service settings in which programmatic goals for autonomy and community inclusion are more likely (based on use of these services and NCI or similar survey responses), then develop claims-based measures regarding shifting the delivery of HCBS into

such settings (e.g.: the growing shift towards smaller, non-congregate scattered-site residential service provision in I/DD service provision, motivated in substantial part by the belief that such settings are more likely to improve autonomy and inclusion outcomes). Additional measure development work is needed, given that prior work around setting transition focused primarily on transitions from institutional settings rather than transitions between different types of community-based settings (e.g., from more formal group settings like assisted living or small group congregate settings collocated on the site of institutional care, to less formal settings such as small group settings in the community or private homes).

Direct Service Provision

Below the level of state program administration is **Direct Service Provision,** defined as the relationship between consumers, providers and care coordinators that define the service provision experience for those receiving HCBS. A limited but growing literature has identified a variety of outcomes that HCBS may impact the lives of HCBS consumers and their families. However, several of our expert panel members felt that researchers should prioritize further work on the impact of HCBS on other payers, the local community, and the broader economy.

How Do Interactions Between Consumer and Families and HCBS Affect Outcomes?

One key goal of HCBS is to divert people with disabilities and older adults from institutionalization. Prior work suggests that admissions to institutions are lower when states expand access to HCBS. HCBS also appears to impact consumers and families along other dimensions. Using the randomization of the Cash and Counseling demonstration, one study documents that a $1,000 increase in HCBS expenditures avoided 2.75 days of nursing home placement and reduced Medicaid expenditures for nursing facilities by $351 among older adults (Guo et al. 2015). A $1 increase in HCBS spending on older adults and people with physical disabilities was associated with a $0.74 increase in total Medicaid LTSS spending, suggesting that approximately 26 percent of the cost of HCBS expansion is offset by reduced nursing facility use (McGarry and Grabowski 2023; Kaye et al. 2009). Additional work is needed to further understand how to design and target HCBS to best divert persons from institutional care and support their return to the community, the setting preferred by the vast majority of people receiving HCBS.

While the existing evidence supports the premise that HCBS does reduce institutional care, it is not a perfect substitute. Although reduced spending on institutional care only partially offsets the cost of HCBS expansion within the Cash and Counseling program, other research suggests that cost-savings may be larger in other contexts. One study exploits variation in HCBS waiting list times in Iowa to find that consumers who applied when wait times were shorter than six months were 25 percent less likely to have long-term nursing home placement than those who applied when wait times were longer, and the largest effect occurred among older applicants. Their analysis finds that the additional cost of a shorter wait time to receive HCBS was more than offset by reduced nursing home spending (Peterson et al. 2014).

The imperfect substitution between HCBS and institutional care may result from the quality advantages of HCBS. Many persons who are unwilling to make use of publicly funded LTSS to support disability- and aging-related needs when offered in institutional settings may use benefits they are entitled to when offered via HCBS. For example, as HCBS availability expanded for people with I/DD, the number of persons receiving publicly funded LTSS from state I/DD agencies grew from 674,044 in 1998 to 1,383,942 in 2021 (Residential Information Systems Project, n.d.). An emerging body of literature suggests that HCBS expansion may increase labor force participation among family members of people with I/DD, especially women (Shen 2024).

For different populations and settings, the effects of HCBS on persons and their loved ones vary widely. For example, one study found that, compared to institutional care, otherwise similar older adults receiving HCBS may experience higher hospitalization rates relative to institutional care (Konetzka et al. 2020; Wysocki et al. 2014). In a different descriptive analysis of older dual Medicare-Medicaid beneficiaries with dementia, despite the high number of comorbid conditions and activity limitations of nursing home residents relative to HCBS users, hospitalization rates were similar (Gorges et al. 2019). These findings (which compare only LTSS users and do not consider people with and without HCBS) differ markedly from the randomized Cash and Counseling evidence, in which greater use of HCBS prevented hospitalization (Dale and Brown 2007; 2005). Such findings highlight how different settings, comparison groups, and study designs yield different estimates of the relative safety of HCBS versus institutional settings for older frail adults. Additional work is needed to assess the robustness of these findings, and how different types of HCBS services impact outcomes. More broadly, there is a larger gap in research regarding the safety of both HCBS and institutional settings.

