

The HCBS Settings Rule:

Looking Back and Forging Ahead

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Executive Summary

This report, based on interviews with stakeholders representing state and national disability organizations and advocacy groups as well as published sources, provides recommendations for the continued implementation of the 2014 Medicaid Home and Community-Based Services (HCBS) Settings Rule after the very lengthy transition phase to implement the new requirements formally ended in 2023. The HCBS Settings Rule seeks to ensure that Medicaid HCBS are provided in settings that promote autonomy, community integration, and individual choice in a safe and respectful environment.

Our recommendations center on five key components to successful implementation:

- effective person-centered planning;
- transparent and multifaceted stakeholder engagement;
- simplified and responsive individual complaint/grievance systems;
- strategic site visits for ongoing monitoring; and
- clearly defined oversight and enforcement roles for CMS and states on the HCBS settings requirements.

A. Introduction

In January 2014, the Centers for Medicare & Medicaid Services (CMS) finalized a landmark regulation for people with disabilities, known as the Home and Community-Based Services (HCBS) Settings Rule.¹ For the first time, the agency established standards to define the characteristics that qualify a setting as “community-based” for the purposes of Medicaid services. HCBS include a range of services, but especially center around supports for completing activities of daily living, like eating, bathing, and moving about, along with other services needed to live in the community, like help with household chores, managing money, or supported employment. The rule aimed to distinguish clearly between funding streams for HCBS and those for institutional long-term services and supports (LTSS). The publication of the final rule marked the end-product after nearly a decade of stakeholder engagement, with multiple rounds of public comment on various proposed approaches.



What are the HCBS Settings Rule Protections?

The settings rule lays out a series of basic rights and expectations for all individuals receiving Medicaid HCBS. For example, settings must:

- ensure autonomy and independence, including control over personal resources;
- protect privacy, dignity and respect;
- ensure freedom from coercion and restraint;
- promote full access to the community; and
- provide choice of setting, including non-disability specific setting option, and of HCBS provider.

Provider-owned and -controlled residential settings must adhere to additional requirements, including provision of:

- lease or legally enforceable written agreement with protections comparable to the evictions protections and appeals in landlord/tenant laws;
- access to food and visitors at any time;
- freedom to decorate;
- lockable doors;
- choice of roommates and option for private unit;
- physical accessibility; and
- modifications documented in person-centered plan.²

The HCBS Settings Rule also began an extended transition period that, over a decade and a pandemic emergency later, has shifted the basic expectations for HCBS programs to better align with the principles of person-centered planning, autonomy, and community integration for people with disabilities and older adults. States have made considerable changes to their policies and procedures to meet the new standards, but stubborn problems—including ongoing and in some cases worsening shortages in HCBS workforce, lack of choice of service provider types, and

insufficient affordable, accessible housing—continue to impede the sea change in HCBS that many expected when the rule was finalized in 2014.

During the transition period, states evaluated and then updated their regulations and policies to incorporate the new requirements. They assessed each HCBS setting for compliance with the new standards and established remediation plans with settings as necessary to bring them into compliance. Many states relied heavily on provider self-assessments to complete this step. Because that process can introduce a conflict of interest, CMS required states to validate through another mechanism, such as site visits or beneficiary surveys. Settings that exhibited qualities that isolate individuals with disabilities receiving HCBS from their communities, or that are co-located with institutional settings, were deemed presumptively institutional. Such settings can still qualify as HCBS settings if, after a heightened scrutiny evaluation, the state finds evidence that they still meet the required standards and CMS accepts the state's findings.

While the transition period formally closed in March 2023 after several extensions, the settings rule still shows signs of a work in progress. Forty-four states requested and have been approved for Corrective Action Plans to finish implementing some part(s) of implementation that got disrupted due to COVID-19-related HCBS workforce shortages. In 2022 and 2023, CMS site visits in a number of states revealed ongoing compliance issues with the settings transition, and also found compliance issues with the person-centered planning requirements of the rule that have been fully effective since 2014.³

The information in this report draws from reviews of federal regulations and relevant CMS guidance related to HCBS settings standards. We also conducted open-ended interviews with 11 key stakeholders representing state and national disability organizations and advocacy groups that have been significantly involved in the settings-rule implementation at all levels. The interviews were transcribed and coded around topics of interest and used to identify common problems with settings-rule implementation as well as promising practices across various states and ongoing challenges and concerns. Quotes and examples from interviewees have been de-identified to protect privacy.

Through the interview process, we identified five topics fundamental to help the settings rule achieve its aim of promoting autonomy and community integration

while protecting the health, welfare, and privacy of people with disabilities and older adults who receive Medicaid HCBS. The topics are:

- person-centered planning;
- stakeholder engagement;
- site visits;
- individual complaint/grievance systems; and
- CMS's enforcement and oversight role on the settings rule.

Each section describes specific policies and approaches that helped strengthen enforcement of the rule during the transition period and recommends strategies to improve HCBS settings going forward. The paper concludes with a segment describing considerations and concerns for settings-rule protections now that the transition period has concluded.

B. Person-Centered Planning

According to key stakeholder interviews, person-centered planning, a central component of the 2014 final rule, may have the greatest potential to promote community integration through HCBS. Over the last several decades, disability and health-advocacy groups have been instrumental in pushing for a system of care that situates the person receiving HCBS at the center of service planning and setting choice and promotes autonomy, community integration, and self-determination. The approach reflected in the HCBS Settings Rule is meant to design services plans around the whole person, not just from a narrow perspective on health or function. Although federal regulations governing person-centered planning have been in effect since March 2014, in many places states have struggled to achieve meaningful implementation of the requirements because they require not only policy changes, but also cultural shifts within states, among providers, and even among beneficiaries, who have not been operating on these principles.⁴

Person-centered planning can be generally defined as, “the processes by which a person directs the development of a plan, based on his or her goals, needs, and preferences, and the coordination of services and supports across providers and systems to carry out the plan.”⁵ It is meant to be a life-planning tool that identifies a person’s broader goals—from interests and hobbies to employment, social

relationships, health needs, living situation, and community activities—and incorporates them into a service plan.⁶ The process involves bringing together a team that cares about (and cares for) the individual, centering the individual’s choices and needs, and then using the collective resources to help achieve the individual’s identified goals.

