LeadingAge LTSS CENTER @UMass Boston
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THE scan FOUNDATION

ATI Advisory

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Policy and Program Opportunities to Address Medicaid HCBS Complexities

About this Work

With support from The SCAN Foundation and in partnership with The LeadingAge LTSS Center @UMass Boston, ATI Advisory (ATI) explored how Medicaid policies impact individual experiences in accessing home and community-based services (HCBS). ATI identified key policy opportunities to improve access to Medicaid HCBS through an analysis of the policies governing HCBS, key informant interviews, and a targeted survey that sought to understand how the design and administration of HCBS can shape access to care.

This brief emphasizes the importance of developing more streamlined, accessible solutions to better serve the diverse HCBS population. Further, recognizing the importance of meaningfully incorporating lived experiences when assessing the impact of policies in practice, the brief also highlights firsthand perspectives and quotes collected from the interviews, survey, and The People Say, an online qualitative database of older adult interviews.

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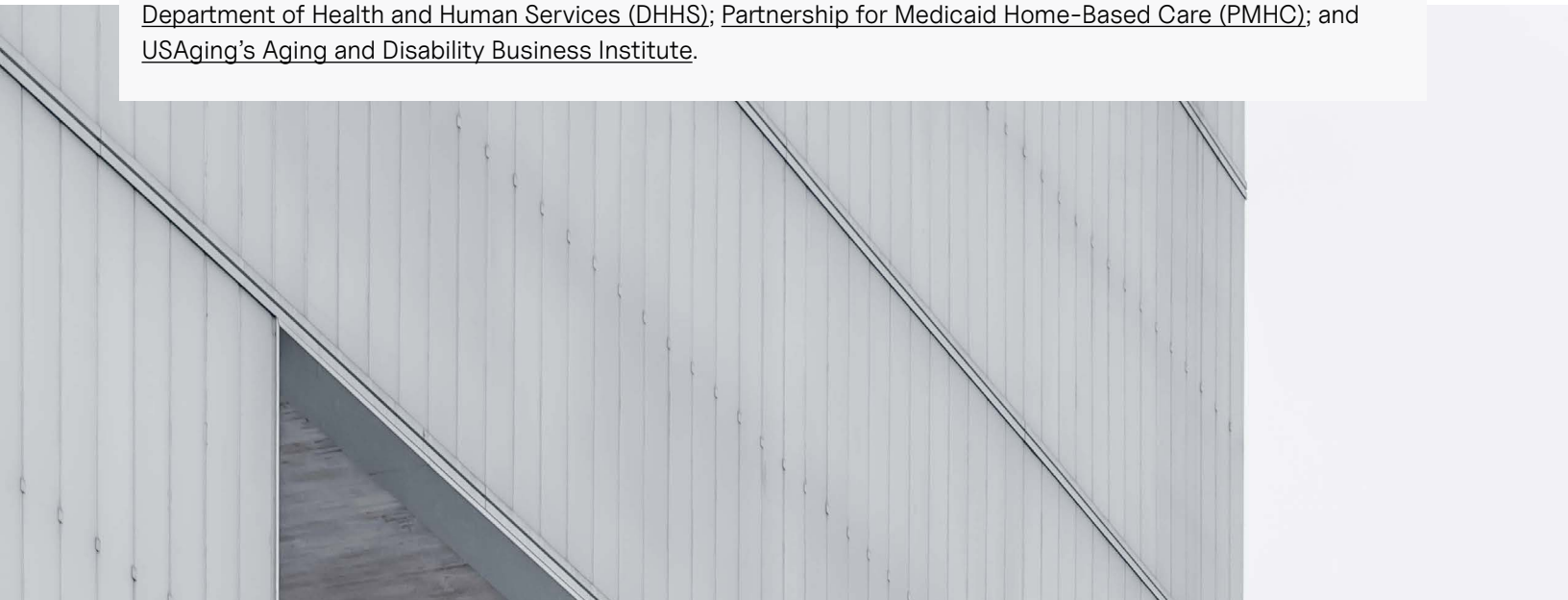


Executive Summary

BACKGROUND

Medicaid-funded home and community-based services (HCBS) are essential for providing millions of individuals with disabilities, chronic conditions, and age-related needs the support to remain in their homes and communities. While these services promote independence and improve quality of life, they are optional Medicaid benefits, which means that states can exercise broad discretion in determining who qualifies, what services are offered, and how care is delivered. In addition to program design flexibility, states also have discretion to shape application and enrollment processes for accessing Medicaid HCBS, many of which are complex, time-consuming, and onerous for individuals who need services.

PURPOSE OF THE BRIEF

This policy brief examines how state Medicaid policies and administrative processes shape access to essential HCBS supports, while highlighting the lived experiences of individuals navigating these systems. Experiences with HCBS are shaped by a broader ecosystem of intersecting factors—including social, economic, demographic, political, geographic, and medical contexts. As such, this work underscores a critical but often overlooked dimension of HCBS access: delivering timely, effective, and person-centered care requires attention not only to service funding, but also to the policies, administrative infrastructure, and day-to-day processes that govern how services are delivered and experienced. Informed by desktop research, key informant interviews, survey findings,[1] and lived experience insights from The People Say, this brief covers the following sections:

- → **Overview of Medicaid HCBS**, including key details on Medicaid policies that define HCBS systems;[2]
- → An **HCBS Process Map**, which demonstrates how HCBS policies and infrastructure influence processes to support beneficiary access to services; and
- → Proposed **state policy and program opportunities** to improve access to and individuals' experience with Medicaid HCBS.

By examining the infrastructure that governs access to HCBS, states can identify challenges and seek solutions that result in delivering more timely, person-centered, and effective care.

POLICY IMPLICATIONS

States have powerful tools within existing Medicaid authorities to improve HCBS access. Drawing on lessons from state experiences and innovations, this brief introduces actionable state-level strategies to streamline access, improve care coordination, and reduce administrative burden within Medicaid HCBS structures. By addressing policy and process challenges informed by lived experiences, states can build Medicaid HCBS systems that not only allocate resources and operate effectively but also support the realities and needs of individuals within the system.

