

Frequently Asked Questions (FAQs) on HCBS Settings Requirements, Part V **MythBusters**

In 2014, the federal Centers for Medicare & Medicaid Services (CMS) published a <u>rule</u> requiring home- and community-based services (HCBS) to be provided in settings that meet certain criteria. The criteria ensure that HCBS participants have access to the benefits of community living and live and receive services in integrated, non-institutional settings. After extensive stakeholder engagement, the Department finalized a rule codifying the federal criteria, new <u>10 CCR 2505-10 section 8.484</u>, which went into effect on January 10, 2022.

The Department's <u>website</u> contains information about implementation of the federal settings criteria, including the <u>Statewide Transition Plan (STP</u>); the <u>Systemic</u> <u>Assessment Crosswalk</u> setting out planned changes to Colorado's statutes, regulations, and waivers; training materials; and additional guidance. The additional guidance section contains the Department's responses to frequently asked questions (FAQs) regarding general requirements of the rule and various aspects of its implementation (<u>FAQ Part I</u>; <u>FAQ Part II</u>) as well as the requirement of a lease or other written agreement protecting individuals from eviction (<u>FAQ Part III</u>) and expectations for settings where employment-related supports are provided (<u>FAQ Part IV</u>).

This document addresses continued misunderstandings of or myths about the federal rule or the state codification of the rule. Each myth is set out and then "busted." (In other words, none of the numbered statements that precede each discussion is "confirmed" or true.) The numbering of the items follows consecutively from FAQ Part IV.

Table of Contents

HCBS Settings Final Rule in General4		
95.	Myth: The rule imposes a "one size fits all" model on waiver participants4	
96.	Myth: Implementing this rule takes too much effort. It's not worth providers' time	
97.	Myth: The Department had no authority to require providers to transition toward compliance before its codification of the federal rule went into effect	
98.	Myth: Nothing will happen to providers that do not submit their final PTP updates7	
Rights Protected by the Rule7		
	Community Integration7	
99.	Myth: It's someone else's responsibility to support community integration7	
100.	Myth: Taking someone to a medical appointment or through a drive-through is plenty of community integration, or, "Leaving the house is enough."	
101.	Myth: Location determines whether a setting is integrated in the community8	
102.	Myth: The provider does not have to offer support for full community inclusion if doing so would be challenging	
103.	Myth: Individuals must have permission from staff to leave the setting9	
104.	Myth: Providers can get people to waive their right to a house key9	
	Privacy 10	
105.	Myth: Providers can get people to waive their right to a bedroom door lock and key	
106.	Myth: We can't put a lock on the bedroom door, because the person could accidentally lock themselves in	
107.	Myth: We can't put a lock on the bedroom door, because there is no door11	
108.	Myth: Staff may/must notify family of any incidents or concerns, without checking whether the relative has a signed release/other legal authority	
	Person-Centered Practices11	
109.	Myth: Separate person-centered training for staff is not needed, since we already provide person-centered care11	
110.	Myth: Training on how to safely restrain people, as covered by the Mandt System®, is person-centeredness training	

	Autonomy/Other
111.	Myth: A doctor's order is required (or the provider can choose to require a doctor's order) to allow an adult to drink alcohol in their home
112.	Myth: Honoring rights creates a free-for-all and requires providers to allow people to partake in illegal activities
113.	Myth: Everyone in the home must mark all their clothing with their name (or the provider can choose to require this)
114.	Myth: Providers can say that nobody is allowed out of their rooms at night
Righ	ts Modifications
115.	Myth: Rights modifications are only an issue for people with IDD
116.	Myth: It's not a rights modification if it's a house rule, a condition of receiving services at a particular setting, or part of a lease/residential agreement
117.	Myth: It's not a rights modification if a majority of participants agree to it
118.	Myth: Providers cannot help people stay upright in their wheelchairs with belts, straps, or buckles
119.	Myth: Providers cannot help people put on their seatbelt in the car
120.	Myth: The doctor ordered this measure, so it is not a rights modification
121.	Myth: This is a home modification, so it's not a rights modification
122.	Myth: Helping someone with medication administration is always, or never, a rights modification17
123.	Myth: The individualized assessment for rights modifications ignores risk to others
124.	Myth: The Department does not care that people are going to make bad choices and hurt themselves or others
125.	Myth: The guardian approves of (or demands) the measure, so it's not a rights modification, or, "We have to implement whatever the guardian wants."
126.	Myth: People can waive their right to accessibility in their home when they or their family/guardian state that they are okay with the home being inaccessible

HCBS Settings Final Rule in General

95. <u>Myth: The rule imposes a "one size fits all" model on waiver participants.</u>

Some stakeholders have said that by establishing criteria for all HCBS settings, the rule imposes a "one size fits all" model. On the contrary, the rule eliminates "one size fits all" approaches. In the past, some practices were based on presumptions that everyone with a given trait needed the same rights modifications—for example, that everyone with intellectual or developmental disabilities (IDD) needed interior cameras to keep them safe in group homes, or that everyone with a history of sexual misconduct had to follow a standardized program with fixed rights modifications. Now, rather than assuming that an entire group can never exercise their rights safely, providers must treat each person as an individual.