Formal person-centered planning practices were conceived in the 1960s and 1970s as a way to “understand the relationship between disability, service policy and practice, and community life.”⁷ They developed in direct response to research that highlighted the detriments of grouping stigmatized, disabled people together—especially when isolated from the broader community—and demonstrated that people with severe disabilities were “habitually, reflexively, and profoundly underestimated by almost all of the professionals who assessed their capacity to learn and to work.”⁸ The early core principles of this growing community of practice included:

- seeing people first rather than relating to diagnostic labels;
- using ordinary language and images rather than professional jargon;
- actively searching for a person’s gifts and capacities in the context of community life; and
- strengthening the voice of the person and those who know the person best in accounting for their history, evaluating their present conditions in terms of valued experiences, and defining desirable changes in their lives.⁹

The person-centered planning requirements in the HCBS settings rule clearly echo these principles and create a mandate and an opportunity to elevate service provision and community integration for consumers. Importantly, early practitioners noted that meeting the needs of this population requires a human service “consciously and systematically committed to developing its own organizational capacity.”¹⁰

Key Person-Centered Planning Requirements in the HCBS Settings Rule

- led by the individual where possible, and including people chosen by the individual;
- provides information necessary so that the person directs the process to the maximum extent possible;
- reflects cultural considerations, and providing information in plain language and in an accessible manner (including accommodations and LEP);
- clear conflict-of-interest protections for all team participants;
- generally prohibiting providers of care from developing the person-centered service plan except when no other willing and qualified entity is available;¹¹
- offers informed choice and allowing for requests to update; records alternative options not chosen with regard to HCBS settings;
- choice of settings made by the individual;
- reflects an individual's strengths and preferences;
- includes identified goals and desired outcomes;
- reflects services and supports (paid and unpaid) needed to achieve those goals;
- understandable to the individual receiving services;
- finalized and agreed to with informed consent in writing of the individual and those responsible for implementing it;
- distributed to the individual and other people involved in the plan;
- includes services that will be self-directed; and
- reviewed at least every 12 months **and** when the individual's circumstances or needs change significantly, or at the individual's request.¹²

From the beginning, providing robust and consistent assistance that responds to a person's needs and wants has proven difficult.¹³ Stakeholders consulted in early evaluations highlighted limited information exchange, lack of options, and lack of

thoughtful engagement with the person about the services and supports they need. In recent site visits, CMS identified other barriers in many states. Plans often did not record what was important to people, or what their preferences or goals were, and there was often no indication in the plans that an individual was offered meaningful choice—whether in living location, employment, or community engagement.¹⁴ As one key stakeholder observed, “we focus a lot on the process around creating the plan, but just in my opinion, I think we struggle to actually make the action and the acting on the plan the core focus.” Although much progress has been made in HCBS programs to challenge outdated, demeaning, and harmful perceptions about people with disabilities, some of the barriers described in initial research continue to impede successful implementation of the HCBS Settings Rule today.¹⁵

Culture change in HCBS settings is also inhibited by other structural barriers stakeholders identified. Insufficient funding and high caseloads contribute to high turnover and hurried interactions. Losing key staff like case managers and direct-care workers can compromise the building and maintaining of meaningful care-team relationships. These realities make CMS’s acknowledgment of the need to “reemphasize the current person-centered planning requirements and renew focus on assisting states in meeting the full obligations of the person-centered planning process”¹⁶ all the more vital.

Recommendations

1. Training and Implementation

Provider, case-manager, and consumer training is key to the successful implementation of the person-centered planning and settings regulations. Statewide trainings for those involved in creating written plans should include case managers, providers, and licensing professionals.¹⁷ In the preamble to the final settings rule, CMS recognized the importance of ensuring that those responsible for the evaluations, assessment, and person-centered service plans are trained in assessment of individual needs for HCBS and knowledgeable about best practices.¹⁸ As part of its site visits, CMS identified states that adopted person-centered planning training as part of their HCBS programs.¹⁹

Technological advancements can also play an important role in filling gaps and making sure the person-centered planning is available to everyone responsible for implementing it. During site reviews, CMS highlighted a state service system that

used an electronic portal for case managers and providers to access person-centered service plans with the goals of increasing coordination among team members and sharing input from individuals served and their families.²⁰ Several interviewees suggested that advances in technology have helped address some accessibility challenges. For example, devices that capture the person’s voice and what they need, and then respond to those needs, have been proposed as mechanisms to improve communication and service planning, manage medications, and perform basic tasks such as controlling the lights or music in a home or ordering groceries.²¹ While the use of technology may provide opportunities in the person-centered planning process, the individual receiving services must understand its risks—including potential incursions on privacy—so they can make informed decisions before deployment. Efforts should also be made to design inclusive technology and to mitigate barriers that could worsen inequities, such as uneven internet access.

While these tools are useful, keeping the individual at the center of all choices is the most crucial element of service planning. As one state disability-rights advocate explained, a person-centered planning meeting should “not have anything spelled out ahead of time but really talk to [the individual] about what their goals are and what services they want and really try to meet their wishes and their desires.”

2. Monitoring and Complaints

Robust monitoring of the planning process is the only way to ensure that disabled individuals receive the services appropriate to meet their goals. Key components of a comprehensive monitoring strategy include quality metric monitoring, audits, and an effective complaint system. Advocates we spoke with generally agreed that an effective monitoring process must include a system that captures complaints whereby consumers and family members can safely, accessibly, and efficiently document issues with the plan and process, though many noted problems with those systems in their states (see Individual Grievances section below). As CMS states, “the degree to which the process achieves the goal of person-centeredness can only be known with appropriate quality monitoring by the state, which should include substantial feedback provided by individuals who received or are receiving services.”²² Ensuring that person-centered plans are regularly updated, include goals, and are distributed evenly across the person’s team is a minimum floor, but states can do more to ensure the process realizes the spirit, as well as the letter, of the regulation.

State Medicaid agencies should also review at least a representative sample of service plans against an individual's actual experiences. They should employ other methods, including tracking quality metrics to ensure that plans have been developed in accordance with applicable policies and procedures.²³ While some states use their quality-assurance process (e.g., licensing reviews and case management visits) to monitor HCBS settings requirements, these practices should supplement, not substitute for, other oversight methods noted above. Advocates have suggested potentially expanding licensing staff to routinely examine representative samples of service plans as another check for compliance with person-centered planning requirements.²⁴

C. Stakeholder Engagement

Representation and participation are foundational tenets of disability rights and healthcare advocacy, expressed succinctly in the core principle and rallying cry, "Nothing about us without us."²⁵ It also stands for the kind of autonomy and independent decision-making embedded in the HCBS Settings Rule. By 2014, when the rule was finalized, thousands of people across the country had submitted public comments over a series of rule-making steps to shape the final requirements. For more than a decade now, disability and aging advocates have collaborated to implement the HCBS Settings Rule, including by creating paths for beneficiary feedback, working with CMS and the Administration for Community Living (ACL) on implementation issues, and educating members of Congress.²⁶ These feedback loops, both formal and informal, have helped push states to follow through on the community-living goal of the rule and they also provide CMS an additional mechanism to hold states accountable.²⁷

During the transition period, CMS relied heavily on stakeholder engagement in the development of statewide transition plans and for the identification and evaluation of settings that are or may be subject to heightened scrutiny. Given CMS's available resources, the federal agency has limited capacity to verify directly state assurances on setting compliance. In lieu of that, CMS established requirements that states put plans out for public comment. The rule required states to post their draft transition plans, give appropriate notice for comment periods, and include a summary of comments received with explanations if recommendations were not adopted during the next iteration. CMS also required states to repost the plan whenever substantial changes were made at each stage, and then respond to the comments it received.²⁸

The effect of public comments on the statewide plans was, according to our interviewees and experience, uneven. The barriers to success hinged largely on two key components: building a transparent process and demonstrating an authentic commitment to meaningful engagement with the public. Many people with disabilities and members of the advocacy community struggled to track when new draft plans were released for comments. States like Missouri have multiple agencies responsible for different state HCBS-waiver programs, and the posted plans often were updated at different times across three separate websites. Whether an individual setting was posted for comment for its settings-rule compliance depended heavily on stakeholder input to identify problems with state assessments. However, the transparency of that comment process often fell short, both because potential commenters may not have known about the comment period and because many states redacted the names and addresses of some settings over privacy concerns that CMS expressed in its guidance. Early on, advocates conveyed to CMS the importance of making State Transition Plans (STPs) available to the public, and CMS's posting of plans and major communications with states was a major step forward in the transparency of the implementation process.

