HCBS Settings Final Rule
Rights Modification Stakeholder Workgroup – Meeting #4
Meeting Minutes

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

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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. Determine group's interest in the development of work product related to informed consent; and
D. Obtain feedback on successful and unsuccessful training approaches and proposed training topics, audiences, and approaches to inform development of training plan.

II. Opening Remarks

A. The Department has received a significant number of comments and questions from workgroup participants about the Draft Rule and would like to thank everyone for their feedback. The Department has reviewed the feedback and is going to put together an informal written response to questions and comments not covered in this workgroup. The Department will share a listening log addressing the comments and feedback and a second Draft Rule with that feedback incorporated in the next month.

III. Presentation on and Discussion of Rights Modifications

Summary: The purpose of this presentation is to explain the Department's approach to rights modifications and informed consent as reflected in the Draft Rule. This presentation responds to questions and concerns raised by workgroup participants at prior meetings and in written submissions and explains why certain alternatives were considered but not adopted. The Department's presentation included a slide deck that was shared with participants.

A. *Draft Rule AAA* outlines basic rights that are guaranteed to people at all HCBS settings *(including that settings are integrated in and support full access to the greater community; are selected by the individual from among various options, including non-disability specific settings, and an option for a private unit; and ensure privacy, dignity, respect, and freedom from coercion and restraint)*. *Draft Rule BBB* outlines additional rights guaranteed to people at provider-owned or -controlled residential settings, and many of these rights apply at other settings as well *(e.g., the individual has a lease giving them the same responsibilities and protections from eviction as other tenants, or they have a written residential agreement giving them comparable protections; the individual has privacy in their residential unit, including: the ability to lock their doors, choose their roommates (if any), and furnish and decorate their room as they like; the individual has the freedom and support to control their schedule and activities and has access to food at any time; the individual can have visitors of their choosing at any time; and the setting is physically accessible.)* The federal HCBS Settings Final Rule as issued only describes a rights modification process for the rights outlined in *Draft Rule BBB*. Broadly speaking, there are three possible approaches for states to take to modify the rights outlined in *Draft Rule AAA*:
    i. These rights can be modified however a given entity (such as the state, or perhaps the provider or case management agency) sees fit.
        1. This approach interprets the absence in the federal rule of a process for modification of the rights outlined in *Draft Rule AAA* as an indication that the Centers for Medicare &

Medicaid Services (CMS) does not have an opinion on how or when these rights can be modified.

2. Some workgroup participants have suggested that the Department take this approach and keep in place current regulations for suspending these rights and using restraints, in which case individuals would receive certain due process protections but would not have to give informed consent.
    a. Comments from various participants: Colorado already has statutes, regulations, and the Human Rights Committee that address the modifications of these rights. The current process does not allow providers to do whatever they want.
    b. Department's response: The Department agrees. However, the existing processes do not always require documentation of informed consent and certain other criteria that play an important role in due process.
3. The Department disagrees with this approach. There is no textual support for this interpretation in the Final Rule or its predecessor issuances (such as a statement that this rights modification process should be up to the states, or to individual providers or case managers). Additionally, the rights outlined in *Draft Rule AAA* are arguably more absolute and highly protected than the rights outlined in *Draft Rule BBB*. For example, it seems doubtful that CMS expected the rights to dignity, autonomy, and respect to be more readily subject to modification than rights like decorating one's room.

ii. These rights cannot be modified at all.

1. This approach interprets the absence of a process for modification of the rights outlined in *Draft Rule AAA* as an indication that CMS did not envision that anyone would ever modify these rights.
2. There is evidence to support this interpretation in the preamble to the Final Rule and the codified rule itself.
    a. Where CMS wanted to allow modifications, it explicitly listed the rights that were subject to modification (as with most of the rights outlined in *Draft Rule BBB*), and then set out the applicable process.
    b. Where CMS intended for a right to be not subject to modification, as with the right to a physically accessible setting, it simply removed it from the list of rights that are subject to modification, without expressly saying in the text of the codified rule that nobody can modify this right. The other rights that are not included in the list of modifiable rights are the rights outlined in *Draft Rule AAA*.
    c. CMS was asked to add an exception that would explicitly allow restraints in some circumstances, and it declined to do so.
    d. CMS stated that the rights modification process should not be left up to the states.
    e. CMS indicated that the rights outlined in *Draft Rule AAA* are "fundamental" and should not be infringed upon for any reason.
3. There is additional evidence to support this interpretation in other sources:
    a. In the *Advance Notice of Proposed Rulemaking (ANPR)*, 74 Fed. Reg. 29453 (June 2009), CMS said that "[s]tandards for community living are to optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services." These core rights are essentially those outlined in *Draft Rule AAA*, not *Draft Rule BBB*.
    b. In the *Proposed Rule (NPRM)*, 76 Fed. Reg. 21311 (April 2011), CMS proposed that HCBS settings need to be "integrated in the community, provide meaningful