1 See Appendix A for a summary of the survey, including findings.
2 See Appendix B for additional background on Medicaid HCBS.

Overview of Medicaid HCBS

Medicaid is the largest single payer of home and community-based services (HCBS)—covering 57% of national long-term services and supports (LTSS) spending—and has a vital role in supporting the wellbeing of millions of individuals with functional needs nationwide.[i] These services span a wide range of supports, including personal care, homemaker services, transportation, home modifications, and assistive technology—all designed to promote independence, community integration, and enhanced quality of life. HCBS enables individuals with disabilities, chronic conditions, or age-related functional needs to live in their homes and communities, rather than in institutional settings.

The People Say spotlight:

"We want to age in place… that would be a definite goal… I don't want to be in a long-term care facility."

- "Evelyn", 76-78, white woman on traditional Medicare

Unlike mandatory Medicaid LTSS benefits like nursing facility care, HCBS are optional services that states may choose to offer and require federal approval under one of several Medicaid authorities, such as 1915(c) waivers. States have broad discretion within federal parameters to design their HCBS programs—determining scope of services, eligibility, and use of waitlists or enrollment caps. This flexibility allows states to tailor HCBS programs to state and local priorities, but contributes to wide variation in access, availability, and benefit generosity across states.

States administer HCBS using a range of payment and delivery models. These may include fee-for-service (FFS) systems, managed FFS arrangements, or fully capitated managed care models. The model a state uses influences which entities are responsible for delivering services, who manages administrative processes, and who bears financial risk. Within these payment and delivery models, states offer various service management approaches—ranging from self-directed models where individuals hire, train, and supervise their own caregivers to agency-directed models where provider agencies handle caregiver management responsibilities.

Individuals who have functional needs and receive Medicaid HCBS represent a highly diverse population, with varying health conditions, disabilities, and support needs. To address this diversity, states may tailor waiver eligibility to serve specific populations, such as individuals with intellectual or developmental disabilities (I/DD), older adults and people with physical disabilities who need help with activities of daily living, individuals with traumatic brain injury, or children with complex behavioral health needs.[ii] Within federal guidelines, states also have flexibility to define HCBS eligibility, using a combination of financial and functional criteria.[3]

For a more detailed overview of how Medicaid administers HCBS, please refer to Appendix B →

3 H.R. 1, the One Big Beautiful Bill Act (OBBBA), was signed into law on July 4, 2025. In addition to many changes to the Medicaid program, OBBBA expands the eligible populations for 1915(c) waivers to include state-specific needs-based criteria that may be less stringent than "institutional level of care" criteria to enroll in HCBS waivers.

Medicaid HCBS Process Map

Accessing Medicaid HCBS can be a complex, time-consuming, and onerous process, shaped by intricate policies, varying eligibility criteria, state-specific benefit packages, and administrative requirements. The process to apply can be challenging and typically involves gathering extensive documentation, coordinating with multiple entities, and managing follow ups related to applications, service approvals, and provider availability, which can deter people from seeking services or result in delays in accessing services. Experiences can also differ widely based on a person's health needs, support system, and personal preferences—as well as the social, economic, demographic, political, geographic, and medical factors that shape how individuals interact with the Medicaid system and access the services they need. For example, people who live in rural areas may have limited access to providers, political priorities within a state may influence Medicaid program design and investments, and demographic disparities can lead to unequal experiences across racial, ethnic, or socioeconomic groups.

To illustrate how Medicaid policies and processes shape access to HCBS in practice, ATI Advisory (ATI) developed a map and accompanying narrative outlining key steps individuals typically navigate when seeking Medicaid HCBS (see **Figures 1** and **2**). These materials are informed by desktop research, interviews, and a survey, and highlight key insights from experts, advocates, and individuals with lived experiences to emphasize the human impact behind the processes. The map provides a high-level, accessible view of the HCBS access process. It is not intended to reflect every state's specific approach but instead offers a starting point for identifying challenges and elevating opportunities for system improvement.

There are several caveats to consider when reviewing the map:

- **FFS Delivery System:** The map does not reflect managed care dynamics or plan-specific processes;
- **Illustrative Process Flow:** Given state variability in policies and processes, the map depicts one plausible sequence of many possible phases and actions (e.g., person-centered service planning occurring after eligibility is determined); and
- **Ideal Execution:** The map assumes that policies and processes function as intended; it does not reflect system failures or deviations.

Grounded in these research methods and set of assumptions, this map is intended to provide a clear, generalizable depiction of Medicaid HCBS processes, while acknowledging the diversity and complexity of individual experiences.