In required response to public comments, some states provided only perfunctory summaries of stakeholder comments and did little actually to adjust their plans in response to feedback. This generally discouraged ongoing feedback, as stakeholders questioned the value of their participation. State-level advocates we interviewed echoed some of these concerns, but also pointed to strategies that led to fruitful engagement with state officials. One noted that advocacy around the settings rule led to the creation of statewide networks of organizations that were able to coordinate their messaging to the state. These coalitions established relationships that helped shape better implementation of the rule and also created relationships that led to opportunities for coordinated action on disability-related issues not directly connected to the settings rule.

There have been a number of promising practices in the area of stakeholder engagement both at the federal and state levels.

Promising Practices

1. Federal Stakeholder Engagement

At the federal level, CMS and ACL made efforts to engage with stakeholders across various disability and health-policy groups. The HCBS Advocacy Coalition, a collection of national disability organizations, health advocates, providers, and aging-focused groups, came together to work with state and federal policymakers, agencies, and disability stakeholders nationwide to push for strong implementation of the rule that results “in opportunities for people with disabilities of all ages opportunities to live, work and fully participate in the broader community.”²⁹ The coalition provides collective feedback, supports state advocacy, and helps identify patterns in state-level implementation of the rule that require federal attention, guidance, and technical assistance, as well as serving as a conduit for sharing key information about the rule with the broader disability community. A key participant representing a provider association shared:

“We are where we are today because of that advocacy and that partnership and really we’re all coming from different perspectives. But the common ground we had was around how do we get the best services possible for beneficiaries.**”**

This participant pointed out that CMS regularly engaged in national calls with providers that helped address misinformation and educate people about the transition process. As the transition progressed, CMS relied increasingly on direct stakeholder engagement to supplement the formal public comment to identify common problems, acknowledging that CMS itself had limited capacity to conduct independent investigations of every state’s HCBS system.³⁰ Importantly, advocates shared that CMS and ACL formed working groups before heightened scrutiny visits to allow for advocates and consumers to identify on the ground issues and implementation goals.

ACL Supporting State Stakeholder Engagement

In 2022, the Administration for Community Living (ACL)—a federal agency dedicated to maximizing the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers—launched a series of initiatives to promote stakeholder engagement around the HCBS Settings Rule.³¹ The efforts focus through state-level representatives of various national networks that support people with disabilities, such as Protection and Advocacy agencies, Developmental Disability Councils, University Centers on Developmental Disabilities, Area Agencies on Aging, Centers for Independent Living, Programs for Rural Independent Living, and several self-advocacy networks.

The goal of these efforts is to strengthen relationships among disability and aging advocates at the state level and encourage them to engage with state government to strengthen HCBS implementation, especially on the settings rule. ACL webinars and federal technical assistance networks have promoted comment writing, coalition-building, and other advocacy strategies to help strengthen the participation of people with disabilities in state implementation of the HCBS Settings Rule.³²

And it is working. In one webinar, Vermont advocates noted that CMS invited state-level advocates to share stories and experiences with federal officials in preparation for a site visit to the state. Several individuals we interviewed also pointed to increased communication among state advocates to gather feedback and comments in preparation for CMS site visits in their states.

2. Advocate and Provide Collaborations at the State Level

In some states, new networks of relationships flourished due to the implementation of the rule. One state advocate shared that an unexpected benefit of the stakeholder engagement process was that it provided opportunities for advocate-provider collaboration, relationships that previously may not have had motivation to grow: “...it’s built bridges between our organization and some of the provider organizations, also some of the client groups. And those relationships have continued...that’s been sort of an unintended consequence.”

Interviewees also spoke about the benefits of collaboration amongst cross-disability organizations:

“ We also have good relationships with some of the aging organizations because our waiver happens to serve all three populations in it.... So, there was a broader pool. We often shared comments across each other or tried to prepare comments in advance and say, hey, use whatever you think is useful. And that did drive in more comments.

A stakeholder representing a national provider organization described similar successes from ongoing stakeholder engagement in the Northeast:

“ Maine also had a really incredible contingency of coalitions that would meet to share information, to share opportunities, to talk about ways we could approach different policies with unified recommendations.... [A]ll of those coalitions and stakeholder groups are still super active and are always looking for ways to engage both in how the state can be better, but also in ways we can learn from other states and ways to support national efforts.

Another key implementation tool often fueled by relationship-building and collaboration are state regulatory and legislative developments. Interviewees spoke with us about how cross-coalition advocacy can build support for laws that help support the disability population even if they are not specifically related to the rule. For example, one state advocate described an in-state coalition of 30 disability and aging organizations and noted that their advocacy on the rule had opened opportunities to push on other related issues: “So the rule, because there has been so much required process and because we participated in all of that process, has led to the department having more open processes on other issues [like managed-care contracting].”

Recommendations

1. Ongoing Comment Strategies

To fulfill the HCBS Settings Rule’s potential to improve HCBS, stakeholders must continue to provide feedback on their state’s compliance with the settings rule now that the transition period has ended. Advocates and stakeholders will continue to have additional opportunities for public input after the close of the settings transition, including if a state makes changes to its Medicaid HCBS program through state statutes or code, amendments to waiver programs submitted to CMS,

the addition of new heightened scrutiny settings, or other mechanisms that require public notice and comment.³³

Before public comment periods, advocates should gather information regarding examples of settings not in compliance, state policies that remain inconsistent with the federal rule, inadequate choice of non-disability specific settings—including employment opportunities—and ongoing monitoring and quality-assurance reports from the state on its HCBS programs.³⁴

2. Continued Education, Technical Assistance, and Guidance

The HCBS Settings Rule can be complicated, technical, and difficult to understand. More than ever, states will need an ongoing and accessible mechanism to provide cross-disability education and training opportunities for people receiving HCBS to help them know their basic rights under the rule.³⁵ This informing is the state's responsibility. However, advocacy groups are often effective messengers and have models for developing and facilitating accessible and meaningful rights information. This includes train-the-trainer models, where experienced self-advocates train new self-advocates and help spread the word in their communities.³⁶ Effective trainings should go beyond just stating rights under the HCBS Settings Rule and focus on how the requirements show up in an individual's daily life. At the federal level, ACL has engaged the state Councils on Developmental Disabilities to educate people with intellectual and developmental disabilities (I/DD) and their families about their rights under the rule, helping people with I/DD give input on HCBS Settings Rule implementation through public comment and working groups.³⁷ These efforts should continue, especially as states shift from transition planning to ongoing implementation of the rule.