The rule does establish the same overall rights for all waiver participants: every participant has the right to access the community, be treated with dignity and respect, be free of restraint, and so on. This is because these are the same rights that everyone else in the community has. However, there is room for individualization: if for a specific person, fully exercising a right would not be safe, the right can be modified via the rights modification process. Additionally, in recognition of the differences between adults and children, the Department's codification of the rule provides that "[f]or children under age 18, a limitation or restriction to any of the rights in [the rule] that is typical for children of that age, including children not receiving HCBS, is not a Rights Modification." New 10 CCR 2505-10 section 8.484.2.N.3.

96. Myth: Implementing this rule takes too much effort. It's not worth providers' time.

Some providers have reported that they will not be completing their Provider Transition Plan (PTP) updates because they do not have the bandwidth, often because of the pandemic and/or the direct care workforce shortage.

The Department is acutely aware of the pressures facing providers and has been working to ease them through various means, such as long-term rate increases to support higher wages for staff, as well as through projects funded by the American Rescue Plan Act (ARPA), such as researching non-wage methods of compensating workers, establishing workforce surveys, and developing new rate methodologies. The Department also understands that completing and updating PTPs can seem like a lot of paperwork. At the same time, we would point out:

 Compliance with the HCBS Settings Final Rule is a federal requirement and is subject to federal deadlines, which have already been adjusted because of the pandemic. These deadlines include identifying which settings cannot or will not comply **soon**—specifically, with enough time to support those receiving services there to transition to other settings or funding sources by March 2023. The more time it takes to identify such settings, the less time affected individuals will have for an orderly transition.

The Department has not yet determined how to proceed under <u>CMS's May 24</u> <u>announcement</u> that because of the "direct-service workforce crisis exacerbated by the COVID-19 PHE," states can request a corrective action plan (CAP) allowing for extra time to implement the rule. Providers should note that even if the Department elects to pursue a CAP, many settings will **not** qualify for additional time under CMS's guidance. These settings will receive provisional notices of noncompliance starting in **September 2022**. If these findings are not changed during informal reconsideration, they will lead to final notices and the beginning of the individual transition process in **November-December 2022**.

- Honoring the rights outlined in the HCBS Settings Final Rule is important, and disregarding them comes at a real human cost. Respecting people's rights enhances their quality of life and makes things easier for providers: as some have noted, using rights modifications only where truly needed and agreed-to can significantly reduce the "daily battle of wills" sometimes seen in the past.
- If a provider is already honoring all the rights, it can demonstrate that fact by uploading the required materials into the PTP platform. Provider-level documents such as policies and procedures need to be uploaded only once (not separately for each PTP). As evidence that the work is manageable, we note that over 65% of settings have been verified as compliant, and that this number grows every day—even during the pandemic and the workforce crisis. Providers are well on their way for the remaining settings.
- Some providers have updated their PTPs without having made all of the required changes, prompting back-and-forths with the Colorado Department of Public Health & Environment (CDPHE) and the need for more updates. In some cases, providers are still following older policies that do not fully support individuals to exercise all of their rights.
- CDPHE has been working one-on-one with providers to find a timeline that works both for the providers and CDPHE's workload. Providers are strongly encouraged to reach out to their CDPHE staff lead as needed to discuss timing.

97. <u>Myth: The Department had no authority to require providers to transition toward</u> <u>compliance before its codification of the federal rule went into effect.</u>

The Department properly required providers to start taking steps toward compliance once the federal rule went into effect three months following its enactment in 2014. The rule provides for a transition period, but this is available only pursuant to the process set forth in the rule, as implemented by each state's Statewide Transition Plan (STP). In turn, as instructed by CMS, <u>Colorado's STP</u> provides for simultaneous, rather than sequential, progress on two fronts: site-specific (ensuring that all settings comply) and systemic (ensuring that state legal authorities comply). In other words, the STP requires providers to take steps toward compliance regardless of when rule updates go into effect. The STP embodying this approach has gone through several rounds of public comment and received CMS's final approval. In addition, Colorado's waiver-specific regulations incorporate their respective waivers, which take precedence, and the waivers, in turn, incorporate the STP. Stated differently, the STP and its sequencing were incorporated by reference into Colorado's rules well before Colorado's codification of the federal rule was adopted. Thus, the STP and its sequencing were and are legally binding on providers.¹ This conclusion is reinforced by the supremacy of federal law over state law, although as explained, the two sets of laws are consistent here.

Colorado's <u>CMS-approved milestone schedule</u> implements the overall sequencing of the <u>CMS-approved initial STP</u>, generally with extensions to that STP's target dates, allowing providers and case management agencies (CMAs) additional time to comply. Under this schedule, providers were required to submit PTP updates demonstrating the completion of their remedial actions by summer 2021, unless CDPHE gave them an extension. The reason for this deadline was that if providers wait too long to submit their evidence, there will not be enough time to review it; complete any further changes still needed; make provisional compliance determinations; allow for informal reconsideration; and finally arrange for individual transitions (which may entail finding new homes), if needed, all before the federal deadline of March 2023. Each of these stages will take time, given how many settings are covered by the PTP process in Colorado.