Figure 1. Map Illustrating the Key Phases in Seeking Medicaid HCBS

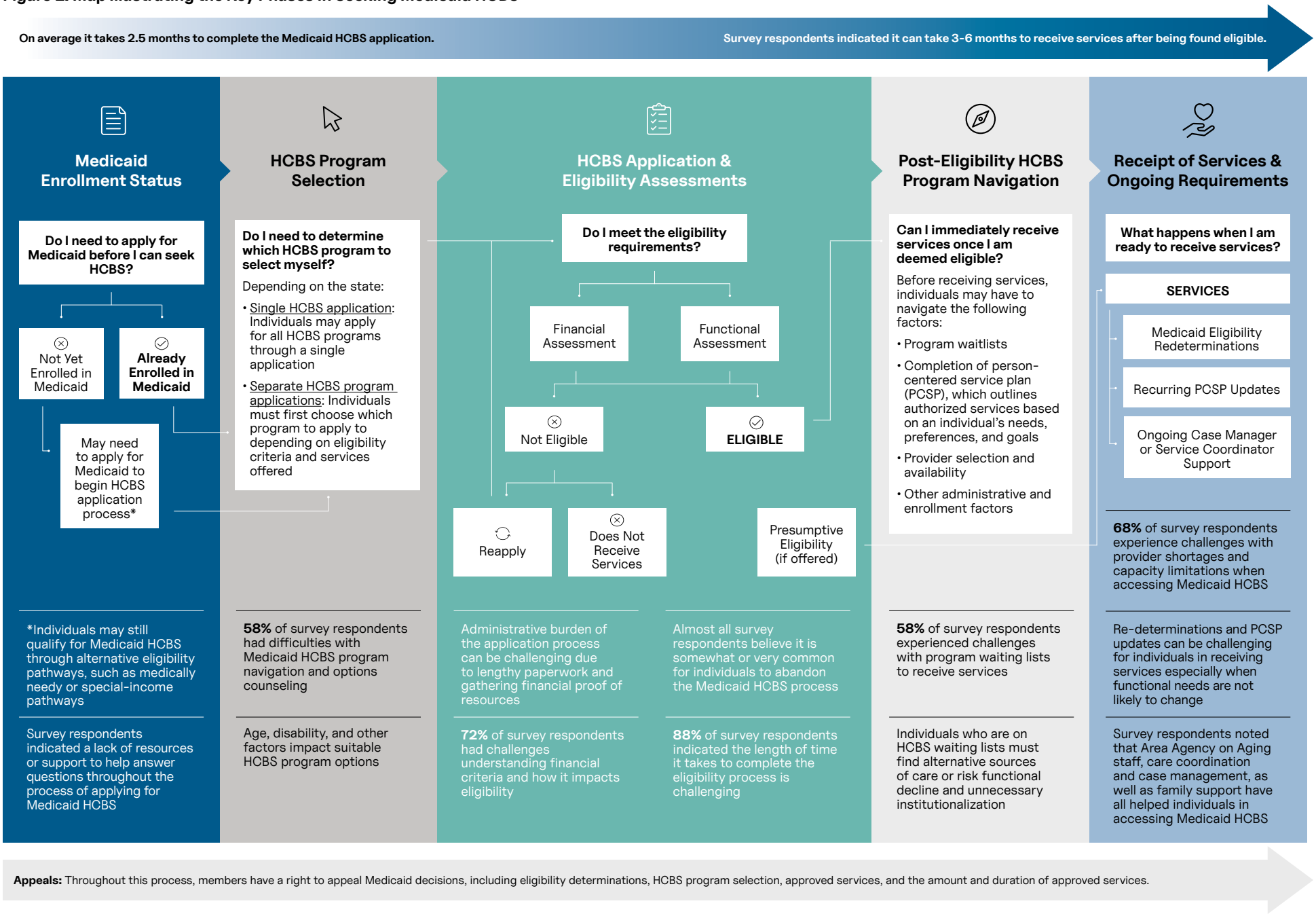


Figure 2. Narrative of Key Phases in Seeking Medicaid HCBS

Medicaid Enrollment Status	**Do I need to apply for Medicaid before I can seek HCBS?** Some individuals are already enrolled in Medicaid when they apply for HCBS. However, for individuals not currently enrolled in Medicaid, they may need to newly apply for both Medicaid and HCBS. Depending on the state, this may be accomplished through a single application process or will require two distinct applications. Additionally, in many states, individuals who do not meet standard Medicaid financial criteria may still qualify for HCBS benefits through alterative eligibility pathways that allow states to extend HCBS to those with higher income or assets.[iii]
HCBS Program Selection	**Do I need to determine which HCBS program to select myself?** States often offer multiple HCBS programs with different eligibility requirements, benefits packages, and operating state agencies. While some states with multiple programs centralize application and options counseling processes, others require individuals to first determine which program(s) they wish to apply for and complete separate application processes.[4]
HCBS Application & Eligibility Assessments	**Do I meet the eligibility requirements?** To be found eligible for HCBS programs, individuals must complete both financial and functional eligibility assessments and meet the criteria of the specific HCBS program(s) to which they are applying. Individuals found ineligible initially may reapply as their financial or functional situations change. **Financial eligibility** is generally determined by a combination of income and asset limits. Related policies, such as spousal impoverishment rules and asset lookback periods, may impact financial eligibility determinations.[iv, v ,vi] **Functional eligibility** requires that applicants demonstrate a level of need, with many states requiring a nursing facility level of care (NFLOC). NFLOC definitions vary but are often defined as requiring assistance with a certain number of activities of daily living (ADLs).[vii] HCBS eligibility assessments and approval can take weeks or even months to complete or receive (according to survey findings, it can take two and a half months to complete), often due to a combination of high administrative burden on applicants, complex application requirements, and systemic challenges. Factors such as language barriers, difficulty with detailed application components, and limited state staffing or resources can further delay access to services. Some states have presumptive eligibility policies, which may allow an individual to receive HCBS prior to the completion of eligibility assessments.[5]

4 Individuals navigating aging and I/DD systems of care are especially prone to encountering fragmented and duplicative application processes when trying to access HCBS.

5 HCBS State Plan services can be authorized retroactively to the date of application. In contrast, services under a 1915(c) waiver can only be authorized prospectively, starting from the date the individual is formally approved for the waiver – unless the state has implemented a presumptive eligibility provision.

Survey spotlight:
"...often the loved ones try to handle [the applications and paperwork]. They have to suddenly become aware of a lot of protected information just to get forms filled out, they don't know where to go and Medicaid often misdirects them to the wrong department or another organization altogether."

- AAA staff

The People Say spotlight:
"I had tried for Medicaid before, but I was rejected... [a social worker] said, well, 'I'll help you fill that application out and send it in'...Guess what? Got rejected... sometimes these applications are so complicated."

- "Sam" 71-75, Black man living in a rural area enrolled in Medicare Advantage

Interview spotlight:
Interviewees highlighted constraints such as state agency staffing capacity to complete applications and care planning processes and administrative complexity of the application process for beneficiaries as practical barriers that prevent them from progressing through the application process.