Advocates we interviewed highlighted that although they strongly value the opportunities that have been available, both mandated and optional, to provide input on the settings rule and the various state plans, they would like to see more of their recommendations in action. CMS could use its administrative tools, such as continuing to provide technical assistance to clarify what is and is not allowed under the parameters of the HCBS Settings Rule to reflect stakeholder recommendations. One advocate emphasized that these clarifications from CMS help “light the fire under our state and others to comply with the spirit and the words of the Rule.... we might need more resources and maybe the state would benefit from more technical assistance.... we would certainly welcome that if we could use it as an advocacy tool.”

D. Site Visits and Ongoing Monitoring

In 2021, CMS began visiting states to evaluate settings proposed for heightened scrutiny under the 2014 HCBS Settings Rule. These site visits, conducted together with staff from the Administration for Community Living (ACL) and CMS's contractor, New Editions, have provided an important window into the faithful implementation of the settings rule. Findings have led CMS to revisit compliance with other requirements, such as person-centered planning, that were not formally part of the settings transition process.

CMS has usefully posted site-visit reports on its website to allow advocates to review their findings.³⁸ A webinar in fall 2022 reviewed recurrent themes identified across the state visits, suggesting some areas where compliance with the new rule was generally strong, such as access to food and visitors at any time, and others where compliance lagged.³⁹ In particular, CMS identified frequent shortcomings in the implementation of person-centered planning and independent case-management, which should have been in place since January 2014. They also found systemic problems with residential settings having written agreements in place that reflect local landlord-tenant protections.

A well-executed site visit may not provide a representative picture of setting compliance across a state, but it can provide valuable grounded data on the effectiveness of a state's ongoing monitoring processes and identify systemic problems. Experts we spoke with noted the importance of site visits to provide insights into the validity of state licensing practices and provider self-assessments. Self-assessment tools were common practice during the settings transition but may present an overly positive picture of provider compliance. Several interviewees noted that states accepted the self-assessment findings without adequate look-behinds to confirm their validity.

One interviewee pointed back to the late 1990s, when CMS regularly conducted site visits to gauge compliance with 1915(c) waivers and often included reviews of a sample of individual service plans and compared them to the individual's actual lived experience. A 2003 GAO report found inconsistent methodologies for these visits, which often relied on interviews with a small, non-representative sample of HCBS participants.⁴⁰ The report pushed CMS to strengthen quality oversight of HCBS waivers—including increased resources—and ensure that methods were

generalizable. Rather than correcting the identified methodological flaws, CMS gradually shifted away from site visits toward a data-oriented performance-measures approach, dropping the requirement for mid-cycle site visits in 2007.⁴¹

In 2009 and then again in 2014, CMS revamped its oversight of state quality assurances and sub-assurances to focus on achieving a sufficient standard on a range of state-reported administrative quality metrics that are representative of the whole waiver population but often lack the specificity necessary to identify actionable deficiencies in program performance. Quality metrics, as currently structured, also provide little useful information at the provider or even provider-type level.⁴²

Several of our interviewees saw value in ongoing strategic site visits alongside data-driven approaches to provide complementary perspectives. Specifically, the in-depth reviews of person-centered plans alongside site visits help CMS officials build relationships with people on the ground and provide “balance to give CMS that inside view or opportunity to engage with people, but to also have a more broad-based reason for the conclusion that they might draw.” If properly resourced and sampled, site visits provide important context and verification of the quantitative approaches.

While no single on-site visit can provide systemic level data, a well-structured visit can reveal how regulations translate into lived experience for people with disabilities who use HCBS. As noted above, CMS’s site visits related to heightened scrutiny of certain settings revealed widespread shortcomings with the implementation of effective person-centered planning across many states and settings and sparked renewed attention to these problems in subsequent technical assistance.

Recommendations

Tips for an Effective Site Visit

While the 2003 GAO report found widespread problems with site visit methodologies, it did not recommend that CMS abandon site visits altogether. Instead, it called for more intentional planning and sample selection to ensure that the data collected is most useful for oversight and performance improvement. Our own recommendations for effective site visits include:

- **Develop a transparent and consistent methodology.** To establish comparability across states and to clarify the scope of site visits, CMS should develop a general structure and methodology for its site visits. The structure should leave some flexibility to adapt elements for conditions in each state (based on stakeholder feedback and relevant data.) CMS should seek input from interested parties to refine the structure and scope of the site-visit template.
- **Shape each visit based on meaningful stakeholder feedback.** CMS's recent site visits have prioritized stakeholder engagement from state advocates familiar with the HCBS programs, like the long-term care ombudsperson, state Developmental Disabilities (DD) council representatives, and advocates from the state Protection and Advocacy agency. Given that resources for site visits will always be limited, effective stakeholder engagement has helped direct the reviews toward state-specific problems with HCBS programs—whether that is case management, a specific class of providers, or a specific type of disability.
- **Commit to transparent reporting.** Advocates who have participated in CMS site-visit preparation meetings stressed the importance of follow-up to demonstrate how CMS uses the stakeholders' investment of time and insight. CMS has now publicly posted recent site-visit reports, which enhances credibility (provided that sufficient protections are in place to protect HCBS participants' privacy). Follow-up reports documenting actions taken to fix identified problems help advertise best practices and show the value of the site-visit process.
- **Seek direct input from HCBS users.** Site visits should regularly incorporate interviews with participants, provided that individuals are chosen by CMS and that each interview uses informed consent, maintains privacy protections, and avoids or mitigates potential conflicts of interest to allow individuals to share freely. CMS could also use results from HCBS experience-of-care surveys, which will be required in every state, to target areas of concern for deeper review during site visits and service-plan evaluation.
- **Interview a representative sample of participants to evaluate the quality of their person-centered plan.** The U.S. Government Accountability Office (GAO) long ago critiqued CMS's methodology for auditing service plans, but

not the inherent value of the practice. Given that CMS site-visit reports have revealed systemic noncompliance with numerous person-centered planning requirements, CMS should consider revisiting this validation technique with more effective methodology. For example, a state could select a statistically valid, representative sample of participant service plans to see how well they address participants' individualized goals.

E. Individual Complaint/Grievance System

Grievance and complaint systems are a critical best practice to address specific problems and needs at the individual level. If well designed and implemented, they can complement CMS and state oversight of the broader HCBS program and thus inform compliance enforcement, continuous quality improvement, and responsiveness for settings that provide HCBS.