In addition to considering how HCBS impacts various user outcomes, future work should also consider how administrative burden and family setting impact HCBS use. HCBS users with fewer barriers to care might be able to access both more effective and more types of care options. For example, an HCBS user who lives with family would have more assistance in researching and applying for services than an HCBS user who lives alone. Similarly, child HCBS users might need more advocacy from family members than an adult with physical disabilities, and older adults experiencing cognitive limitations will again need more help navigating access to HCBS. However, existing research largely fails to capture the nuances of person-specific barriers to HCBS access. More research is needed to understand the relationship between barriers to HCBS and service utilization measures.

Transitions Within the HCBS Spectrum

HCBS spans a wide range of services; different populations have significantly different needs and preferences for different types of services. For example, older adults may have less need for supported employment services than younger people with disabilities. In recent years, HCBS for people with disabilities under age 65 – particularly for persons with I/DD – has begun to shift towards less congregate, more individualized forms of service provision scattered throughout the broader community in ways that emphasize greater consumer control and community integration (Larson et al. 2024). These shifts have been encouraged by the 2014 CMS Settings Rule, which set minimum requirements for HCBS that emphasized autonomy and community integration, and established a more rigorous regulatory standard for provider-owned residential settings seeking to qualify as HCBS (Machledt and Pickern 2024). While most prominent in the context of residential services, these shifts have also taken place within the realm of day and employment services, which also receive substantial support from HCBS financing via 1915(c) waivers (Winsor et al. 2025).

Our expert panel highlighted these shifts across settings as another area that would benefit from future research. Studies using causal designs to examine the impact of alternative settings on the person receiving HCBS and family or caregivers are rare outside of studies of the Cash and Counseling Demonstration. Existing work, although primarily descriptive and cross-sectional in nature, indicates that less congregate settings in which housing and service provision are not administratively linked are associated with improved autonomy and community inclusion

outcomes (Moseley et al. 2015). However, additional research is necessary to establish whether a causal relationship exists between setting type and outcomes related to autonomy and inclusion. Such research, which should also consider the impact of family and caregiver support, is critical to understanding how an optimal mix of HCBS services can be delivered. In addition, relatively little research has examined the impact of transitions across settings within the HCBS spectrum (as distinct from transitions between institutional care to HCBS) on expenditures or other dimensions of quality. As states continue to shift people and resources towards less congregate forms of HCBS provision (e.g.: out of group homes and towards supported living in independent housing), a stronger evidence base on the causal effects of these changes would provide decision-makers with valuable insights. Further research should also attempt to understand how the CMS Settings Rule has affected the types of HCBS services delivered.

Transitions between care settings are also relevant for policymakers striving to set financing standards and manage costs. Panel members expressed concern that the amount and type of care delivered may be influenced by factors such as reimbursement rates. For example, a care provider might be incentivized to provide a high-cost service, even when a low-cost service might be optimal for the patient. Similarly, panelists explained that programs face difficulty transitioning individuals from high to low acuity levels of care. Such instances divert resources that could otherwise serve more patients.