- "Sandra" 76-80, Black woman living in an urban area, on traditional Medicare and Medigap

Post-Eligibility HCBS Program Navigation	**Can I immediately receive services once I am deemed eligible?** Becoming eligible for HCBS does not necessarily mean an individual can immediately receive services. There are additional elements individuals may have to navigate, including program waitlists,[viii] completion of person-centered service planning (PCSP), provider selection and availability, and other factors. Individuals awaiting services must find alternative sources of care or may remain unsupported, which increases the risk of functional decline or requiring institutional care regardless of a preference to remain in the community.
Receipt of Services & Ongoing Requirements	**What happens when I am ready to receive services?** Once an individual has a service authorization and finds a provider, they can begin receiving services according to their PCSP. Although ideally services are delivered in a timely manner, according to survey findings it can take up to three to six months. Individuals typically receive ongoing supports from a case manager or service coordinator, who monitors the quality, effectiveness, and adequacy of services based on the individual's needs. PCSPs are updated on an annual basis and/or due to changes in health or circumstances.

Interview spotlight:
Several interviewees noted that while person-centered approaches for HCBS are the goal and required under federal regulations, these approaches may not be consistently practiced. As one interviewee with lived experience noted, "when you're making these decisions about providing services, is your client part of the conversation? If they're sitting there with a question mark, then it's not patient-centered…you need to meet their individualized needs".

The People Say spotlight
"I find that in speaking to my doctors, I'm like… are they listening to me?… It's like they've got this whole plan [that] doesn't do… what I'm asking for. And so I have to be very emphatic…. Sometimes it can be very difficult, to get them to hear you. And I think that's my biggest challenge getting older…. Even when you tell them, no, I don't think that's the best thing for me they will still come back with, 'This is what you need to do.'"

Survey spotlight:
"[There is] discouragement due to the long waiting list for services in [state redacted], even after they are approved."

- Social worker

Interview spotlight:
Interview spotlight: "An issue is a lack of HCBS providers…and not being able to find [them]. It takes time, and that's an issue for many [individuals in many states] – just that lack of providers for HCBS."

- State Medicaid staff

The People Say spotlight
"…I want to know that I can get the care that I need, in-home service that I need, and not have to fight and wait for three months or two months…"

- "Jason" 71-75, dual eligible, non-Hispanic white man living in a rural area

State Policy and Program Opportunities

Improving access to Medicaid HCBS begins with a clear understanding of the barriers that individuals face in availability and receipt of timely, appropriate care. States have powerful tools at their disposal to drive meaningful change within existing policy frameworks and authority pathways. The proposals that follow outline actionable, state-level strategies designed to address core challenges individuals experience when navigating the HCBS system, as identified through this brief. These solutions are intended as a starting point for states to consider practical, person-centered reforms that expand access and enhance service delivery.

Critically, states considering such reforms should engage and actively solicit feedback from stakeholders—including those receiving services, caregivers, HCBS providers, and other key partners—to identify state-specific barriers and vet proposed solutions. Beyond existing stakeholder forums,[6] states may benefit from additional structured engagement methods, such as listening sessions, surveys, consumer testing, and roundtables. Centering the lived experiences of those navigating HCBS can help states uncover operational pain points and unintended barriers across eligibility and enrollment, care planning, and service receipt.

Below, we outline common pain points associated with navigating HCBS and offer select policy proposals to address these issues, highlighting examples from states that have implemented relevant reforms. For each solution, there are often multiple avenues states can pursue to achieve the intended outcomes. States can take many approaches to adapt these or similar ideas and consider additional, innovative solutions tailored to their unique needs and system dynamics.

Note: The policy recommendations in this section are based on the federal and state Medicaid policy landscape at the time of publication. Ongoing developments at the federal level - such as the recent enactment of H.R. 1, the One Big Beautiful Bill Act (OBBBA) - may influence the relevance or feasibility of these recommendations over time as regulatory and sub-regulatory guidance is released. For example, OBBBA expands the eligible populations for 1915(c) waivers to include state-specific needs-based criteria that may be less stringent than "institutional level of care" criteria to enroll in HCBS waivers.

6 Existing councils, such as Beneficiary Advisory Councils and Medicaid Advisory Committees required under the Medicaid Access Rule or Medical Care Advisory Committees, can serve as key mechanisms for gathering direct input from individuals receiving services.

Figure 3. Example Federal Supports for State Scenarios

Medicaid HCBS can be complex and difficult to navigate. *Enhancing the application and enrollment experience with more accessible information, individualized assistance, and streamlined processes can improve consumer navigation and reduce administrative friction.*

Policy or Program Solution	*State Example*
Adopt a Single, Unified Application Process for All Medicaid HCBS Programs. Requiring individuals to apply separately for multiple HCBS programs—often through different state agencies—creates unnecessary complexity and delays. To streamline access, states can align processes and consolidate front-end application procedures that result in a single, consolidated application for all Medicaid HCBS programs. For states where a single application is not feasible, states can designate a single administrative entity to centrally process applications to reduce confusion regarding program options and eligibility, and administrative burden on applicants and their loved ones. Centralized intake and eligibility can also support data integration and enable better tracking of service utilization and unmet needs. To the extent information technology system updates are required to accomplish this, states may be able to leverage Medicaid Enterprise Systems (MES) enhanced federal matching funds.[ix]	**Colorado** supports a Single Entry Point (SEP) system which allows individuals seeking long-term care services to access a broad range of HCBS through a centralized application process.[x]
Designate Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs) as Official Central Access Points. States can formally designate AAAs and ADRCs as central access points for navigation assistance on Medicaid HCBS eligibility, application processes, service planning, and transitions of care. States can use memoranda of understanding (MOUs) to formalize such partnerships between Medicaid agencies and ADRCs/AAAs, outlining responsibilities, operational requirements, and financing protocols. When ADRCs/AAAs provide these functions, states can claim federal Medicaid matching funds for eligible expenditures under Medicaid Administrative Claiming (MAC). Leveraging MAC provides a more sustainable funding source to support the critical role AAA/ADRCs play in connecting individuals to Medicaid HCBS.[xi]	**Wisconsin's** ADRC model serves as the single-entry point for publicly funded LTSS programs, including for individuals seeking HCBS through Medicaid programs, including the Include, Respect, I Self-Direct (IRIS) and Family Care programs.[xii]
Increase Outreach and Education to Potential HCBS Beneficiaries and Caregivers. A lack of awareness and understanding remains a significant barrier to HCBS navigation and timely access, particularly among individuals who may be eligible but are unfamiliar with available services or how to apply. States can address this gap through targeted outreach campaigns, community-based education, and plain language and culturally and linguistically appropriate materials. In addition to mass communication strategies, states can consider partnerships with community-based organizations, healthcare providers, and managed care plans to deliver tailored information directly to individuals likely to benefit from HCBS. Outreach efforts could also highlight preventive and early-intervention HCBS options, particularly for individuals at risk of institutionalization, to reduce avoidable nursing home admissions. For certain education and outreach activities directly related to Medicaid, states can leverage MAC to support initiative financing.	**Maryland's** Money Follows the Person program includes robust outreach and education initiatives to inform individuals in institutional settings about their HCBS options and facilitate their transition to community living.[xiii]