Until very recently, states using 1915(c) waivers and state-plan HCBS authorities were encouraged, but not required, to implement a formal grievance process.⁴³ CMS's May 2024 Medicaid Access Rule established a new requirement after considerable information gathering and deliberation.⁴⁴ In 2022, as the end of the HCBS settings transition approached, CMS required states to describe in writing how a beneficiary receiving Medicaid HCBS can notify the state of their settings-compliance problems, and how the state addresses that feedback.⁴⁵ Most states ultimately provided descriptions of piecemeal grievance processes, some of which linked to the same forms provided to nursing-facility residents, or described reliance on general managed-care grievance procedures not specific to HCBS, or to on-line portals that may not be accessible for some waiver participants.⁴⁶ The descriptions, now posted on CMS's website, often lack information on enrollee outreach and education specific to the HCBS setting requirements, protections from potential retribution, or timelines to resolve identified problems necessary for an effective grievance process.⁴⁷ Their inconsistency demonstrates the need to improve and simplify grievance processes as we move into the post-transition period.

Our interviews revealed ongoing frustrations with the pathways for individuals to address problems in HCBS settings where they receive services. Disability advocates noted that waiver participants often do not know where to turn if they have problems. One California advocate noted that different components of the state's HCBS system are regulated by different state agencies and regional centers.

Moreover, an individual may have a managed-care plan, or multiple providers, and it may not be clear where or to whom to direct their complaint. Other interviewees pointed out that some people with disabilities fear that lodging a complaint could have negative repercussions or even lead to an unwarranted discharge.

To be effective, any system for grievances must have several key components in place. At a minimum, an effective complaint/grievance system must adequately address the following elements:

- **People need to know their rights.** Information provided about participants' HCBS rights and protections must be presented in a meaningful way so that they understand what their day-to-day experience is supposed to be like in a setting and during the planning process. Posting a list of rights is important but not sufficient to ensure that the rights are understood. Reminders of these rights should be incorporated into regular meetings, such as case-management check-ins and periodic person-centered planning meetings.
- **People need to know the grievance system exists and how to use it.** Advocates in California pointed out that the existing grievance system was broken partly because no one knew to whom they were supposed to complain. Having a single point of contact for all participants, akin to 1-800-MEDICARE but at the state level, would be far simpler. The process of directing a grievance to the appropriate entity should be the state's responsibility, not the individual's.
- **The system needs to be accessible to all.** Educational materials and official communications must be available in multiple languages and accessible in alternative formats to accommodate the needs of people with various disabilities. Such materials should offer plain-language descriptions that are easy to read and understand for HCBS users. Individuals should be able to submit grievances through multiple modalities—written or oral.
- **People need protection from potential retribution.** Another potent deterrent to lodging a complaint or grievance arises from the risk of a provider finding ways to punish participants who lodge them. A number of disability advocates we spoke with raised concerns about fear of reprisals, like being discharged from a residential provider, chilling use of the process. CMS's recent proposed rule on individual grievances would explicitly prohibit

such retribution but provides little detail on how the provision would be monitored and enforced.

- **The adjudication of the grievance needs to be transparent and fair.** Individuals should have access to their files and to information that may be relevant to their situation. They should be able to present evidence and have their grievance adjudicated by a qualified individual who is free of conflicts of interest.
- **People need to see timely results.** If a person lodges a suggestion or complaint and nothing happens, they will eventually stop using the system. An effective grievance system will be nimble enough to achieve resolutions that prevent additional harm, including the option for expedited decisions.

CMS has addressed many of these key components in the recently finalized Medicaid Access Rule, which requires all states to implement an individual grievance process for all participants in fee-for-service § 1915(c), (i), (j), and (k) HCBS-waiver programs.⁴⁸ States that use managed LTSS programs rely on parallel regulations that require managed-care grievance systems, but do not have the same level of detail on outreach and enrollee protection.⁴⁹

This new rule requiring HCBS grievance systems can create important new channels for addressing problems in HCBS access and service delivery. However, some of the recently finalized protections do not appear in the managed-care grievance regulations, including protecting individuals from potential retribution or threats for filing a grievance.⁵⁰ Other authorities for delivering HCBS, such as regular state-plan services like optional personal-care services, are not subject to these new requirements.⁵¹ Still, the new Medicaid Access regulations take important steps toward strengthening and potentially streamlining the system for reporting complaints and grievances. If well implemented, they can create another mechanism to improve ongoing compliance with the HCBS Settings Rule.

CMS's HCBS Grievance System

The final rule would require states to develop a grievance process that any 1915(c), (i), (j) or (k) HCBS program participant could use. By May 2026, states will have to:

- provide assistance to beneficiaries to ensure the system is accessible;
- allow grievances to be submitted orally or in writing, including by the beneficiary's authorized representative;
- prevent punitive actions or threats against an individual filing the grievance;
- provide notice and information on beneficiary's rights and how to file a grievance;
- provide the beneficiary access to their case file and to records relevant to the grievance free of charge and the opportunity to present evidence face-to-face and in writing;
- provide qualified conflict-free adjudicators;
- apply 90-day timeline for standard grievance resolution, and 14 days for expedited resolution;
- provide timely notice of grievance resolution; and
- document the grievance and its outcome and make both available to CMS on request.⁵²

Recommendations

1. Identify Systemic Issues

The first goal of an individual grievance/complaint system should be to address individual problems and help improve service-delivery and access for the complainants. But if states can successfully implement more streamlined, responsive, and protective systems, they will also create a powerful data source to help identify systemic problems from the ground up, and in real time. Building a systemic approach into the HCBS grievance process could reinforce other components of an effective oversight system. Periodically identifying and publicly reporting systemic issues encountered in the course of processing grievances could

provide valuable insights into how well other oversight mechanisms are working. Several states already have similar mechanisms through their ombuds office or managed-care beneficiary-support system.⁵³

Reporting requirements for grievances, complaints, and appeals in the Access Rule regulations focus mostly on quantitative metrics—how many are received, how quickly are they resolved, and so forth. As states implement these systems in fee-for-service (FFS) Medicaid, reporting on grievances would benefit from a qualitative, and not just quantitative, approach. For example, it would be valuable to have an independent evaluator periodically review the grievance process to identify common barriers, trends, participation rates, and the effectiveness of resolutions.

F. CMS Role and Authority

One of the most consistent themes in our conversations with state and federal stakeholders centered on the role CMS plays to ensure that state HCBS programs faithfully implement the HCBS Settings Rule.

The regulations give CMS the ultimate responsibility for approving certain settings deemed “presumptively institutional” and evaluated through heightened scrutiny. This includes settings co-located with institutions and settings that exhibit characteristics that have the effect of isolating individuals receiving Medicaid HCBS from the broader community.⁵⁴ This regulatory structure is relatively unusual for Medicaid, where CMS typically conducts oversight of state processes rather than involve itself with specific providers. It created a challenging dynamic where at times states look to CMS to make the hard political decisions, such as shifting away from sheltered workshops or refusing funding for disability-specific gated communities. One interviewee described this expectation as “waiting for the CMS hammer.”

CMS officials, however, may feel reluctant to deny approval for specific settings, particularly if the state represents to federal officials that it believes evidence shows that the setting has overcome the institutional presumption. Knowing how individual HCBS users experience a particular HCBS setting across the range of settings types creates a daunting task from a federal perspective. The agency may not have the resources for material scrutiny of evidence put forward by the state, even though limited evidence from CMS’s heightened scrutiny site visits suggests that many of these settings fell far short of compliance at the time of the visit.