access to the community and community activities, and choice about providers, individuals with whom to interact, and daily life activities." These again are the rights outlined in *Draft Rule AAA*, not the rights outlined in *Draft Rule BBB*. In this issuance, CMS mentions "regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community" as things that would also prevent a setting from being HCBS, but it envisions these as factors it would consider without needing to be codified in the rule.

i. Comments from various participants: These rules, the comments, and responses were initially created for Community First Choice and Section 1915(i) waivers. They were extended to Section 1915(c) waivers at the last minute. This is not taking into account state statute and regulations. This is an overinterpretation.

ii. Department's response: The cited materials go back to 2009 and are specific to HCBS provided under Section 1915(c) waivers. The Department is aware of state statute and regulations but believes that the HCBS Settings Final Rule is aimed in part at updating such approaches. Even if the Department's approach is not required by the federal rule, it is allowed by it and is supported by strong policy considerations.

c. Ultimately, if the rights in *Draft Rule AAA* are not more important than those in *Draft Rule BBB*, they are at least not less important or less protected. People should have at least as much due process, including the opportunity of giving or withholding informed consent, before their exercise of these rights is restricted.

iii. These rights can be modified, if at all, with a process that is at least as protective of the individual's rights, and gives the person at least as much due process, as when their rights in *Draft Rule BBB* are modified. This is the approach that the Department proposes in the draft state rule.

1. There is evidence to support this approach in various instances of CMS guidance issued over several years, for example:

a. The Final Rule states that people have the right to integration in and access to the community. However, in the *FAQs Concerning Medicaid Beneficiaries in Home and Community-Based Settings who Exhibit Unsafe Wandering or Exit-Seeking Behavior*, CMS states that providers can use controlled-egress measures, which limit people's access to the community, if they use the same individualized process as they would use for modification of the rights outlined in *Draft Rule BBB*.

b. In the preamble to the Final Rule, CMS equates the use of restraints to a rights modification, to be handled like other rights modifications.

c. In its *Initial Approval Letter to Utah*, CMS says that if the state is going to allow restraints, it will have to require that all the federal criteria for a rights modification be followed, which would include informed consent.

i. Comment: Utah uses restraints in conjunction with behavioral support plans. Colorado does not currently allow for the use of restraints in plans, only in the person-centered plan, for which the person gives consent. Colorado already requires informed consent for any behavioral support plan that requires a restriction of rights.

ii. Department's response: to the extent that informed consent is already required in Colorado, the Department believes it should be obtained through a single streamlined process. Requirements for planning documents can be updated to conform to the Draft Rule.

d. In the *Colorado Systemic Assessment Spot Check*, CMS told Colorado that its existing rules on restraints were not consistent with the Final Rule and would have to change, ideally by not allowing restraints at all, but failing that, by treating them as a rights modification. CMS indicated to both Colorado and Utah that compliance with the applicable waiver is also required, referring to Appendix G for each waiver, which sets waiver-specific policies for restraints and restrictive procedures.

e. The Department wants to clarify the point of dispute between it and some of the workgroup participants on the issue of restraints. The Department has clarified based on CMS guidance* that providers can do what they need to do keep people safe during a crisis, subject to whatever constraints there may be in Appendix G of the applicable waiver or waiver-specific regulations, which in some cases may preclude the use of restraints or certain kinds of restraints. The gap between the Department and the workgroup participants is the procedure for what happens after the immediate crisis is taken care of. The Department is saying that the provider has to bring in the case manager and get an understanding of the individual's preferences going forward. The alternative is that the process could keep repeating without getting the individual's long-term buy-in about how they are treated. That position does not align with the evidence summarized by the Department.