Stringent eligibility criteria can limit access to Medicaid HCBS. *Expanding access to new populations and implementing more flexible eligibility criteria can reduce eligibility barriers and support a more inclusive HCBS framework.*

Policy or Program Solution	*State Example*
Expand HCBS Access to Individuals "at-risk" of Institutionalization. Many Medicaid HCBS programs limit eligibility to individuals who meet institutional level of care (LOC), excluding those with emerging or moderate functional needs who could benefit from early intervention. Through several possible HCBS authority pathways, including new opportunities under H.R.1., states can improve access by expanding eligibility for HCBS to "at-risk" individuals—those who do not yet meet LOC requirements but will be likely to require institutional care without supportive services. This not only promotes community-living for a broader range of individuals with functional needs, but also may help delay or defer more costly care in the future.	**Hawaii** has utilized its Section 1115 Demonstration waiver to extend HCBS to individuals classified as "at-risk" of requiring institutional care, which addresses the needs of those who do not yet meet NFLOC criteria but are likely to require such care without supportive interventions.[xiv]
Introduce Financial Eligibility Flexibilities to Expand Access. Financial eligibility criteria restrict access to HCBS for individuals with moderate resources who still need support. States can adopt a range of financial flexibilities to broaden access, including: → Disregarding HCBS program asset limits for individuals enrolled in Medicaid through Modified Adjusted Gross Income (MAGI) -based pathways[7] to ensure that individuals with higher asset levels can access HCBS, rather than only being eligible for institutional care, in line with the Olmstead Decision;[xv] → Eliminating or increasing asset limits; → Eliminating or shortening Medicaid's five-year asset lookback period; → Increasing income limits; and → Eliminating income and asset limits for the Ticket to Work[8] population; and associated HCBS programs.	**North Dakota** broadened access to Medicaid by expanding the asset limit from the standard $2,000 amount to $3,000.[xvi]

7 Eligibility for MAGI Medicaid populations (e.g., children, pregnant women, and low-income adults) is determined by income from tax returns and does not consider assets, while eligibility non-MAGI populations (e.g., seniors and individuals with disabilities) is assessed based on both income and assets.

8 Ticket to Work is a Social Security Administration (SSA) employment program for beneficiaries aged 18 to 64 that receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) that allow them to return to work or enter the workforce without losing their benefits. See here for more.

Stringent eligibility criteria can limit access to Medicaid HCBS. *Expanding access to new populations and implementing more flexible eligibility criteria can reduce eligibility barriers and support a more inclusive HCBS framework.*

Policy or Program Solution	*State Example*
Minimize the Impact of Medicaid Estate Recovery. Estate recovery requirements can act as a deterrent to HCBS use, especially among older adults concerned about preserving assets for their families. While federal law requires states to recover certain long-term care costs from the estates of deceased beneficiaries age 55+, states have significant discretion in implementation. To reduce the burden on low-income families and increase uptake of HCBS, states can modify their Medicaid estate recovery programs[xvii] by limiting estate recovery to federally mandated services only, expanding hardship waivers, establishing cost-effectiveness thresholds for when recovery is pursued, and increasing transparency around the process. Enhanced consumer education can also dispel myths and reduce the fear associated with estate recovery, encouraging greater use of community-based care.[xviii]	**Oregon** offers broad hardship exemptions and evaluates recovery efforts based on cost-effectiveness. These measures aim to alleviate potential financial burdens on beneficiaries' families and encourage greater use of HCBS.[xix]
Extend Limited HCBS to "Near-dual" Populations. Individuals with Medicare, but who are not Medicaid-eligible, and have significant health and functional needs often fall through the cracks—particularly those who may spend down and become dually eligible for Medicare and Medicaid. States can use Section 1115 demonstrations to create limited HCBS benefit packages for these "near-dual" populations with incomes near the Medicaid threshold, supporting aging in place and delaying full Medicaid enrollment. These benefits are typically capped and include basic HCBS such as personal and respite care. Although relatively uncommon to date, such models have the potential to reduce system costs and improve health outcomes by proactively supporting near-dual individuals before their needs escalate and they spend down into Medicaid eligibility.[xx]	**Washington's** Tailored Supports for Older Adults (TSOA) program is a proactive HCBS coverage program offering near-dual eligible individuals limited HCBS, such as home modifications, respite care, and other caregiver supports. The benefit is capped at $830 per month and intended to delay or prevent both institutionalization and spend down into Medicaid.[xxi,xxii]

Delays in service initiation undermine timely access to HCBS. *Incremental solutions that address lengthy application and care planning timelines, HCBS program waitlists, and workforce shortages can meaningfully improve the timeliness of service delivery.*