Consequently, CMS put significant emphasis on public comment to identify potential problems with HCBS settings. One state advocate noted: “CMS also told us early on that they were going to consider the state’s assessment as accurate unless they heard from stakeholders.” Every setting submitted for heightened scrutiny must undergo notice and comment, but that process has not always been transparent. Advocates experienced repeated problems in some states with late notice and poor publicity around comment opportunities that compressed the already short comment window to gathering evidence on posted settings. States often redacted setting addresses to comply with federal privacy protections, which further complicated information gathering. Particularly during the COVID-19 public health emergency, settings may have slipped through without much public scrutiny.

This dynamic has created scenarios where CMS continues to ask for additional information from the state in lieu of making formal decisions about a setting. Advocates and other stakeholders are not often privy to these interchanges and may not even know when CMS is reviewing a setting so they can provide relevant information. If CMS does not get clear responses to its questions, it may not be able to justify a firm decision. Such dynamics can lead to decisions getting pushed down the road or watered down.

Heightened scrutiny approval is just one example that shows the difficulties enforcing the HCBS Settings Rule, and the need for clear delineation of responsibilities for enforcement. Many requirements of the HCBS Settings Rule require grounded evidence about community engagement, choice of daily activities, and relationships with support staff. As one state advocate noted, even state licensing agencies may struggle to collect and evaluate this kind of information, let alone CMS officials who are another step removed:

“ I think it’s reasonable to think they’re going to look at whether there’s a lock on a door because they can just easily see that. They can be like, where’s the lock? Let me watch you turn it. Good, you check that off. But do you have a person-centered plan? Is someone actually listening to you talk about what you want your day to be like? That’s not something licensing is going to do.

Other requirements, like the right to choose to receive services in a non-disability-specific setting, can also be difficult to verify. A person-centered plan may list alternative settings that are not chosen, but determining if the listed alternatives

were actually available to the individual may require contextual information not easily available to federal officials.

Further complicating the ongoing enforcement of the settings regulation, many of the responsibilities for ensuring adequate oversight have recently shifted from CMS's Medicaid Benefits and Health Policy Group (MBHPG) to the Medicaid and CHIP Operations Group (MCOG), which is charged with enforcing the ongoing oversight of 1915(c) waivers. MCOG collects and reviews quality-measure reports from state 1915(c) waivers and conducts several state site visits annually, primarily focused on evaluating the state's systems for assuring health and welfare of HCBS recipients. MBHPG continues to manage HCBS policy, including the contents of the 1915(c)-waiver application and approvals for HCBS waivers and state-plan amendments. Because renewals and applications are an important leverage point for enforcing compliance, MBHPG and MCOG must closely coordinate and share information to make sure needed changes are promptly implemented.

The 1915(c)-waiver technical guide, application, and reporting requirements are due for a major update to incorporate changes from the recently finalized HCBS Access Rule. The last major update was finished by 2014 and did not incorporate the HCBS Settings Rule requirements at the time. The currently reported quality measures differ from waiver to waiver and are not reported publicly, so it can be hard to track how well state HCBS programs have done implementing the settings rule across their systems. But this will soon change.

The recently finalized HCBS Access Rule changes how states track and report performance metrics, individual complaints, grievances and appeals, and critical incidents in 1915(c) and other HCBS authorities.⁵⁵ Federal officials at MBHPG will have to decide how to link new reporting requirements for 1915(c) waivers to ongoing monitoring and enforcement of the HCBS settings requirements. As part of requiring states to report publicly on a new core set of HCBS measures for all their 1915(c), (i), (j) and (k) HCBS waiver programs, the HCBS Access Rule also requires statewide use of HCBS experience-of-care surveys across the state's HCBS programs. These surveys ask questions related to community integration, control over daily schedule, unmet need, and other questions that shed light on compliance with important components of the settings rule. While the statewide sample will likely be too small to identify problems at the provider level, the results can point to specific areas for improvement and serve as a guide for closer follow-up evaluation

in those areas. Other required measures track the timeliness and completeness of HCBS needs assessments and person-centered service-plan reviews.

Recommendations

Going forward, CMS officials should:

- **Establish clear lines of responsibility for enforcing setting requirements federally and at the state level.** CMS should reinforce its position to ensure that state-level processes are in place to assess ongoing compliance with the settings rule and person-centered planning regulations. That includes active oversight of how well those systems function, including direct testing and periodic audits, particularly when ongoing monitoring metrics or stakeholder feedback identifies credible problems with one or more state-developed processes.
- **Create channels for HCBS users and advocates to seek recourse when state officials are not responsive to problems.** The rule required states to respond to public comment, but those summaries of state responses were often perfunctory. Stakeholders' willingness to provide input waned when people felt their input was ignored. State-level officials we interviewed pointed to situations where they saw little recourse from the federal level. One even suggested that mixed messages from CMS impeded efforts to push for needed changes. States bear the responsibility to create Medicaid programs that comply with federal regulations, but when states neglect or refuse to acknowledge stakeholder feedback, CMS has an obligation to use its authority to push states to respond meaningfully and ensure they comply with HCBS requirements.
- **CMS should use its regulatory authority to establish clear boundaries and expectations for state Medicaid programs.** Work on HCBS settings implementation is multi-faceted. Settings include day programs and residential providers, workplaces and private homes in rural and urban areas. This diversity lends itself to a case-by-case approach on compliance. But CMS does not have the capacity to review every case, or even to review every state system used to monitor compliance with the rule. Providing clear boundaries and expectations through subregulatory guidance makes it easier for state officials and advocates to direct their efforts. Absent guidance, public

transparency in specific enforcement actions, such as mitigation plans, letters to state agencies, and corrective action plans, can provide reference points to advocates and other state officials on CMS's expectations. As one state advocate noted:

“ I think that is important and you want to give states some flexibility, but our work would be easier if CMS could be more specific and be like: ‘You can have a lot of ways you figure out how you accomplish this, but we’re telling you these things are unacceptable.’ Like you did at the beginning. Not having locks on your doors is unacceptable. You figure out what that means. But not having access to food is unacceptable. We need the same kinds of things, but now in these different situations.

- **Identify levers for ongoing compliance actions.** As we move beyond the transition period, CMS should seek ways to continue to require states to meaningfully consider and respond to stakeholder feedback, especially on HCBS Settings Rule compliance, through other regular feedback channels, such as waiver amendments and renewals or other important policy changes. The recently finalized Access Rule will require CMS to substantially revise its 1915(c)-waiver ongoing monitoring process to incorporate new quality-reporting requirements. These updates to the application and technical guide provide opportunities for CMS to ask states to describe more explicitly how they will monitor HCBS settings for compliance with the rule, and to establish criteria against which state quality-assurance and auditing systems will be evaluated when they apply to implement or renew a 1915(c) waiver.