Although the Department expected providers to complete and update their PTPs, it has not been "enforcing" its codification of the federal rule or the PTP process within the typical meaning of that term. Specifically, for settings covered by the transition period, CDPHE surveyors have not been citing deficiencies or recommending immediate adverse actions such as suspension of payments, revocation of program approval/certification, or termination of provider agreements. Rather, the Department and CDPHE have worked with providers via an iterative, extended transition process with ample reminders and technical assistance. The Department's rule will be enforced as stated in new Section 8.484.1.B.

¹ Although some states adopted their versions of the federal rule years ago, doing so was not required (in fact, CMS instructed states to proceed with site-specific work regardless of where they were with systemic remediation), and a number of states waited. By waiting to develop and enforce its codification, the Department was able to extensively engage with stakeholders, hear real-world questions/concerns, understand which common questions could be resolved by adding details to the rule, obtain clarity from CMS about the meaning of certain provisions, and learn about potential cost impacts (or lack thereof, as it turns out). This process has yielded a rule that is clearer, fairer, and more concrete than other states'.

98. <u>Myth: Nothing will happen to providers that do not submit their final PTP updates.</u>

Providers that do not promptly submit their final PTP updates are at risk of losing their Medicaid funding. PTPs in the following Compliance Statuses still need updates demonstrating that all required changes have been made:

(2) Setting is NOT subject to heightened scrutiny and NOT YET compliant with rule;

(3) Setting is NOT subject to heightened scrutiny and NOT timely able to comply with rule;

(5) Setting IS subject to heightened scrutiny and NOT YET able to overcome institutional presumption;

(6) Setting IS subject to heightened scrutiny and NOT timely able to overcome institutional presumption; and

(7) Not yet known (default) or blank.

As noted in Item #96, provisional notices of noncompliance will soon be going out for some, if not all, settings in these statuses. After such notices go out, the informal reconsideration process will be available in case the Department overlooked or misunderstood evidence contained in PTPs; the time available for the process will **not** accommodate providers that still have major work to do to come into compliance. If the noncompliance determination stands after reconsideration, it will be noted in a final determination, under which providers will be precluded from accepting new enrollees at the noncompliant site(s), be required to inform affected members of the need to transition, and see their Medicaid reimbursement end no later than March 2023.

Rights Protected by the Rule

Community Integration

99. Myth: It's someone else's responsibility to support community integration.

A number of providers assume that they need not support community integration because some other provider will do so. For example, some day programs assume that because people are not there 24 hours a day, they will have as much community engagement as they want during the hours they are away. Similarly, some residential providers assume that because their residents attend day programs, they will have as much community engagement as they want there. Some providers assume that because a person has friends and family that visit and take them out, they are not responsible for supporting further community integration. If everyone assumes that someone else is handling this task, nobody will actually step forward and do it. The HCBS Settings Final Rule requires that **all** settings where people live or receive HCBS be integrated in and support full access of individuals to the greater community. This means that all providers must support individuals to engage in community life, including with people who are not paid staff and do not have disabilities. This includes helping individuals to access public transportation, rather than relying on just the community of people served at the setting and their staff, volunteers, and visitors. Reverse integration is not enough for community integration. See <u>FAQ Part I</u>, Item 2.

We appreciate that the pandemic has made it difficult for everyone to safely engage with the community in the ways they ordinarily prefer. And with the direct care workforce shortage, some providers have been struggling to provide even basic care, leaving community integration for later. At the same time, we have seen some providers identify creative and safe ways to support community engagement. Further, as the weather has warmed up, safe outdoor gatherings are again possible. We encourage providers needing help to reach out to their CDPHE staff leads to better understand how to explore available options, based on individuals' interests, and then determine what will work best for the individuals they serve and their workforce.

100. <u>Myth: Taking someone to a medical appointment or through a drive-through is</u> plenty of community integration, or, "Leaving the house is enough."

As evidence of their support for community integration, some providers point to the occasional trip to a doctor's office, park, or restaurant. Although people should be supported in such activities, they are not sufficient to establish community integration. The requirement is for people to be supported to engage in community life to the same degree of access as individuals not receiving HCBS. People not receiving HCBS typically access the community through a variety of forums: those focused on work, recreation, hobbies, exercise, education, religion, entertainment, and more. The individual must have the opportunity to choose which venues are of interest to them, and at what frequency. In turn, staff need to support individuals to have the opportunity to interact with non-disabled, non-staff people in their community, to ensure activities are integrated. In the end, some people might still choose to stay in most of the time, but others might take advantage of more engagement activities, if available.