HCBS Workforce

HCBS providers span a range of roles, from licensed nurses to home health care workers hired and trained by agencies to family members delivering paid and unpaid care. Longstanding strains on the workforce, exacerbated by the COVID-19 pandemic, led many panel members to prioritize workforce stability above other questions. Recent work has shown that since 2013, the number of home care workers per person utilizing HCBS has declined or stagnated, depending on the denominator used to define LTSS need (Kreider and Werner 2023; Ne'eman 2024). Recent evidence from NCI – State of the Workforce surveys suggests that workforce challenges put constant pressure on limited resources available to deliver HCBS and may lead to low-quality care. In the 2024 survey 26 percent of direct support professional agencies stopped accepting or turned away new referrals due to staffing issues. The survey suggests 37 percent of agency workers were separated from the agency in 2024 (National Core Indicators Intellectual

and Developmental Disabilities 2025b). Due to the cost of hiring and training new staff, high turnover rates are likely to raise the cost of HCBS. Additional research is needed to understand the motivations of home care workers for entering the profession, and to understand policies or processes adopted at the agency, local, or state level that contribute to lower rates of turnover.

One recent analysis finds that home care workers are much more likely to reside with persons with LTSS needs than demographically matched non-home care workers (even after excluding those employed to provide care in their own household). Such findings raise the possibility that unpaid care responsibilities might lead people to enter the paid home care workforce (Ne'eman and Niknam 2025). Other recent work using a novel linkage of public data on communities with survey data from the National Health and Aging Trends Study shows strong associations between community context, like area deprivation, and person-reported care experiences (Fabius et al. 2023). Finally, other research has shown that unpaid caregiving from children to parents – both a substitute for and a complement of paid HCBS – is countercyclical (i.e. rising in periods of recession) while caregiving from spouses is procyclical (i.e. rising in periods of growth), suggesting that prevailing economic conditions may shape both the workforce need and availability (Mommaerts and Truskinovsky 2020). Panel members agreed that more research is needed to understand the challenges facing the HCBS workforce, with some panel members characterizing the current state of the HCBS workforce as a "crisis" that has severe implications for all other topics under discussion. One additional issue highlighted by panel members for further research was the role of unionization in the HCBS workforce (Abraham-Aggarwal et al. 2024; Jang et al. 2025), with panelists noting that many states had adopted unique structures for collective bargaining for workers in self-directed HCBS.

Panel members also expressed a need to further understand how recent immigration policy changes will impact the HCBS workforce. Recent work has shown that restrictive immigration policy exacerbates HCBS workforce shortages (Kreider and Werner 2025). Given recent policy changes that have already lowered the entry and labor force participation of immigrants, a large part of the LTSS workforce, many questions were raised about how best to recruit, train, and retain workers. A significant level of uncertainty remains regarding the direction and impact of federal immigration policy on the HCBS workforce. Future work should explore the short- and long-term impacts of a curtailed foreign labor supply on HCBS delivery and outcomes.

Provider Ownership

Panel members raised questions about the quality and cost implications of private equity ownership of HCBS providers. Prior work in the context of institutional LTSS has found that private equity acquisitions of nursing homes yielded substantial harmful impacts on mortality and the quality of care, as well as increased costs (Gupta et al. 2021). Recent reports of growing private equity acquisitions in I/DD HCBS service provision raise concerns about similar negative impacts on the quality of HCBS (O'Grady 2025). Panel members highlighted the requirement within CMS's 2024 Medicaid Access Rule that at least 80 percent of Medicaid payments for homemaker, home health aide, and personal care services be spent on compensation for direct care workers as a potential policy that might mitigate potential harms of private equity (U.S. Department of Health and Human Services 2024). Research on the impacts of private equity acquisition within HCBS and both federal and state policy options for mitigating or preventing potential harms emerging from it were highlighted as priority areas for future work.

Care Coordination

Although it goes by many names (e.g., case management, support coordination), care coordination is a crucial service in the context of HCBS provision. Many persons receiving HCBS, particularly those enrolled in 1915(c) waivers, receive high-intensity care coordination interventions, with far smaller caseload ratios than are typical. For example, many state MLTSS contracts mandate caseload ratios as small as one care coordinator for every 40-60 recipients of HCBS (Ne'eman 2017; Crisp et al. 2014). Panel members emphasized that care coordination is thought to play an essential role in facilitating the autonomy and community inclusion outcomes promoted by HCBS, while also resolving challenges related to medical care and preventing institutionalization. This represents an arena for further research. Existing meta-analyses highlight the different strategies employed in care coordination; however, little is said about outcomes or value (Albertson et al. 2022), suggesting further research could help states allocate appropriate resources to care coordination.

