HCBS Settings Final Rule
Rights Modification Stakeholder Workgroup – Meeting #3
Meeting Minutes

Meeting Facilitator: **Jamin Barber, Public Consulting Group**

Present:

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I. Meeting objectives

Participants agreed on the following objectives for the meeting:

A. Obtain feedback and perspectives from workgroup participants and people workgroup participants talk(ed) to
B. Identify set of action items to achieve alignment on draft rule prior to its release for public comment
C. Confirm action items for training deliverables

II. Review of draft state rule

Rule BBB – Additional Criteria for HCBS Settings

Summary: The purpose of this section is to outline qualities that Provider-Owned or -Controlled Residential Settings, Provider-Owned or -Controlled Nonresidential Settings, and Other Nonresidential Settings must have and the individual rights these Settings must protect, based on the needs of the individual as indicated in their person-directed service plan, subject to the rights modification process in Rule CCC.

A. Discussion
    a. Question regarding *Section A, #2, Part b* (*The lease, residency agreement, or other written agreement may provide for a security deposit or other provisions outlining how property damage will be addressed)*: Is there any expectation a lease or residential agreement would address damage to the home caused by a person receiving services?
        i. Answer: Providers may address potential damage to the home caused by a person receiving services in their lease agreement, but this is not a requirement set forth in the Rule. Additionally, language surrounding loss of security deposits and damage to the home should be appropriate for the individual and their unique needs. Also, refer to Question 80 of the third set of Frequently Asked Questions (FAQs) for more details on security deposits and property damage in lease agreements (https://www.colorado.gov/pacific/sites/default/files/HCBS%20Settings%20Final%20Rule%20FAQ%20III.pdf). (CDPHE and HCPF)
    b. Question regarding *Section A, #7* (*A provider may not discharge an individual who has nowhere else to live)*: Does the term "provider" refer to the PASA or the host home provider?
        i. Answer: *Section A, #7* applies to the PASA specifically, not the host home provider. (CDPHE and HCPF)
        ii. Additional comment that *Section A, #7* conflicts with the regulation that allows the PASAs to give notice and then discharge an individual. The Department hears this view but notes that other provider types have been able to work with a rule against discharging people who have nowhere else to live. (HCPF.)
        iii. Additional comment regarding *Section A, #7* that there have been instances of individuals wanting to live at a Supportive Living Program (SLP) facility without receiving services, while other existing regulations require that individuals living under an SLP provider's care receive services. This commenter was invited to email HCPF with citations to the rules that created the apparent bind. (CDPHE)
        iv. Additional comment that *Section A, #7* should not assume that community-based services and facility-based services are the same.
    c. Question regarding *Section B, #1* (*Individuals must have a key or key code to their home, a bedroom door with a lock, lockable bathroom doors, privacy in changing areas, and a lockable*

place for belongings. Only appropriate staff may have keys to said areas and must obtain permission to enter those areas.): Should language surrounding individuals' rights to have keys and the circumstances under which staff are allowed to enter their spaces be outlined in their leases?

i. Answer: This language from the rule does not have to be recited in lease agreements, but providers may include it if desired. If there is a need for an individual to have more restrictions or if staff may need more access to an individual's room, this information should be included in that individual's person-directed plan, but not in their lease. This may be especially important from a privacy perspective, in case a landlord or other third party has access to the lease. Also, refer to Question 73 of the third set of FAQs (https://www.colorado.gov/pacific/sites/default/files/HCBS%20Settings%20Final%20Rule%20FAQ%20III.pdf) for more details on language that must be included in lease agreements. (HCPF, CDPHE, and PCG)

ii. Additional question regarding *Section B, #1*: How is the Department handling issues for individuals that are physically or developmentally unable to use keys or keypads? Providers have been told to implement a rights modification in these cases.