101. Myth: Location determines whether a setting is integrated in the community.

Some providers believe that because their setting is "in the community"—meaning not located in a secure campus—it must be deemed integrated. Location is relevant to whether a setting is subject to heightened scrutiny by virtue of proximity to an inpatient institution. However, a setting could be subject to heightened scrutiny regardless of its location, if it has the effect of isolating those receiving Medicaid HCBS from the broader community. Further, all settings—whether or not they are subject to heightened scrutiny—must support community integration. This requires action, not passive reliance on location. For example, if a day program is near a bus stop, it should actively support those who want to learn how to take the bus. What typical community access looks like may vary from one area to another (*e.g.*, urban vs. rural/remote), but in all cases, HCBS participants can expect to have as much access as their neighbors.

102. <u>Myth: The provider does not have to offer support for full community inclusion if doing so would be challenging.</u>

Some providers have asserted that they do not have to offer such support if the individual has a particular diagnosis or disability (such as dementia, brain injury, or severe or profound IDD), is medically fragile, has a history of sexually offending behaviors, has current behavioral challenges, is "really hard to deal with," seems happy going along with whatever their caregiver wants to do, or does not ask to participate in new or different activities. Other providers have said that they will not allow anyone to engage in outside activities during the pandemic, when only one staff member is on duty, when an individual's person-centered service plan includes only site-based services/Specialized Habilitation, or when a guardian wants an individual to stay in.

None of these situations eliminates the requirement to support community integration. The HCBS Settings Final Rule establishes a right to community integration for all populations, regardless of disability or history. This right applies at all settings. Rights cannot be restricted for provider convenience. Even during the pandemic, providers have identified ways to safely support community integration. If full and free access to the community would be dangerous for the individual or others, that concern must be documented and addressed through the rights modification process. As addressed in more detail below (see Item #125), a guardian's preference that their ward not exercise a right is not the same as an individualized assessed need to restrict that right.

103. Myth: Individuals must have permission from staff to leave the setting.

People have a right to access the community and engage in community life. As part of this right, people can leave HCBS settings when they choose, without having to ask for permission or ask for help to disengage locks or alarms. If it would not be safe for someone to go out alone whenever they want—because of danger to themselves (as with unsafe wandering) or to others (as with behaviors warranting constant staff supervision)—an individualized approach is required. Specifically, under new Section 8.484.2.N, restrictive or controlled egress measures and certain situations involving intensive supervision must be handled as rights modifications.

104. <u>Myth: Providers can get people to waive their right to a house key.</u>

The right to leave (see Item #103) is not meaningful without the ability to return when ready. For example, telling someone that they are free to see an evening movie in the theater, but that if they do, they cannot come back in the house until new staff come on shift at 8:00 a.m., means for all practical purposes that they cannot see the movie. Further, requiring them to knock/ring for staff assistance is not typical and can hinder community engagement. Therefore, in a provider-owned or -controlled residential

setting, house keys must be given to every individual, regardless of the provider's perception of their lack of physical/cognitive ability or interest.²

We have found that providers tend to be too hasty in saying that someone cannot use a lock/key or is not interested in doing so. Often, the person can use these items (or alternatives) with assistance and gets reassurance and pride from having them, like a typical adult. Alternatives that are easier to use, such as fobs, codes, and modified door handles (e.g., lever instead of knob) can be considered. Where needed, the provider should work with the person to help them get comfortable with the lock/key/alternative by showing them how to operate these things on a different door, assuring them that they will never be locked in, etc. Often, when these things are provided, the person likes them and uses them. Or they can simply choose not to use them, without the need for a rights modification.

In rare cases, it may be appropriate for the provider to refrain from giving someone a house key. There must be something more than the provider's assessment that the person lacks the interest or ability to use a key, as in that situation, the individual should simply be given the key, and they can choose not to use it. An example of something more might be someone with dementia who is easily confused and becomes demonstrably upset or anxious because of the key. In these rare cases, based on an individualized assessment of need, it might be appropriate to pursue a rights modification. The lock/key or alternatives are never taken away without a rights modification in place, with all required criteria, including informed consent, documented. Only the case manager can obtain informed consent.

Privacy

105. Myth: Providers can get people to waive their right to a bedroom door lock and key.

In a provider-owned or -controlled residential setting, bedroom door locks must be installed and a key given to each resident, regardless of the provider's perception of their ability or interest. As with house keys (see Item #104), we have found that providers tend to be too hasty in saying that someone cannot use a bedroom lock/key or is not interested in doing so. Again, alternatives like fobs and modified door handles can be used, and the person may need training or orientation to the technology. They can choose not to use their lock/key without the need for a rights modification.

As with house keys, in rare cases, it may be appropriate to refrain from giving someone a lock/key for their bedroom, in which case a rights modification would be documented. For example, not providing someone who has uncontrolled nighttime seizures with a

² Some have asked whether having staff open the door on request could substitute for keys. The answer is no, because people need a way to let themselves in independently, like typical adults. CMS, *HCBS Final Regulations 42 CFR Part 441: Questions and Answers Regarding Home and Community-Based Settings*, p. 8 (2015) (confirming that individual "should have a key to the residence as well as [their] bedroom").

bedroom lock/key (so that staff can enter and help as needed) would be a rights modification for which all required criteria, including informed consent, should be documented. For more details, see Item #104 (on house keys) and Item #120 (on doctors' orders).