Policy or Program Solution	*State Example*
Adopt Presumptive Eligibility Policies to Accelerate HCBS Access.[9] Timely access to HCBS is often hindered by delays in Medicaid eligibility and waiver approval processes. To address this, states can leverage presumptive eligibility policies that allow individuals to begin receiving HCBS before the completion of full financial and/or functional eligibility determinations.[xxiii] Presumptive eligibility for HCBS, which nine states operate as of 2024,[xxiv] is especially valuable for individuals transitioning out of institutional settings or those in crisis who require immediate support to remain safely in the community. Presumptive eligibility can also serve as a continuity measure during redetermination periods, temporarily maintaining services while re-evaluations are underway to avoid unnecessary disruptions in care.	**Ohio** uses presumptive eligibility in its Home Care waiver to allow individuals at risk of institutionalization—especially those transitioning from hospitals or in crisis—to begin receiving HCBS before full Medicaid determinations are complete.[xxv]
Allow Self-Attestation of Income and Assets to Expedite Eligibility Processing. For individuals in non-MAGI Medicaid eligibility groups—such as older adults and people with disabilities—the standard 90-day window for processing financial eligibility often delays access to HCBS. States can streamline these timelines by allowing individuals to self-attest income and asset information at the point of application, reducing administrative burden and enabling more rapid service initiation. This approach is particularly beneficial for individuals with limited ability to gather necessary documentation, such as those experiencing cognitive decline or lacking caregiver support.[xxvi]	**New Jersey's** Section 1115 Demonstration allows for self-attestation of asset transfers during the five-year look-back period for applicants with incomes up to 100% of the Federal Poverty Level (FPL) seeking access to HCBS, allowing the state to eliminate its review of assets entirely. As part of the demonstration evaluation, New Jersey must perform a quality control check on a limited sample of cases.[xxvii]

9 For more information on presumptive eligibility and authority pathways, see here.

Delays in service initiation undermine timely access to HCBS. *Incremental solutions that address lengthy application and care planning timelines, HCBS program waitlists, and workforce shortages can meaningfully improve the timeliness of service delivery.*

Policy or Program Solution	*State Example*
Implement Provisional Plans of Care to Begin Services During Assessment Periods. In situations where comprehensive assessments and care planning processes extend over multiple weeks, states may adopt provisional or interim plans of care to initiate key services quickly. Centers for Medicare & Medicaid Services (CMS) guidance permits states to authorize an initial plan that outlines essential supports, including HCBS, for up to 60 days, allowing individuals to access services while the full assessment and individualized plan is developed. This policy can be critical in preventing institutionalization, relieving caregiver burden, and ensuring continuity of care during transitional periods. To implement this strategy effectively, states must ensure clear criteria for provisional services and establish a mechanism to transition to a comprehensive plan without service disruption.[xxviii]	Most of **Montana's** 1915(c) waiver programs allow for interim service plans for up to 30 days that allow individuals to begin receiving essential services while awaiting the completion of comprehensive assessments and care plans.[xxix, xxx]
Expand Self-Direction and Paid Family Caregiving Opportunities to Address Workforce Shortages. Workforce shortages remain a persistent barrier to timely HCBS delivery, particularly in rural or underserved areas. To mitigate this challenge, states can leverage self-direction models to allow family members—especially those already providing unpaid support—to be compensated caregivers. Self-directed HCBS, which are allowed through most HCBS waivers, gives individuals the flexibility to hire, train, and schedule their own care providers, including qualified family members, improving service timeliness, cultural appropriateness, and patient satisfaction. States could consider necessary infrastructure supports for self-directed models, such as fiscal intermediaries and caregiver training.[xxxi]	**Minnesota's** Consumer-Directed Community Supports (CDCS) program allows participants to manage their own budgets and hire caregivers of their choosing, prompting flexibility and personalized care. In response to workforce challenges, the state has also increased reimbursement rates for family caregivers within the program.[xxxii, xxxiii, xxxiv]

Looking Ahead

Accessing Medicaid HCBS can be a complex and confusing process for individuals and their caregivers. This brief introduces how Medicaid policies shape HCBS access and how they impact people's real-world experiences trying to receive care. Although significant research around the challenges of navigating HCBS exists, this brief brings a different lens—assessing the intersection of individual experiences and formal Medicaid processes—to help illuminate barriers. It identifies policy and program solutions that reflect key concerns that individuals report to respond to the realities individuals face when navigating the system. At the same time, it emphasizes the need for continued attention from policymakers, advocates, and other key stakeholders to identify and implement more comprehensive reforms. Despite the challenges that states must navigate to reform HCBS navigation and access, such as fiscal constraints, workforce limitations, and administrative requirements, there remains significant opportunity to build on existing processes, streamline access, and extend the promise of high-quality, person-centered, and equitable HCBS.

Appendix A

From January 20 to February 27, 2025, ATI Advisory (ATI)—with the support of key partners—distributed a survey to explore the complexity of Medicaid home and community-based services (HCBS) through the lenses of individuals accessing and/or receiving services and the providers which serve them. **Figure A-1** provides an overview of survey respondents.

Figure A-1. Survey Respondents Organized by Respondent Type

Respondent Type	Percentage (Count)
Caregiver of an individual using or seeking Medicaid HCBS	52.17% (24)
General HCBS provider	13.04% (6)
Other *(Included: health plan staff, former county staff, service coordinator in public housing, professional counselor, social workers)*	13.04% (6)
Area Agency on Aging (AAA)	8.7% (4)
Community based organization	4.35% (2)
Advocacy group	4.35% (2)
Individual using or seeking Medicaid HCBS	2.17% (1)
State Health Insurance Assistance Program (SHIP)	2.17% (1)

Importantly, there are key limitations to acknowledge that likely influenced responses and key takeaways in ATI's findings:

The surveys utilized a sample of convenience. Survey data does not represent a random sampling of the population and no adjustments, including survey weights, were made to account for potential non-response or selection bias. Results are reported as a point or best estimate.

No hypothesis testing or interval estimation was conducted to account for sampling error.

Responses to survey questions were optional; respondents could opt out of questions.

The following provides a high-level summary of ATI's survey findings.

Applying for Medicaid HCBS is difficult.

Almost all respondents feel it is somewhat or very difficult to apply for Medicaid HCBS (96%).

Almost all respondents feel it is somewhat or very common for individuals to abandon the process (85%), with most citing difficulties in applying or determining eligibility as common reasons.

Most common challenges reported in applying for Medicaid HCBS include:

- The length of time it takes to complete the eligibility and/or program application processes (88%);
- Understanding financial eligibility and its impact on eligibility (72%); and
- A lack of resources or support to help answer questions throughout the process and guide individuals through next steps (68%).

Even after approval for HCBS, accessing services can remain challenging.