1. Answer: Providers should still provide a key to the home or code for a keypad, as well as a key/keypad for the bedroom, without regard to the individual's physical or cognitive skills, and the individual can simply choose not to use it. A rights modification must be done when a key or key code is being taken away or can't be given to an individual because of an assessed need, and this must also be documented in their person-directed plan. An example of this situation would be for an individual with advanced dementia who becomes confused and anxious about having a key, causing distress. Additionally, it is critical that anyone, regardless of cognitive or physical ability, can get out of their bedroom without any additional burden other than simply opening the door, such as having to unlock it from the inside or pushing a button. (CDPHE and HCPF)

iii. Comment regarding language surrounding key use and appropriate staff use of keys: Language and discussion on this topic could be placed in *Section A, #1, Part j (The lease, residency agreement, or other written agreement must: specify that staff will not enter a unit without providing advance notice and agreeing upon a time with the individual(s) in the unit).*

Rule CCC – Rights Modification

Summary: The purpose of this section is to outline the rights modification process, including the information that must be documented in the individual's person-directed service plan.

A. Discussion

a. Question regarding *Section B (The rights modification process outlined in this section applies to all situations in which an individual is limited in the full exercise of their rights, including . . . modifications to the rights in Sections A through F of Rule BBB):* The "modifications to the rights in Sections A through F of Rule BBB" part leaves out *Section G* of *Rule BBB (The setting is physically accessible to the individual, and the individual has unrestricted access to all common areas of setting).* There may be some instances where a rights modification is necessary based on an individual's assessed need. For example, for an individual with Prader-Willi syndrome, they may not have access to the pantry or the refrigerator. An additional example could be for an individual in a wheelchair with contracted arms, but their laundry room is downstairs, so technically their laundry room is not accessible, even though they wouldn't be able to

participate in doing their laundry regardless of the location of the laundry room. How would this section apply to these situations?

i. Answer: The reason for this language is that the federal rule does not allow for modifications to the right to physical accessibility. The intent is to guarantee physical accessibility and prohibit limiting individual participation in daily activities. For example, this was meant to ensure that an individual in a wheelchair could access their bathroom or shower. This language can be reviewed for possible changes to enhance clarity. The examples provided may warrant a rights modification as to other rights, like access to food. (CDPHE and HCPF)

b. Comment regarding *Section B (The rights modification process outlined in this section applies to all situations in which an individual is limited in the full exercise of their rights, including . . . all situations formerly covered by the processes for rights suspensions and restrictive procedures [as set forth in the version of 10 CCR 2505-10 8.600.4, 8.604.3, and 8.608.2 being replaced by this rule]).* The references to the versions of 10 CCR 2505-10 8.600.4, 8.604.3, and 8.608.2 being replaced by this rule have many other areas involved that aren't mentioned in this section, including definitions of consent, human rights committees, and emergency suspensions that need to be addressed somewhere.

i. Response: A crosswalk between the HCBS Settings Final Rule and all existing authorities was developed to ensure that any incongruencies were resolved. An additional crosswalk will be developed specifically to address the topic of restraints and other subjects covered by the rules slated for deletion to ensure that nothing critical is left out of the new rule. (HCPF)

c. Question regarding *Section C, #7 (For a rights modification to be valid, the individual's person-directed service plan must include the informed consent of the individual [or, if authorized, their guardian or other legal representative], in writing, outlining the specific modification and circumstances for its use):* Does the informed consent need to be a separate form from the modification letter?

i. Answer: It is best for the informed consent to be documented on a separate form from the notice of rights suspension (required by current rule). This is because the documents lose clarity when they contain too much information. (CDPHE)

ii. Comment regarding *Section C, #7, Parts a-g*: These parts do not align with the current training and guidance given in the FAQs. For example, the documentation of the positive interventions and supports that were attempted unsuccessfully or the less intrusive methods that were attempted unsuccessfully along with the plan for regular data collection, time limits of the modification, and the no harm statement.