106. <u>Myth: We can't put a lock on the bedroom door, because the person could accidentally lock themselves in.</u>

The provider should install a single-action mechanism that prevents outsiders from coming in (unless the occupant opens the door or disengages the lock), while allowing the occupant easy egress (even when the door is locked) by simply turning the doorknob or pushing a lever. Many affordable, safe solutions are available. On the rare occasions when even these measures would entail health and safety concerns for the individual, a rights modification should be documented.

107. Myth: We can't put a lock on the bedroom door, because there is no door.

As part of its protections for privacy, the federal rule requires bedrooms/units to have lockable doors. Sleeping areas that are separated from common areas by a curtain or open space (e.g., lofts) must have doors/walls added to create privacy.

108. <u>Myth: Staff may/must notify family of any incidents or concerns, without checking</u> whether the relative has a signed release/other legal authority.

The HCBS Settings Final Rule protects individuals' right to privacy. This includes the right to be protected like anyone else under federal and state privacy law. Detailing all such authorities would be beyond the scope of this FAQ, but simply put, disclosure of personal health information and some other sensitive information is limited to certain situations, such as those involving a signed authorization to release the information. Outside of the legally authorized situations, such disclosure is inappropriate.

Person-Centered Practices

109. <u>Myth: Separate person-centered training for staff is not needed, since we already</u> provide person-centered care.

In working with providers, CDPHE and HCPF have been impressed by many stellar examples of person-centered practices throughout the state. However, personcenteredness currently means different things to different providers. Some have simultaneously expressed the beliefs that they are person-centered, and that personcentered practices cannot work or are inappropriate for many of the people they serve, including such large populations as "anyone with IDD." Some have asserted that they are person-centered while engaging in practices that are just the opposite. The training requirement is a starting point to generate common ground on what personcenteredness means in theory and in practice. For similar reasons, CDPHE has included such a training requirement in its licensing rules for assisted living residences (ALRs). The Department offered a free <u>training</u> on this subject in 2015 and partnered with Support Development Associates, the Council on Quality and Leadership, and others to provide free <u>trainings</u> throughout Colorado in 2015-2018. Courses offered by others, such as those certified by the <u>Learning Community for Person Centered Practices</u> to offer training in person-centered thinking, may also be suitable. The <u>Colorado Office of</u> <u>Employment First</u> offered such trainings recently. (Fees may be charged in some cases. The Department is considering options for providing a free, updated course.)

110. <u>Myth: Training on how to safely restrain people, as covered by the Mandt</u> <u>System®, is person-centeredness training.</u>

The Mandt System® trainings are about deescalating dangerous situations involving aggressive behaviors. Although these trainings may touch on concepts relating to person-centeredness, they do not focus on these concepts in enough detail and do not discuss the application of such concepts to the entire range of daily life and decisions where they are relevant (outside of dangerous situations). While potentially valuable for some providers, they are not a substitute for person-centeredness training.

Autonomy/Other

111. <u>Myth: A doctor's order is required (or the provider can choose to require a doctor's order) to allow an adult to drink alcohol in their home.</u>

A typical adult is free to keep alcohol in their home and decide when to drink it. A waiver participant in a provider-owned or controlled residential setting has the same freedom as part of their rights to dignity, autonomy, independence in making life choices, and controlling personal resources to the same degree as those not receiving HCBS. Broad restrictions on this freedom, such as house rules barring alcohol without a doctor's note, are inappropriate. If access to alcohol would create a health/safety concern for a particular person, an individualized rights modification may be pursued.

112. <u>Myth: Honoring rights creates a free-for-all and requires providers to allow people</u> to partake in illegal activities.

The expectation under the HCBS Settings Final Rule is that people receiving HCBS enjoy the same kinds of rights and freedoms as everyone else. If everyone is prohibited by law from doing something, the provider need not allow waiver participants to do partake. In protecting individuals' health and safety, the provider may consider providing other resources or involving law enforcement, if needed.

Determining what kinds of rights and freedoms typical community members enjoy is context-specific. For instance, while most adults can freely drink alcohol at home, doing so in most daytime settings, such as the workplace, grocery store, or library, would likely violate the venue's/employer's policies and result in an instruction to stop or a request to leave. In keeping with such norms, we would not expect a day program to allow participants to drink alcohol on-site, even though we would expect that for residential settings. However, if staff are supporting individuals at a typical community event (such as a festival) where others are drinking, we would expect waiver participants to have the same freedom, absent an individualized rights modification.