Just over half of survey respondents believe it is somewhat difficult or very difficult for individuals to access Medicaid HCBS (57%) after they are determined eligible. Some individuals approved for HCBS programs face waitlists to receive services. Common concerns raised around individuals on an HCBS waiver waiting list include having to go without long-term services and supports (LTSS) and its impact on individuals and their caregivers, remaining in unsupported living situations which can increase the risk of falls, and feeling frustrated with the application process. More generally outside of HCBS waiver waitlists, respondents continue to note provider shortages and capacity limitations as the top barrier to care (68%).

Respondents believe the process could be improved.

Respondents noted that AAA staff, care coordination and case management, as well as family support have all helped individuals in accessing Medicaid HCBS. Survey respondents would like to see additional support and clearer guidance from state Medicaid agencies for gathering documents, eligibility guidelines, options counseling, and overall streamlined information and simplification of program options.

Near dual individuals encounter a lack of affordable options and face many barriers when trying to access affordable HCBS without Medicaid eligibility.

Respondents noted a lack of non-Medicaid programs to meet the needs of this population and that those available have long wait lists or provide limited services.

Appendix B

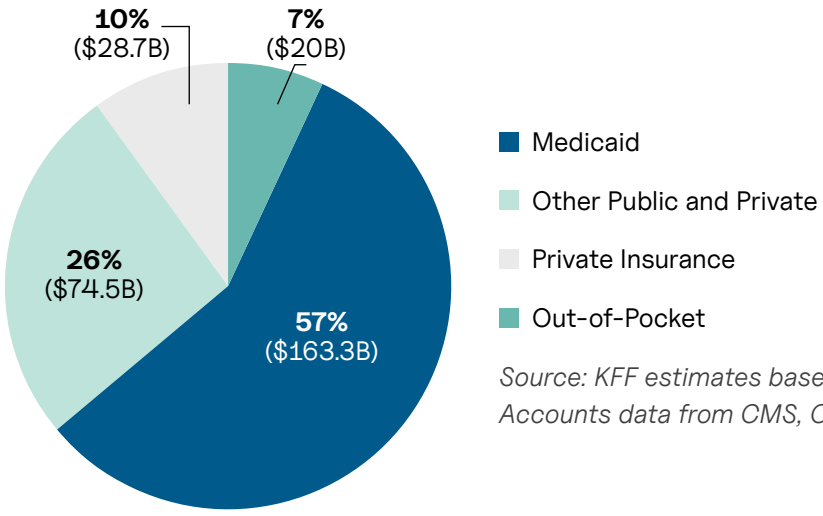
OVERVIEW OF HCBS

LTSS encompass a range of services that provide assistance to individuals with functional limitations due to disability, chronic illness, and/or aging-related conditions.[xxxv] Within the spectrum of LTSS, HCBS provides individuals the opportunity to receive services at home or in the community as an alternative to institutional care, promoting independence, community integration, and enhanced quality of life.[xxxvi,xxxvii]

HCBS offerings vary, but generally include personal care assistance, homemaker services, meal preparation or delivery, and other services that help with activities of daily living (ADLs) such as bathing, dressing, and toileting.[xxxviii] HCBS may also include assistive technology, home modifications, transportation supports, and other services that enable an individual to remain living in the community. Beyond direct personal and environmental supports, HCBS can also include services aimed at promoting skill development and social engagement, such as employment assistance, adult day programs, peer supports, and behavioral consultations.[xxxix]

Individuals can obtain HCBS through a patchwork of private and public sources—including Medicaid, private insurance, out-of-pocket payments,[10] and other limited state and local programs. Medicaid is the largest single payer of HCBS, accounting for 57%, or $163 billion, of total spending (see **Figure B-1**). Separately, and not captured in **Figure B-1**, is the significant portion of HCBS support that comes from unpaid caregiving, primarily provided by an individual's family members, friends, and community networks. These supports account for an estimated economic value of more than $600 billion annually.[xl]

Figure B-1. HCBS Spending by Payer (2020)xli,[11]



Source: KFF estimates based on 2020 National Health Expenditure Accounts data from CMS, Office of the Actuary

10 Within the subset of individuals who pay for HCBS out-of-pocket, there is a group referred to as the "gray market" that includes individuals who receive some public funding for HCBS but also pay out-of-pocket for additional services or to cover any remaining costs. See here for more.

11 Total HCBS expenditures include spending on residential care facilities, home health care services, and home and community-based waiver services. Expenditures also include spending on ambulance services. The chart does not include Medicare spending on home and community-based post-acute care ($46 billion in 2020). All home and community-based waiver services are attributed to Medicaid. Other public payers may include the Veterans Health Administration and the Indian Health Service.

MEDICAID HCBS ADMINISTRATION

Federal Authorities

Unlike mandatory Medicaid benefits, such as nursing facility care, state coverage of HCBS is largely optional and states must obtain federal approval to offer them (see **Figure B-2**). Within federal parameters, states have broad discretion in shaping their HCBS programs, determining key elements such as scope of services, eligibility criteria, funding levels, and use of waitlists and enrollment caps.[12] As a result, while all state Medicaid programs offer HCBS, the design and delivery of these services vary widely. While this flexibility enables states to tailor programs to their local needs and budgets, it also contributes to substantial variation across states in services access, availability, and benefit richness.