G. Conclusion

The end of the HCBS settings implementation window marks both an end and a beginning. For the first time, federal regulations define what it means to provide services in an integrated, community-based setting. In the coming months, CMS will finish adjudicating remaining heightened scrutiny settings and states will remediate their outstanding corrective action plans. The rule will be, technically, fully implemented.

However, the rule was originally intended to advance access to integrated HCBS options. Has it achieved that goal? Several states began the transition period with ambitious plans to phase out sheltered workshops and transform adult day

programs into a more individualized model. Some of those plans have been waylaid by politics and process.

One key provision in the rule requires every individual receiving Medicaid HCBS to have a meaningful option to live, work, and interact in a non-disability-specific setting that supports robust interaction with the broader community. Almost everyone we spoke with agreed that many regions fall far short of compliance even after implementation.

Generally, when people have access to safe, reliable HCBS they choose more integrated options that optimize their opportunities to interact in the community as they would like. But the ongoing HCBS direct-care workforce shortage, exacerbated by the COVID-19 pandemic, makes it even harder to find providers to provide that consistent, baseline service supply.

Addressing shortages and other common barriers like access to affordable housing in the community will require political will and substantial resources. The close of the settings transition window comes also with the phasing out of extra federal funding for state Medicaid programs—including specifically for HCBS programs—to help states cope with COVID-19. As that funding scales back, the prospects for expanding HCBS capacity look cloudy. Many states have long underfunded their HCBS systems, including by establishing individual budget restrictions that force people to make decisions between getting enough hours to fill the day with services they need against choosing options for more integrated settings and services. In many ways, the successful implementation of some HCBS settings requirements, such as offering every person using HCBS an option to receive services in non-disability-specific settings, will require a substantial increase in state and federal resources.

The driving force for creating a society more inclusive of people with disabilities comes from the principles established in law by the Americans with Disabilities Act of 1990 and the anti-discrimination protections in Section 504 of the Rehabilitation Act of 1973. Those requirements, which demand that people with disabilities have opportunities to live integrated into the fabric of our communities free from discrimination, also undergird the requirements and principles of the HCBS Settings Rule.

The settings rule represents one tool to meet that challenge, provided it is faithfully implemented. As noted above, successful strategies to push states toward that goal

include many shared components: inclusive care-planning teams that center the person receiving services as the key decision-maker, strongly coordinated stakeholder coalitions, transparent public comment, effective and responsive grievance and complaint processes, and attention to the letter and the spirit of person-centered planning standards.

When we think about the expectations for person-centered planning laid out in federal regulation, we need to keep in mind not only the community integration mandate that drives it forward but also the benefits of thoughtful implementation to the spectrum of service providers involved in HCBS care. In the same way that there has been a push by the medical community to incorporate social determinants of health into the provision of care for the cost-reduction benefits, HCBS providers must take a broad view of well-being as they implement person-centered planning. This process is and has always been fundamentally about furthering the lives of disabled people in our communities in truly meaningful ways and not allowing people to be systematically isolated from their non-disabled peers.

Federal regulators, for their part, have the responsibility to conduct active oversight of state processes, including both quantitative metrics and qualitative approaches like site visits and service-plan audits to ensure that state processes are functioning as claimed. In cases where states are consistently unresponsive to individuals who use HCBS and state advocates, CMS must also intervene on behalf of Medicaid beneficiaries to ensure compliance with the letter and the spirit of the rule. Finally, CMS should more transparently communicate the boundaries of unacceptable or insufficient compliance, especially in cases where states have numerous settings that indicate systematic noncompliance. Rejecting certain practices in specific settings or circumstances can set examples for others, ultimately making implementation simpler and more consistent.

The settings rule was a watershed moment in the history of Medicaid HCBS. Now, ten years on, we stand at another crossroads. Taking some of the lessons learned from successful efforts to transform HCBS settings during the transition will help push us to a more inclusive future for all people with disabilities.

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Notes

¹ Centers for Medicare and Medicaid Services (CMS). (January 16, 2014). State plan home and community-based services, five-year period for waivers, provider payment reassignment, and home and community-based setting requirements for Community First Choice and home and community-based services (HCBS) waivers.

<https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

² See 42 C.F.R. §§ 441.301(c)(4).

³ Centers for Medicare and Medicaid Services (CMS). (November 16, 2022). Themes identified during CMS' heightened scrutiny site visits.

<https://www.medicaid.gov/sites/default/files/2022-12/themes-identified-during-cms.pdf>

⁴ 42 C.F.R. § 441.301(c)(1)-(3); "Person-centered service planning is a complex concept and requires both commitment and skill to implement." (January 16, 2014). 79 Fed. Reg. 2948, p. 3006.

⁵ National Quality Forum. (July 31, 2020). Person-centered planning and practice, final report, p. 6.

https://www.qualityforum.org/Publications/2020/07/Person_Centered_Planning_and_Practice_Final_Report.aspx

⁶ The Arc, King County. Person centered planning. <https://arcofkingcounty.org/resource-guide/personcentered-planning/person-centered-planning.html>

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⁸ O'Brien, C. L, & O'Brien, J. (2000). The origins of person-centered planning, pp. 9, 7.

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¹⁰ O'Brien, C. L, & O'Brien, J. (2000). The origins of person-centered planning, p. 10.

¹¹ O'Brien, C. L, & O'Brien, J. (2000). The origins of person-centered planning, p. 10.

¹² 42 C.F.R. § 441.301(c)(1)(vi).

¹³ See 42 C.F.R. § 441.301(c).

¹⁴ 42 C.F.R. § 441.301(c).

¹⁵ Center for Medicaid & CHIP Services (CMCS). (January 2024). Person-centered service planning in HCBS: Requirements and best practices. Themes identified during CMS' heightened scrutiny site visits. Themes identified: Person-centered service plans (3 of 3), p. 23. <https://www.medicaid.gov/sites/default/files/2024-01/person-centrd-servc-plan-hcbs-req-best-pract.pdf>

¹⁶ Lagu, T. Haywood, C., Reimold, K., DeJong, C., Walker Sterling, R., & Iezzoni, L. I. (2022). "I am not the doctor for you": Physicians' attitudes about caring for people with disabilities. *Health Affairs*, 41(10), pp. 1387-1395; Ames, S. G., Delaney, R. K., Houtrow, A. J., Delgado-Corcoran, C., Alvey, J., Watt, M. H., & Murphy, N. (2023). Perceived disability-based discrimination in health care for children with medical complexity. *Pediatrics*, 152(1), e2022060975.

¹⁷ Center for Medicaid & CHIP Services (CMCS). (January 2024). Person-centered service planning in HCBS: Requirements and best practices. Themes identified during CMS'

heightened scrutiny site visits. Themes identified: Modifications of additional conditions/rights restrictions (4 of 4), p. 28.

<https://www.medicaid.gov/sites/default/files/2024-01/person-centrd-servc-plan-hcbs-req-best-pract.pdf>

¹⁷ Priaulx, E. (December 10, 2020). Collaborating with protection and advocacy agencies (P&As) on HCBS Settings Rule. Settings Rule: Getting disability and aging input off life-support. HCBS Conference, p. 39.