113. <u>Myth: Everyone in the home must mark all their clothing with their name (or the provider can choose to require this).</u>

A broad-based rule like this would violate individuals' rights to dignity, autonomy, independence in making life choices, and controlling personal resources to the same degree as those not receiving HCBS—given that people not receiving HCBS, even those living with roommates, are not required to label all of their clothing. Providers are free to suggest, but not require, that residents label their clothing. If disputes about ownership become a concern for certain people, the provider may consider other approaches, potentially including individualized rights modifications.

114. Myth: Providers can say that nobody is allowed out of their rooms at night.

HCPF and CDPHE have seen some group homes and alternative care facilities (ACFs) with rules such as "nobody can be out of their room after 10:00 p.m., so staff can sleep on the sofa" or "nobody can be out of their room at night except to go to the bathroom." These rules violate several rights, including residents' right to unrestricted access to all common areas of the home, dignity, autonomy, and independence in making life choices. Just like typical adults, people receiving services have the right to stay up late in the living room, get a midnight snack from the kitchen, and so forth. If a particular person is disruptive to other residents, the provider should work with them to resolve the issue, starting with methods other than proposing a rights modification.

Rights Modifications

115. Myth: Rights modifications are only an issue for people with IDD.

The HCBS Settings Final Rule applies to all waivers and populations. Although rights modifications may be more familiar to those who work with people with IDD, given the historical concepts of rights suspensions and restrictive procedures, they can and do occur within the other waivers, and in such cases, the same procedure applies. For example, we have seen ACFs with house rules imposing broad-based restrictions on all residents' rights (e.g., to have visitors in the evening), just like group homes. We have required such providers to eliminate these rules and work with the particular individuals, if any, about whom there are concerns, potentially by proposing a rights modification. If a rights modification is proposed, the case manager at the Single Entry Point (SEP) agency would have the same role as a case manager at a Community Centered Board (CCB). To ensure that all providers and all CMAs share a common understanding of their respective roles, the Department has provided them with the same required trainings (see January 2019 training slide deck, recording, and transcript; June 2021 self-paced training and slide deck).

As a reminder, case managers at SEPs and CCBs should be entering rights modification information into the Benefits Utilization System (BUS) or, once they have access, the new Care and Case Management (CCM) system. *See* <u>HCPF OM 20-103</u> & <u>Attach. 1: BUS</u> <u>Screenshots and Data Entry Instruction for Rights Modification Screens</u>. Given that all existing rights modifications have come up for annual review/renewal at least once since January 1, 2021, when use of these screens was first required, all rights modifications should now be reflected in the BUS. It appears from the data available to date that this section of the BUS is not always being filled out as required.

116. <u>Myth: It's not a rights modification if it's a house rule, a condition of receiving</u> services at a particular setting, or part of a lease/residential agreement.

Some examples, in addition to those given elsewhere in this FAQ, include "a condition of living here is that residents agree to be on camera at all times, including in common areas," and more broadly, "by agreeing to receive services here, people agree to waive their right to privacy." Such measures broadly restrict everyone's rights and are therefore inappropriate. If there is an individualized need to restrict someone's rights, it must be addressed through the rights modification process.

117. Myth: It's not a rights modification if a majority of participants agree to it.

As an example, suppose a majority of residents in an ACF or group home take a vote and agree that no overnight visitors will be allowed. The residents are free to reach this agreement among themselves. However, if staff enforce the agreement or add it to the house rules, then there is a provider intervention, and it is inappropriate because it broadly restricts rights (here, to visitors at any time). If someone's guests disturb other residents, the provider should work with that person to resolve the issue, starting with methods other than proposing a rights modification.

118. <u>Myth: Providers cannot help people stay upright in their wheelchairs with belts,</u> <u>straps, or buckles.</u>

Whether these measures are restraints depends on the circumstances. Even as restraints, they may be used if the rights modification process is followed.

A belt/strap/buckle in a wheelchair is not a restraint if the individual can undo it on their own, because in that case, the item does not restrict their ability to move their body. If the item is not a restraint, it can be used without HCBS Settings Final Rule implications.

A belt/strap/buckle in a wheelchair is a restraint—and therefore a rights modification—if the individual cannot remove it themselves for any reason. Even in this case, the item can still be used if the process for implementing a rights modification is followed. All required criteria, including informed consent, should be documented.

Some have questioned the need to follow the rights modification process for such items. The Department appreciates that these items are generally used to promote

comfortable, safe posture and not to hurt people or control their behavior. However, whether something is a restraint, or a rights modification in general, is determined not by the intent of the provider/caregiver implementing the measure, but rather by the effect of the measure: that is, whether it restricts the movement of a person's body, in the case of restraints, or otherwise interferes with their exercise of some other right, in the case of rights modifications in general. Being strapped into place is the classic example of being restrained. For this reason, if the person cannot undo the straps, there must be recognition that they are being restrained.

At the same time, it is important to reduce administrative burden where possible. As part of the ongoing Human Rights Committee (HRC) stakeholder engagement process, we will consider whether any categories of rights modifications subject to HRC review, such as the kind at issue here (depending on the waiver), might warrant some form of streamlined review. One possibility might be a desk review in lieu of a committee meeting. Such a change would not affect the underlying documentation requirements.