1. Response: This list regarding informed consent is from the CMS slide deck from November 2019. This was shared with the group after the first Rights Modification meeting and again on 4/14/2020. The distinction between the two is what has to be documented in the informed consent document itself versus the larger set of items that needs to be included in the documentation for the rights modification. Changes to promote clarity here can be considered. (HCPF)
2. Additional comment regarding *Section C, #7*, *Parts a-g* There is a definition of consent at 10 CCR 2505-10 8.600.3 in relation to psychotropic medications that is different than the new definition laid out in this Rule. The Department should consider aligning these two definitions.

d. Proposed new language (additional part, proposed #9) to be added to *Section C*:9. Prior to collection of informed consent:

a. The case manager must offer the individual the opportunity to have an advocate, who is identified by the individual, present at the time that informed consent is collected.
b. The case manager is responsible for providing email or postal mail meeting confirmation to the identified advocate for the subsequent meeting during which informed consent is collected and during which sections 7. and 8. above are implemented.
c. The process described in section 9., including the offer to have an advocate present and the provision of written meeting confirmation, must be documented by the case manager.

The Departments appreciate this input and will consider it. (HCPF and CDPHE)

e. Comment regarding *Section D (If restraints are used with an individual at an HCBS Setting, their use must meet the requirements outlined in this section):* There aren't any requirements here for training, safety, documentation, incident reports, HRC review of the event that resulted in the use of restraints, or a team meeting when a pattern of 3 uses of restraints occurs. Response: these issues will be considered in the new crosswalk to be developed to ensure that critical provisions are not deleted. (HCPF)
    i. Comment regarding *Section D, #4* (*If restraints are used with an individual at an HCBS Setting, their use must be reassessed over time):* Please define "over time" more specifically.
f. Comment regarding *Section F (If there is a serious risk to anyone's health or safety, a rights modification may be implemented or continued for a short time without meeting all the requirements of this Rule CCC, so long as the provider immediately [a] implements staffing and other measures to deescalate the situation and [b] reaches out to the case manager to set up a meeting as soon as possible. At the meeting the individual can grant or deny their consent to the rights modification):* Please define "short time" and "as soon as possible" here. Request that both of these terms be defined in terms of "no more than (specific number of hours)."
    i. Response: This section is based on CMS guidance referring to emergency and near-emergency situations. CMS has indicated that in these situations, the provider should take steps to mitigate the health and safety concerns while also asking the case manager to set up a meeting as soon as is feasible. So, as soon as the meeting can be set up, it should occur. (HCPF)
    ii. Question and comment regarding *Section F:* Does the HRC have to approve the modification? There is a huge lack of HRC inclusion in the draft rule.
        1. Answer: The federal rule does not speak to HRCs at all. That process remains in place as it was. If a measure had to be approved by the HRC before, it still does; if it did not, it still does not. (HCPF)
    iii. Additional comment regarding *Section F:* It is important to include a section about what process providers and case managers should take when a person does not agree to the modification, as it could be challenging to find placements. This would leave case managers with many challenges in attempting to meet needs with services.
    iv. Question regarding *Section F*: In light of the COVID-19 pandemic, it has been noted that the Settings Rule is not yet in place and for the time being, keeping people safe is the ultimate responsibility of the provider. What would occur regarding individuals not consenting in the event these rules were already in place? For example, what should providers do about individuals who are unwilling to follow the stay-at-home orders?
        1. Answer: Other states that have already implemented the federal rule have addressed this through a Section 1135 Waiver or an Appendix K to their HCBS waivers. It is also important to note that the Settings Rule is in place and has

been effective since March 2014, but CMS has given states until March 2022 to become fully compliant. This pandemic and the Governor's stay-at-home order have created a unique situation that may not require clarification in the state's draft rule. (CDPHE) For the time being, providers should (1) follow CDPHE guidance and the Governor's stay-in-place orders (as providers), being sure to follow guidance specific to their setting type if it exists; (2) encourage individuals to follow the stay-at-home order and explain what this means, how to social distance, etc.; and (3) keep in mind that the stay-at-home order doesn't mean people can never go out. All people, including people receiving services, have the right to go out and stretch their legs and get fresh air. If providers have a reason to believe that a person can't or won't follow social distancing procedures, then they should work with them on an individualized basis. (HCPF)