4. Data, research questions, and opportunities for HCBS Research

We see rich opportunities to close the identified HCBS knowledge gaps described above. To do so, we suggest that researchers pursue promising data sources, expand state-researcher partnerships, build novel data linkages, and foster a best-practice community.

Data Sources

Compared with early studies on HCBS, over the past decade a variety of data sources used to research HCBS have emerged or expanded their coverage of HCBS. *Table 1* summarizes the pros and cons of data sources available for HCBS research, many of which were mentioned above. Although no one data source can offer a definitive summary of all critical domains of HCBS quality and costs, the combination of modern Medicaid administrative data (with a growing knowledge base regarding how to best use new files like TAF) combined with multiple years of survey data (which include crucial measures of patient outcomes) offer opportunities for carefully crafted research questions that start to fill evidence gaps. In addition, expanding the Medicaid sample or increasing state-representativeness in survey data could further aid research on the value of Medicaid HCBS.

Research Questions

Drawing on the HCBS framework above, which explains evidence on Medicaid-financed HCBS to date, *Table 2* highlights key research questions that arose across several domains (federal-state incentive structure, state program administration, and direct service provision). The questions span varied dimensions from high-level questions around program design, like those about the effects of state efforts to use alternative payment and delivery models, to questions around direct service provision and how specific services affect quality and costs for people who need long-term services and supports. The rest of *Table 2* outlines broad opportunities to advance research in HCBS that go beyond opportunities related to data sources in *Table 1*.

Expand State – Researcher and other Partnerships

In some states, Medicaid program staff have signaled interest in added ways to understand the reach and effectiveness of their HCBS programs. Our state policy panel shared innovative programs, data sources, and an ongoing need to learn more. Some states, like Pennsylvania,

already pursue partnerships with local universities and vendors to collect and analyze key data and run their HCBS programs. Expanding efforts to partner with interested states offers several opportunities. First, it guarantees that research covers topics that are most salient to those making decisions in a rapidly evolving environment. Second, most states have limited resources for internal analyses, so researchers can help states expand their analytic capacity without making long-term financial commitments. As one area of opportunity, researchers with experience analyzing Medicare data can often add insights less readily available to states for their dual-eligible population. Third, state-level partnerships enable researchers to examine questions that are outside targeted federal priorities but important for state Medicaid programs. Additional infrastructure for connecting researchers with interested state Medicaid agencies and assisting state Medicaid policymakers in understanding the benefits of research collaborations could help lay the groundwork for such partnerships. Of course, this approach applies to states that are interested in engaging with research partners.

Although the use of claims data for quasi-experimental and descriptive work likely represents low hanging fruit, other research partnership opportunities exist. In pursuit of strategies to improve quality at all levels - from individuals to state and federal system views - it is important to build upon those tools and strategies that are well-developed and in use across the country. As states expand their use of NCI and other state-administered surveys to measure HCBS quality, researcher partnerships with measure stewards may help states maximize the use of these high-quality samples. For example, research could examine survey techniques such as discrete choice experiments to gain insight into how HCBS consumers prioritize different service characteristics. Similarly, researchers may be able to offer state policymakers actionable insights on how to model the cost and quality implications of various policy options under consideration through the construction of dynamic microsimulations, a tool that has previously been employed to assess the impact of federal LTSS financing changes (Favreault and Dey 2015) but that has not yet been applied to state Medicaid HCBS policymaking.

In addition to interacting directly with states, researchers can also collaborate directly with other key stakeholders to leverage existing tools in the field. For example, researchers could work directly with the developers of National Core Indicators to further align survey questions with current needs. By working with developers of existing measures, researchers can most

effectively harness additional areas of expertise without reduplicating efforts in a research area with many existing standards.