<https://www.advancingstates.org/sites/nasuad/files/u24453/HCBS%20Settings%20Rule%20Getting%20Consumer%20Engagement%20Off%20Life%20Support%20.pdf>

¹⁸ 79 Fed. Reg. 2948, 2993 (January 16, 2014); 42 C.F.R. § 441.730(c).

¹⁹ Center for Medicaid & CHIP Services (CMCS). (January 2024). Person-centered service planning in HCBS: Requirements and best practices. Themes identified during CMS' heightened scrutiny site visits. Themes identified: Person-centered service plans (1 of 3), p. 21. <https://www.medicaid.gov/sites/default/files/2024-01/person-centrd-servc-plan-hcbs-req-best-pract.pdf>; 79 Fed. Reg. 2948, 2990 (January 16, 2014). (It is expected that the providers would have adequate training to perform the function consistent with the requirements set forth in the regulation.)

²⁰ Center for Medicaid & CHIP Services (CMCS). (January 2024). Person-centered service planning in HCBS: Requirements and best practices. Themes identified during CMS' heightened scrutiny site visits. Themes identified: Person-centered service plans (1 of 3), p. 21. <https://www.medicaid.gov/sites/default/files/2024-01/person-centrd-servc-plan-hcbs-req-best-pract.pdf> (Whether an electronic portal is used or not, it is the state's responsibility to ensure that the case managers work with each individual served and their families to have access to their person-centered service plan to view and request updates/changes at any time and make certain that the person-centered service process is upheld and that requirements are always met.)

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²² 79 Fed. Reg. 2948 (January 16, 2014), p. 2988.

²³ Centers for Medicare and Medicaid Services (CMS). (January 2019). Application for a §1915(c) home and community-based waiver [Version 3.6]. Instructions, Technical Guide and Review Criteria, pp. 196, 197.

https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

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<https://www.advancingstates.org/sites/nasuad/files/u24453/HCBS%20Settings%20Rule%20Getting%20Consumer%20Engagement%20Off%20Life%20Support%20.pdf>

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- ²⁷ Barkoff, A., Administration for Community Living. (March 31, 2023). Beyond the conversation: Putting “Nothing About Us Without Us” into action. <https://acl.gov/news-and-events/acl-blog/beyond-conversation-putting-nothing-about-us-without-us-action>
- ²⁸ 79 Fed. Reg. 2948, (January 16, 2014), p. 3,031; Edwards, E. (2014). Home and community based settings: A primer. *Health advocate: E-newsletter of the National Health Law Program*, 22., p. 2. (The heightened scrutiny process will also require the state to solicit public input and CMS will also consider input from stakeholders and its own reviews.)
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- ³⁴ HCBS Advocacy Coalition. (May 2019, updated). The Medicaid HCBS settings rule, p. 13, n. 5.
- ³⁵ Friedman, C. (2018). Stakeholders’ Home and Community Based Services Settings Rule Knowledge. Research and Practice for Persons with Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, 43, pp. 54, 56. <https://doi.org/10.1177/1540796917743210>
- ³⁶ Friedman, C. (2018). Stakeholders’ Home and Community Based Services Settings Rule Knowledge; Ray-Leonetti, J., Temple University’s Institute on Disabilities College of Education and Human Development for the Administration for Community Living. (September 3, 2020). Strategies to meaningfully engage Medicaid HCBS beneficiaries. 2020 HCBS Technical Assistance Series, HCBS Stakeholder Education and Advocacy in Action, PA Project Methods: Advocacy and Education. https://www.aahd.us/wp-content/uploads/2020/09/StrategiestoMeaningfullyEngageHCBSBeneficiaries_Sep-3-ACL-CMS.pdf
- ³⁷ Barkoff, A., Administration for Community Living. (March 31, 2023). Beyond the conversation.

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⁴⁰ The name was changed in 2004 to the Government Accountability Office by the [GAO Human Capital Reform Act](#) to better reflect the mission of the office. The GAO's auditors conduct not only financial audits, but also engage in a wide assortment of performance audits.

⁴¹ Center for Medicaid & CHIP Services (CMCS). (August 2017). HCBS quality 101: Quality in the 1915(c) home and community-based services (HCBS) waiver, p. 7. <http://www.advancingstates.org/sites/nasquad/files/HCBS%20Quality%20101.pdf>

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⁴³ Centers for Medicare and Medicaid Services (CMS). (January 2019). Application for a §1915(c) home and community-based waiver instructions. Technical Guide and Review Criteria, V.3.6, p. 235. https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

⁴⁴ Centers for Medicare and Medicaid Services (CMS). (May 10, 2024). Ensuring access to Medicaid services, final rule, 89 Fed. Reg. 40542. <https://federalregister.gov/d/2024-08363>

⁴⁵ Centers for Medicare and Medicaid Services (CMS). (November 16, 2022). Themes identified during CMS' heightened scrutiny site visits, p. 29. <https://www.medicare.gov/sites/default/files/2022-12/themes-identified-during-cms.pdf>

⁴⁶ New York State. (January 1, 2023). January 1 Submission Report, p. 10. <https://www.medicare.gov/media/166241> (sending recipients of adult day services to an on-line nursing facility complaint form).

⁴⁷ Centers for Medicare and Medicaid Services (CMS). Statewide transition plans. (Site including links to state January 1 submissions describing beneficiary grievance processes.) <https://www.medicare.gov/medicaid/home-community-based-services/statewide-transition-plans/index.html>

⁴⁸ Centers for Medicare and Medicaid Services (CMS). (May 10, 2024). Ensuring access to Medicaid services, final rule, 89 Fed. Reg. 40542, <https://federalregister.gov/d/2024-08363>; 89 Fed. Reg. 40573 (codifying 42 C.F.R. § 441.301(c)(7)).

⁴⁹ 42 C.F.R. §§ 438, subpart F. For example, the managed-care grievance process does not require plans to have mechanisms in place that protect enrollees from retribution.

⁵⁰ For example, the managed-care regulations protect providers from punitive actions by a plan if they file a grievance or support a beneficiary's appeal, but they do not explicitly protect the individual from potential retribution or threats from their provider. See 42 C.F.R. § 438.416(b).

⁵¹ 89 Fed. Reg. 40573 (codified at §§ 441.307(c)(7), 441.464(d)(2)(v), 441.555(b)(2)(iv), and 441.745(a)(1)(iii)).

⁵² 42 C.F.R. § 441.301(c)(7). Implementation is required by two years after the effective date of the Medicaid Access Rule. 89 Fed. Reg. 40550.

⁵³ See, e.g., North Carolina Medicaid, Your advocate for quality care.

<https://ncmedicaidombudsman.org/>

⁵⁴ See, e.g., 45 C.F.R. § 441.301(c)(5)(v).

⁵⁵ Centers for Medicare and Medicaid Services (CMS). (May 10, 2024). Ensuring access to Medicaid services, final rule, 89 Fed. Reg. 40542. <https://federalregister.gov/d/2024-08363>