2. Follow-up comments on *Section F*: There are occasions when individuals' lack of ability to give informed consent or weigh decision-making puts them under significant health and safety risks in situations like these (COVID-19 pandemic) and there should be some language in the rule to reflect that. For example, for someone that has Prader-Willi syndrome may not want to have any calorie restrictions or may not want to have any of their possessions locked, so it is a serious risk to their health and safety. Another participant added that this is why Colorado currently distinguishes between suspensions of rights and restrictive procedures, and by rolling them together, we put people at risk by asking permission to keep them safe. At the same time, some participants observed that there are some unnecessary rights suspensions that seem to go on forever, and that interdisciplinary teams have not done a good job in pursuing the least restrictive means available.
    a. Response: The principle of the federal rule is that individuals are the ones who decide what risk they are willing to take and what measures they agree to in terms of keeping themselves safe. (HCPF) This is about dignity of risk and the ability of people to make their own choices. It seems that in many states, teams are implementing restrictions based on staff convenience instead of what the individual really needs and wants. If there is a true health and safety need, the individual should be educated about all of their choices; enhanced staff training can improve the results of these conversations. Keep in mind the goal of lifting parts or all of the modification over the time. (PCG)
    b. Additional comment on this subject: Supported decision-making should be used before defaulting to guardianship.
    c. Additional comment on *Section F* and the COVID-19 pandemic: This situation is not different from any other situation where health and safety issues have to be balanced with the greater good. People without disabilities have the right to violate the Governor's order and are doing so. The larger issue for providers is simultaneously (a) operating a congregate setting and (b) trying to act like an individual's home.

B. Additional comment: HCPF's interpretation of the HCBS Settings Final Rule overall is too broad in terms of what constitutes a rights modification that is subject to the federal rights modification process. An example of this is in *Rule CCC, Section D (If restraints are used with an individual at an HCBS Setting, their use must meet the requirements outlined in this section)*. Current regulations

provide for significant safeguards in the use of restraints. The provisions in the draft rule that require a rights modification for the use of restraints and restrictions to rights not listed in the "additional conditions" in Rule BBB are too broad. Other states are not using this approach.
   a. Response: HCPF hears this point and understands but disagrees. (HCPF) Because of technical difficulties, HCPF was not able to elaborate on this point, but will address it at the next meeting.

C. Additional comment: this rule is for all ten HCBS waivers, and this language is very important. For Single Entry Point (SEP)-administered services, current rights modification processes are essentially nonexistent.

D. Decisions
   a. Before the meeting, PCG asked one participant whether her written comments could be shared with the group and did not hear back. During the meeting, other participants expressed interest in reviewing these comments, and the author agreed that they could be shared. PCG will send the comments to the group.

III. Training Development

A. Participants suggested the following training topics:
   a. Dignity of risk
   b. Supported decisionmaking
   c. HRC inclusion
   d. The rights modification process, along with templates for associated forms and documents, including the informed consent form

B. Instructions to complete the training worksheet
   a. Participants should consider the topics on which we should develop trainings based upon the needs of each stakeholder affected by the HCBS Settings Final Rule and complete the training worksheet provided by PCG before the next meeting.
   b. Participants should keep in mind successful trainings and lessons learned from less successful trainings as they complete the document.
   c. The worksheet is just a guide and can be adjusted if needed as it is being filled out.
   d. Once completed, participants may submit the completed worksheets to hcpf_stp.publiccomment@state.co.us. Participants should indicate with their submission whether or not they want their worksheets to be shared with the group.

V. Next Steps

A. Questions or thoughts: Email hcpf_stp.publiccomment@state.co.us
B. The next HCBS Settings Final Rule Rights Modification Stakeholder Workgroup (Meeting #4) will take place on Tuesday, May 29, 2020 from 12:00 – 2:00pm MT