Novel Data Linkages

If data use agreements are in place, researchers might explore novel data linkages. For example, in a 2024 report for the Assistant Secretary for Planning and Evaluation, authors assessed the feasibility of linking Financial Management Services data with claims data or other sources to provide enriched information on the self-directed care workforce (Srinivasan et al. 2024). Efforts like this one suggest ample opportunities from linking administrative data across settings, with careful attention to the least burdensome ways to promote linkage and access while maintaining individual confidentiality.

HCBS Researcher Best-Practices Knowledge Base

As the role of HCBS grows, the research community in this space is expanding, and the data used to study these questions are expanding as well. Past work includes constructed taxonomies for identifying HCBS services, identifying effective quality measures, and determining 1915(c) waiver contents. Other groups have also created forums to share best-practices related to key data sources, such as AcademyHealth's Medicaid Data Learning Network (MDLN) (Kennedy et al., n.d.) created to facilitate research using Medicaid TAF data (but without any specific focus on HCBS). To promote future research, we encourage HCBS researchers to share best practices, develop a joint knowledge base, and engage with existing collaborative efforts, including the MDLN. We recommend a seminar series or conference that facilitates the exchange of knowledge among researchers interested in HCBS (and LTSS more broadly) and across target populations. As part of this effort, researchers could also commit to publishing detailed methods when using complex data likely to be shared by many. This will help promote efficiency, reduce duplicate or overlapping research efforts, and increase transparency and reproducibility.

Multi-State Research Projects

When conducting analyses across multiple states, researchers could be encouraged to document and highlight programmatic features and data strengths from each state's HCBS system. By reducing information barriers between state agencies, states could learn research and

reporting best practices from one another. Panel members emphasized the value of developing a more comprehensive taxonomy of policy options available to states across areas of HCBS policy, including MLTSS, self-direction, quality measurement, and value-based purchasing. By more clearly articulating a 'menu' of state policy choices, researchers would be both better equipped to evaluate the effects of different state policy measures on costs and quality and could better assist state policymakers in understanding the range of options available to respond to the priorities of HCBS consumers, families, providers, and other stakeholders.

5. Barriers to HCBS Research

There is a broad array of barriers that HCBS researchers face. Although some of these barriers are not unique to studying HCBS, the hurdles highlighted propose unique and immediate challenges to HCBS research.

Data Use Hurdles

There are significant hurdles to access restricted-use claims data, such as TAF data and Medicare claims. A lengthy Data Use Agreements (DUA) process with both the federal government and specific states can slow down the research process. Furthermore, DUAs can be prohibitively expensive for many researchers and health agencies. While the data may exist in theory, many researchers are unable to access them. Even once they have access to TAF data, researchers have faced significant difficulty identifying HCBS claims in these data. The publication of several algorithms designed to help researchers with identification, and ongoing comparisons of these algorithms could accelerate research on HCBS. However, it is important for researchers to recognize the significant barriers to launching such research.

Non-Standard Waivers, Services, Eligibility Criteria and Reporting across States

HCBS services, especially those provided through a waiver, vary state-to-state and are often opaque to researchers (Rohde et al. 2024). Services provided in one state are often not comparable to services provided in another state. Unfortunately, the data on specific state-level services are lacking. Foundations, such as the KFF, have attempted to identify how services are distributed across states through surveys and research (Sowers et al. 2016). Researchers have also used Freedom of Information Act, or FOIA, requests to access information on HCBS

waivers (Miller et al. 2025). Improving reporting standards to yield accurate reports of services, service users, and spending that are comparable across areas over time could help.

Similarly, state and federal entities do not archive data, which means many pieces of historical information have been lost (and are not available via FOIA). One useful resource for the research community would be a platform in which to store current and historical information on state plans, waivers, amendments, and appendices to state plans, contracts and other features that convey choices states make regarding their HCBS services.