119. Myth: Providers cannot help people put on their seatbelt in the car.

Physical or hand-over-hand assistance is a restraint if the individual verbally or nonverbally expresses that they do not want the assistance (e.g., "leave me alone"—in words or gesture) or if the assistance is already subject to existing rules for safety control/emergency control procedures, rights suspensions, or restrictive procedures. If these conditions are not present, then the assistance is not a restraint; this will often be the case for individuals who are content with or ask for the assistance. Even if the assistance is a restraint, it is allowed if the rights modification process is followed.

The reason for this approach is similar to that relating to the use of belts, straps, and buckles in general (see Item #118). While we appreciate that the intent of helping someone put on their seatbelt is to protect their safety, we are concerned not with the intent but rather with the effect: handling the person's body in a way they may not want. While the person may not have the option to travel without a seatbelt (where seatbelts are required by law), they often do have the option to skip the trip altogether, rather than traveling at the cost of perceived manhandling. The rights modification process balances these interests by allowing such measures to be employed, if needed, on an individualized basis, with informed consent and other criteria documented. If a person needs to be re-buckled in the middle of a trip, new Section 8.484.5.G's provision for short-term measures to address immediate risks may come into play.

120. Myth: The doctor ordered this measure, so it is not a rights modification.

People can choose whether or not to follow their doctor's "orders," which are really advice, not mandates. If the individual can follow their doctor's recommendation on their own and chooses to do so, there is no rights modification. However, if (a) the individual needs staff intervention or staff use of a device (or Medicaid is paying for the device) to follow the recommendation, and (b) the staff intervention/use of a device

interferes with the individual's exercise of rights protected by the HCBS Settings Final Rule, then that intervention/use of a device is a rights modification for which informed consent and the other federal criteria must be met.

Example: an individual's doctor recommends that they sleep with an audio monitor in their room and not lock their bedroom door, so that if they have a seizure, staff can come to their aid. Here, (a) the individual needs staff to monitor the device and enter when they believe a seizure is underway, and (b) this interferes with their right to privacy. This situation should be treated as a rights modification. Presuming that informed consent and the other criteria are documented, provider staff may use the audio monitor and have the individual keep their room unlocked at night, while allowing them to lock the room for privacy while they are away (unless there is an additional reason not to provide a bedroom lock/key at all, see Item #105—in which case, the individual still needs a secure way to store their belongings).

Example: an individual's doctor recommends that they follow a certain diet. The individual understands the advice and chooses to follow it on their own by making certain selections from the food offered by their residential provider. Occasionally, knowing the risks involved, they have a "cheat" meal, and staff do not intervene. This situation does not involve a rights modification.

Variation: sometimes, the person asks staff whether a given food fits within the recommended diet. Staff answer to the extent they are qualified to do so, but do not pressure the person. This situation does not involve a rights modification.

Variation: staff only allow the individual to eat food that is part of the recommended diet. This is a rights modification, as (a) staff are intervening, and (b) the intervention interferes with the individual's right to access food of their choosing at any time.

Variation: every time the person wants to eat a "cheat" food, staff remind them of the dietary recommendations or ask, "are you sure you want to eat that?" These badgering approaches pressure the person and amount to a rights modification, along the same lines as in the preceding variation.

121. Myth: This is a home modification, so it's not a rights modification.

If Medicaid pays for the home modification as part of someone's HCBS benefits, the benefit is subject to the HCBS Settings Final Rule. Most home modifications, such as ramps and widened doorways, enhance an individual's access to their home and community. However, some hinder such access—e.g., by restricting egress (in the case of a secure fence or security system to prevent unsafe wandering). If a Medicaid-funded HCBS benefit interferes with an individual's rights, it must be treated as a rights modification. Case managers can help members and their families navigate the rights modification process, as the contractor/vendor may be unfamiliar with it.

122. <u>Myth: Helping someone with medication administration is always, or never, a</u> rights modification.

Much like hand-over-hand assistance is a restraint, and therefore a rights modification, if the individual indicates that the assistance is unwelcome (see Item #119), assistance with medication administration is a rights modification if the individual indicates that they would prefer to handle such tasks on their own. Where the individual wants to self-administer, but the provider does not want to allow this, the provider is interfering with the individual's rights to dignity, autonomy, independence in making life choices, and controlling personal resources to the same degree as those not receiving HCBS. Where the individual is content with or asks for the assistance and has not expressed a contrary preference, the assistance is not a rights modification.

123. Myth: The individualized assessment for rights modifications ignores risk to others.

Some providers have expressed the view that in assessing whether a rights modification is necessary, they can consider only risks to the individual's health and safety. In fact, the assessment should also consider risks to others, such as staff, fellow service recipients, and members of the community. For example:

- Intensive supervision may be warranted not only because of an individual's propensity to endanger themselves (e.g., with self-harming behaviors or unsafe wandering) but also because of their propensity to endanger others (e.g., with aggression or sexual misconduct).
- Restrictions on the ability to keep alcohol in one's room/unit may be warranted not only because of an individual's disordered drinking (e.g., drinking to the point of becoming sick) but also because of their inability to keep the alcohol away from those who should not have it (e.g., they lack the skills to store the alcohol securely and/or to turn down requests by housemates who cannot drink safely).