Figure B-2. Federal Medicaid Authorities for HCBS

Authority	Description
1915(c) HCBS Waiver (47 states)[xlii]	Allows states to provide HCBS to individuals who would otherwise require institutional care (e.g., in a nursing facility). States can target specific populations and offer a wide range of services (e.g., personal care, respite, homemaker). States may cap enrollment, limit services geographically, and maintain waitlists. Must demonstrate cost neutrality.[xliii]
1915(i) State Plan Option (34 states)	Permits states to offer HCBS as part of their Medicaid state plan. Services must be available statewide and can target specific needs-based populations. States can define functional eligibility criteria, including allowing coverage for individuals not yet meeting a Nursing Facility Level of Care (NFLOC). No cost neutrality requirement exists, and no enrollment caps are allowed.[xliv]
1915(j) Self-Directed Personal Assistance Services[13]	Allows states to permit Medicaid beneficiaries to self-direct personal assistance services offered under other HCBS authorities. Individuals can hire and manage their own workers, including family members. States must offer participant budgets and support systems. No enrollment caps are allowed.[xlv]
1915(k) Community First Choice (10 states)	Offers states enhanced federal match (six percentage points) for personal attendant services to individuals who meet an institutional level of care. Must include a person-centered planning process and support for self-direction. No enrollment caps are allowed.[xlvi]
Section 1115 Demonstration (14 states)	Broad waiver authority that allows states to gain both waiver and expenditure authority to implement new benefits, expand eligibility, and/or introduce program flexibilities that would not otherwise be permitted. Some states rely on Section 1115 Demonstrations to authorize their entire HCBS programs (e.g., Hawaii), while others use them alongside other HCBS waivers to extend eligibility or benefits (e.g., Washington). States may cap enrollment, create tiered benefit packages, and waive certain federal rules. Must demonstrate budget neutrality.[xlvii]
State Plan Benefits	States can (and sometimes must, depending on the benefit) offer certain HCBS, like personal assistance services and medical supplies, as state plan benefits. Services must be available statewide to all eligible populations and cannot have enrollment caps.[xlviii]

12 Beginning July 2027, CMS will require states to publicly report the number of people on waiting lists for HCBS, along with average wait times, as well as how they maintain their waiting lists. See here for more.

13 State adoption of 1915(j) waivers is limited, as many states opt for other waiver authorities such as 1915(c), 1915(i), or 1915(k).

Payment and Delivery Models

States also leverage different payment and delivery models for HCBS—including fee-for-service (FFS), managed FFS, or managed care models—which shape who administers benefits and who assumes financial risk.[14]

- FFS, where the state assumes both administrative functions and financial risk of HCBS;
- Managed FFS, where the state delegates administrative functions to other entities, but still bears financial risk; and
- Managed care, where the state delegates both administration and financial risk of HCBS to managed care plans.

Within these models, HCBS can be self-directed, agency-directed, or a hybrid, such as agency with choice (AwC).[xlix,15] In self-directed care, individuals manage their own caregivers—including hiring, training, and scheduling—which offers greater autonomy but adds administrative responsibilities.[l] In contrast, agency-directed care relies on provider agencies shifts those tasks to provider agencies, reducing the burden on individuals, but potentially limiting flexibility, choice, and customization of services.

Eligibility and Populations Served

Individuals who need and receive Medicaid HCBS represent a highly diverse population, with varying health conditions, disabilities, and support needs. For example, while HCBS is often associated with older adults, data shows that approximately 80% of individuals who use Medicaid HCBS are under age 65, reflecting the program's important role in supporting younger individuals with disabilities and complex care needs. To address this diversity, states may tailor waiver eligibility to serve specific populations, such as individuals with intellectual or developmental disabilities (I/DD), traumatic brain injury, or children with complex behavioral health needs.[li] States also have flexibility within federal parameters to define HCBS eligibility, typically using a combination of financial[16] and functional[17] criteria. For example, in many states, a Medicaid-enrolled individual may qualify for HCBS if they:

- Have assets less than or equal to $2,000;[18]
- Have income below 300% of the Federal Benefit Rate (FBR), or $2,901 in 2025;[19] and
- Meet a functional need of institutional care, such as NFLOC.

Note that income criteria for HCBS is often more generous than for standard Medicaid coverage. In most states, standard Medicaid income limits range from 100% of the Federal Poverty Level (FPL) for the aged, blind, and disabled to 138% FPL for expansion adults. This means that some individuals who do not qualify for full Medicaid coverage may still be eligible for HCBS via special income eligibility rules if they meet the functional criteria and fall within the more generous HCBS program financial limits.

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14 Financial risk refers to the obligation an entity—such as a managed care health plan or state Medicaid agency—assumes for the cost of care delivery. In managed care models, for example, this risk is assumed by health plans, which must deliver covered services within a fixed per-member payment from the state, known as a capitation rate.

15 AwC uses a joint employer model, where the agency acts as the primary employer and the individual or their representative takes on the role of the secondary or managing employer.

16 States can expand HCBS access to individuals with incomes or assets above standard Medicaid limits through options such as Medicaid Buy-In programs for working individuals with disabilities or by using Section 1902(r)(2) in the Social Security Act to apply more generous income and resource methodologies than those used by Supplemental Security Income (SSI).

17 States have flexibility in determining its level of care requirement, which vary by type of authority (see Figure 4).

18 Includes most assets, with exclusions for capped amounts of assets such as primary residences or burial funds.

19 Includes wages, salaries, Social Security benefits, pensions, rental income, and investment income, with exclusions for certain types of income, such as the value of federal benefits like Supplemental Nutrition Assistance Program (SNAP).

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About the LeadingAge LTSS Center

The LeadingAge LTSS Center @UMass Boston conducts research to help our nation address the challenges and seize the opportunities associated with our nation's growing older adult demographic group. The LTSS Center combines the resources of a major research university with the expertise and experience of applied researchers working with providers of long-term services and supports (LTSS).

This joint venture of LeadingAge – a national organization representing 6,000 non-profit aging services providers – and the University of Massachusetts, Boston translates research into policy and practice to improve quality of care and quality of life for the most vulnerable older Americans. As an independent entity, the LTSS Center conducts applied research for the benefit of government agencies and other policymakers, providers and the general public. It builds on UMass Boston's partnership with Community Catalyst, a national consumer health advocacy organization. For more information, visit ltsscenter.org.

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The SCAN Foundation envisions a society where all of us can age well with purpose. We pursue this vision by igniting bold and equitable changes in how older adults age in both home and community. We work at the diverse intersections of aging with partnerships that expand across the aging, healthcare, disability, policy, social entrepreneur, racial justice, and social justice sectors. With deep roots across the state of California, our work aims to influence national transformation of the systems and supports that enable all older adults to age well at home with purpose. For more information, visit thescanfoundation.org.

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