No Taxonomy of Payment/Delivery Models

Although states are exploring different ways to finance and deliver HCBS, there is no classification of all types of HCBS payment methods and delivery models offered by states. Several groups have developed their own classification scheme of HCBS services in Medicaid MAX (Peebles and Bohl 2014) and TAF data (S. Wang, Qi, et al. 2024; Greener et al. 2023; Rooney et al. 2023; Medicaid and CHIP Payment and Access Commission 2024; Rutledge et al. 2025). However, no such taxonomy exists for payment and delivery models. A taxonomy is important to researchers because it helps identify the full breadth of financing and delivery models offered nationwide, and it could enable comparable analyses across studies evaluating different states and settings. This taxonomy could enable researchers to consistently compare payment and delivery models across states when conducting multi-state or nationwide analyses.

6. Conclusion

During a period of rapid demographic changes and policy debates, the need for evidence to deliver high-value HCBS is critical. Early research on HCBS has outlined the contours of state programs, and state and federal efforts have successfully reduced the use of institutional services among a population that repeatedly expresses a preference for receiving care in their communities. However, the evidence to date has failed to provide states with the tools needed to design the most beneficial programs at any given level of spending. As modern data sources, partnerships, techniques for linking, analyzing, and sharing expertise become available, actionable insights to help guide HCBS implementation are within reach.

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Figure 1

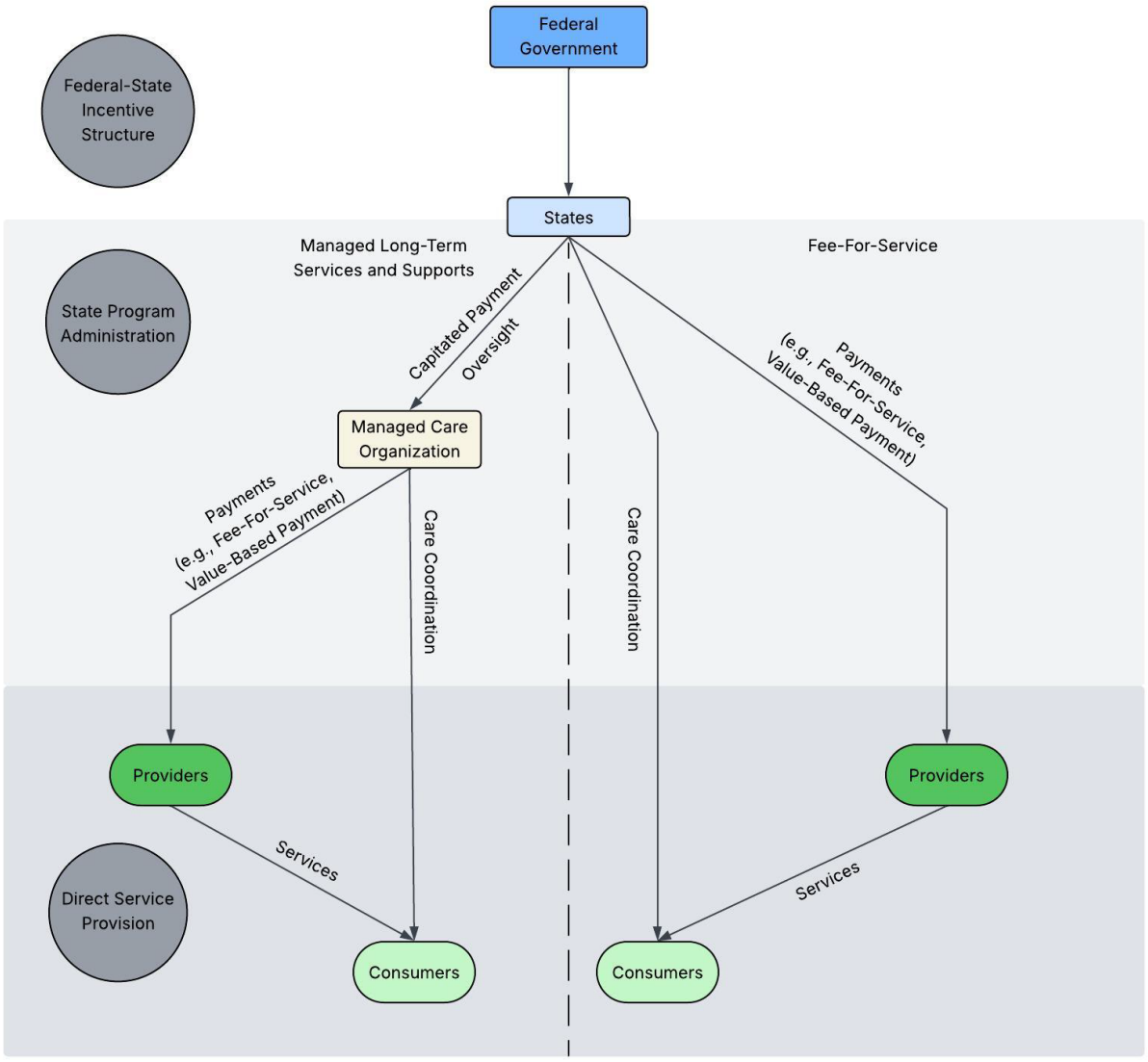
Federal Government
Federal-State Incentive Structure
States
Managed Long-Term Services and Supports
Fee-For-Service
State Program Administration
Capitated Payment
Oversight
Payments (e.g., Fee-For-Service, Value-Based Payment)
Managed Care Organization
Payments (e.g., Fee-For-Service, Value-Based Payment)
Care Coordination
Care Coordination
Providers
Providers
Services
Services
Direct Service Provision
Consumers
Consumers