These examples involve individualized assessments of risks, as the risks arise from the specific individual's behaviors and skills. Someone with different traits (e.g., someone who wants to keep alcohol in their room, is proficient at locking up their belongings, and is comfortable turning away housemates who want a drink) would be assessed as not needing a rights modification. If a rights modification is appropriate based on risks to others, positive approaches to enhance the individual's ability to safely exercise the right around others (e.g., building assertiveness skills) would be appropriate and could eventually eliminate the basis for the modification.

124. <u>Myth: The Department does not care that people are going to make bad choices</u> and hurt themselves or others.

Some stakeholders have pointed out that if providers cannot impose rights modifications based on their own assessment of need, but rather have to ask the individual to provide informed consent to their case manager, some individuals will

refuse to consent. Without the proposed rights modification in place, they may make poor choices and end up suffering harm or harming others. A few stakeholders have suggested that the Department is being careless about these risks.

The Department takes the concerns about potential bad outcomes seriously and believes that there is a workable path forward based on (1) adhering to the federal rule while (2) supplementing it with additional processes as appropriate.

First, as to the rule: honoring the dignity of risk, CMS decided that rights modifications cannot be imposed without informed consent. We agree with this decision, and in any event, must implement it to preserve federal funding for our HCBS programs. At the same time, we continue to expect providers to protect the health and wellbeing of the members they serve, their staff, and others. To that end, we expect providers to help people make good choices and minimize the risks of bad choices by working with them on an individualized, person-centered basis.

Second, as to additional processes: risks have always existed in the HCBS world, and individuals could always choose to withhold their consent to proposed restrictive procedures (within the waivers serving people with IDD), to not cooperate with imposed rights suspensions (for which our rules for those waivers officially required only notice), to disregard house rules, and/or to walk away from providers seeking to implement such measures. Providers already have techniques for dealing with these situations, including:

- Pursuing measures other than rights modifications. As noted in Item #96, minimizing rights modifications and using them only where truly needed and agreed-to can reduce frequent "battles of wills" and create a more cooperative, positive environment with everyone's buy-in.
- If the provider believes a rights modification is necessary, explaining this belief to the individual. The provider can lay out the risks and concerns and show how the individual can choose to be part of the solution by agreeing to the proposed rights modification. Only the case manager can obtain the signature.
- Encouraging the individual to consult with trusted friends, peers, and others to help with supported decisionmaking. <u>Recent state legislation</u> provided more official recognition and expectations for this process. A trusted natural support may be more persuasive than paid provider staff or case managers.
- Encouraging the individual to consult with independent advocates, such as those who work with local Arcs or the Long-Term Care Ombudsman offices. Advocates may be able to help negotiate a solution that works for everyone.
- Documenting the risks of concern on the <u>Informed Consent Template</u>, even if the individual does not sign it, and documenting the conversations suggested above. If the individual does not consent and does end up getting hurt or hurting

someone else, this material, maintained as a best practice, could be relevant to an assessment of the provider's actions to preserve health and safety. Case managers should also document such conversations in their log notes.

• Considering whether it is possible to safely serve the individual without the proposed rights modification. If it is not, the risk that services may be terminated should be explained to the individual (see <u>Informed Consent Template</u>, Item 6). Providers may not routinely specify this consequence, because not every seeming impasse on a rights modification automatically warrants termination. Ultimately, if warranted, the provider may initiate the process for terminating services according to existing procedures and new Section 8.484.4.A.1.d (for provider-owned or -controlled residential settings, requiring documented efforts to resolve problems and a substantial reason for seeking any move/eviction).

125. <u>Myth: The guardian approves of (or demands) the measure, so it's not a rights</u> <u>modification, or, "We have to implement whatever the guardian wants."</u>

Informed consent is just one of several requirements for a rights modification. There must also be documentation of the specific and individualized assessed need for the modification, the positive interventions and supports already used, the less intrusive methods of meeting the need that were tried but did not work, and more. In the course of attempting to document these criteria, it often becomes clear that the proposed rights modification (or historic rights suspension or restrictive procedure) is not needed and should not be implemented (or continued).

126. <u>Myth: People can waive their right to accessibility in their home when they or their family/guardian state that they are okay with the home being inaccessible.</u>

Under the federal rule, the right to physical accessibility cannot be modified. The Department's codification of the rule specifies that "[m]odifications to the rights to dignity and respect, the rights in Sections 8.484.3.A.6-11 (covering such matters as person-centeredness; civil rights; freedom from abuse; and Plain-Language explanations of rights, dispute resolution policies, and grievance/complaint procedures), and the right to physical accessibility are not permitted." New Section 8.484.2.N.2.