Table 1. Data Sources Used in HCBS Research

Data Source Type	Examples	Advantages	Disadvantages
Individual claims data	• Medicaid Analytic Extract (MAX). • Medicaid Transformed Analytic Files (TAF). • Medicare claims.	• Detailed person-level information. • Large sample sizes.	• Data use agreements are onerous. • HCBS use difficult to identify. • Does not include information on families or social context. • Requires attention to data quality and data missingness. • Data are expensive.
State reports	• CMS-64 report. • CMS-372 report.	• Data are accurate and reported frequently. • CMS-372 targets 1915(c) users.	• Data are aggregated, not at beneficiary level. • Data aren't subset to the entire HCBS population.
Third-party surveys	• Kaiser Family Foundation (KFF) Medicaid HCBS surveys. • University of Minnesota's Residential Information System's Project. • National Core Indicator Surveys (I/DD, Aged and Physically	• Easier to attain than claims data. • Created by professional sources. • Cover many states and many time periods.	• Some years/geographies are missing. • Data are less granular than claims data.

Table 1. Data Sources Used in HCBS Research, Continued

Data Source Type	Examples	Advantages	Disadvantages
	Physically Disabled, State of the Workforce). • Consumer Assessment of Health Plans (CAHPS) Home and Community-Based Services Survey.		
Publicly available data	• Medical Expenditure Panel Survey (MEPS). • Health and Retirement Study (HRS). • Medicare Current Beneficiary Survey (MCBS). • National Study of Caregiving (NSOC). • American Community Survey (ACS) data on LTSS workforce. • National Health and Aging Trends Study (NHATS).	• Longitudinal or cross-sectional survey data. • Publicly available files are easier to access than restricted-use data. • Includes data on family and social context.	• Some public files are deidentified. • Study populations are smaller than individual claims data.

Table 2. Research Questions and Opportunities

Federal-State Incentive Structure	
Federal Financing	*Olmstead v. L.C. Enforcement*
How do policy changes impact state (and consumer) behavior and outcomes?	Does legal enforcement meaningfully improve HCBS quality?
How does state-level heterogeneity impact the effectiveness of specific initiatives?	What is the impact of *Olmstead v. L.C.* enforcement on costs of HCBS or total LTSS?
How do FMAP incentives and financing mechanisms target specific states according to HCBS quality or costs?	
How do Medicaid HCBS spillovers impact spending on other federally funded programs (such as Medicare)? How do Medicare policies impact Medicaid LTSS spending and provision?	
State Program Administration	
Value-Based Payments and other payment policy	*Managed Long Term Services and Supports*
What value-base payment (VBP) programs currently exist?	How does MLTSS vary between states?
How do provider behavior and consumer outcomes change based on the type of incentives offered?	How do differences in MLTSS programs impact care delivery and consumer and family outcomes?
What is the effectiveness of VBP in providing high-quality HCBS?	How do HCBS MLTSS outcomes compare to traditional FFS outcomes? Which populations are impacted more?
What policies exist to adjust level of care (up or down) in response to change in care needs (e.g., from an acute crisis to stable care)? How do they affect the cost and quality of HCBS?	
Self-Direction	*Quality Measurement*
How have labor law changes affected access to self-directed services?	How can HCBS quality measures used by policymakers and researchers be streamlined and harmonized?
What role does administrative burden play in shaping consumers and families' ability to control supports?	How can quality measures not easily captured in claims data (such as autonomy) best be measured?
What tradeoffs exists in how states contract with fiscal intermediaries?	What is the right balance between claims-based quality measures and more subjective measures?

Table 2. Research Questions and Opportunities, continued

Self-Direction	*Equity related to HCBS*
Which models of care are most effective at supporting patient autonomy?	Do choices made by states affect differently according to income, rural residence, race and ethnicity, type of disability?
Financial Integration Across Payers	
In what ways are HCBS financial incentives aligned/misaligned for Medicaid, Medicare, and commercial payers?	
What are the major impacts of misaligned financial incentives on HCBS?	
How can financial incentives better be aligned across key actors?	
Direct Service Provision	
Consumers and Family Outcomes	*Transitions Within the HCBS Spectrum*
What does optimal care look like? For families without strict budget constraints, which services do they purchase?	How have people and resources shifted within the HCBS spectrum over time?
How can HCBS be designed to best support community integration? Within HCBS what level of integration occurs?	Why are types of service utilization within the HCBS spectrum changing?
To what extent and under what circumstances does HCBS expansion reduce the use of institutional care?	Which forms of HCBS are most effective? For whom?
What are the quality implications of HCBS transitions?	
HCBS Workforce	*Provider Ownership*
Why do home care workers enter the HCBS workforce?	How has the ownership structure of HCBS providers changed?
What are the major challenges facing the HCBS workforce (as opposed to other healthcare opportunities)?	How does private equity impact HCBS?
How will recent legislation/federal policy changes impact the HCBS workforce? How can employers best respond?	

Table 2. Research Questions and Opportunities, continued

HCBS Workforce	*Provider Ownership*
How do states or agencies determine the appropriate amount of care (e.g. number of worker hours) for each HCBS recipient? How does this vary based on individual needs?Are there settings in which technology effectively can offset worker hours?	
Care Coordination	
How does care coordination impact the quality and costs of HCBS care?	
Research Opportunities	
Expand State – Researcher Partnerships	*Novel Data Linkages*
How can states and researchers collaborate to respond to evidence gaps faced by state agencies and advance research on HCBS?	How can administrative data from a variety of settings be linked?
How can states make the most out of partnership with researchers?	What are candidate data sources for novel linkages?
What are the unique barriers facing state-researcher partnerships? How can they be surmounted?	
HCBS Researcher Best-Practices Knowledge Base	*Multi-State Research Projects*
What HCBS research areas could most benefit from a best-practice knowledge base?	How can researchers work with multiple state agencies to develop a taxonomy of HCBS services?
Which knowledge-sharing formats are best suited to promote a knowledge base?	