* The following text (referenced but not read aloud during the meeting) is an example of CMS guidance the Department has reviewed: "If individuals place themselves or those around them in danger, we expect the state and provider to take the appropriate action necessary to address the situation. However, after the immediate crisis is resolved, we would expect a reassessment of needs to occur using the person-centered service planning process and an update to the person-centered service plan." (*Preamble to HCBS Settings Final Rule*.) CMS has also said: "there may be a need for immediate action in emergent or changing circumstances—that is the purpose of backup strategies. In thinking through risk, the planning team will identify temporary measures to be used if needed, and then update the plan when needs have stabilized." (*Id.*)

2. CMS has blurred the distinctions between the rights outlined in *Draft Rule AAA* and *Draft Rule BBB*, which gives further support for the Department's approach.
   a. The Final Rule does not expressly say that any of the rights outlined in *Draft Rule BBB* apply to nonresidential settings. However, CMS later stated that things like being able to access food at any time, visit with friends, and have physical accessibility are part of ensuring that HCBS participants experience day settings in the same way anyone else would, which is in turn a part of community integration and respecting people's privacy, autonomy, and individual choice (which are rights outlined in *Draft Rule AAA*). This position may be subject to question as a legal matter, but Colorado and other states have agreed with it as a policy matter.

i. There are examples on the Department website, on CMS's website, and various other states' websites. The Department has incorporated this approach into the FAQ guidance and the draft state rule.

ii. Comment: The Final Rule does not indicate that the *Draft Rule BBB* rights apply to nonresidential settings. It expressly states at *441.530(a)(1)(vi)* that these rights apply to residential settings. The state is overinterpreting the rule in saying that this process should apply to nonresidential settings, and this presents a challenge to the community because it is not clear what rules we are playing by.

1. Response: CMS has stated that these rights do apply to other settings. We agree that it is not an obvious interpretation of the Final Rule, but the bottom line is that CMS has indicated that these rights do apply to other settings and Colorado has agreed to that as a state. The Department also looked to other states when we were confronted with that question. (HCPF)
2. Follow up comment: This is concerning because providers are bound by rules and regulations, not the interpretations of those. This is a longstanding issue, particularly in the state of Colorado, where a rule or regulation states something and then a state authority says "we really meant this." In this case, we have a federal regulation that says "residential settings." I think it's a problem on the side of the rulemaking process to interpret it differently.
    a. Response: That does make sense. We think the answer is to make sure that the rule that we are currently drafting and codifying in Colorado is clear. That is what we are trying to do here. (HCPF.) Additionally, CMS has indicated that it considers the additional commentaries, subsequent guidance, training, conversations, and letters that it has issued sub-regulatory guidance. The state is required to follow that sub-regulatory guidance which is not in the original plain text of the law. Colorado is also allowed to add more restrictions than what is written in the federal rule, it just cannot be more lenient than what the federal regulation indicates. (PCG.)
    b. Follow up comment: The Developmental Disabilities Council supports the most expansive interpretation of the Final Rule and not a narrowing of the rule in any regard. This is the most important CMS rule of the past 30 years. It is time to not restrict what people are able to do in the community; do the hard work of training and preparing providers and people in the community to fully incorporate real choice. We strongly urge people to not more narrowly interpret the rules. This is a matter of human rights and also a legal matter.

b. The blurring of these two categories of rights supports having a single modification process for all rights. Otherwise, for example, there might be a full

rights modification process, including informed consent, for limits on access to food at someone's residential setting, but potentially a different, more lenient process for the same limits at the same individual's day program. It makes more sense for there to be a single rights modification process regardless of whether the setting is residential or not and regardless of whether the right is listed under *Draft Rule AAA* or *Draft Rule BBB*, given that CMS has treated some rights as being in both categories.

3. Comment: The reason that some individuals are under guardianship is because the courts have adjudicated that they cannot consent. They cannot go through the process with the case manager without an independent advocate. Everyone who is having their rights modified needs to have an independent advocate available to them, and that needs to be codified in the revised rule. Also, streamlining the process for making modifications to someone's rights should not mean that a modification necessarily applies everywhere. For the examples of needing a rights modification to not have access to food in the home and at work, they present the same issue, but they are vastly different contexts in the home and in the work setting.
4. Department's response: The Department is adding a provision to *Draft Rule CCC* to ensure individuals have the opportunity to include an advocate. The Department's references to streamlining relate to eliminating unnecessary, separate processes in its rules, not to creating a process that is overly quick or results in overly broad rights modifications. *Draft Rule CCC* requires any modification to be directly proportionate to the specific assessed need.

B. The Department has heard questions regarding what approaches other states have taken. Some states have basically codified the federal rule verbatim or even just added a cross-reference to the federal regulation and left it at that. But that alone does not establish how these states are approaching these questions, because as previously discussed, the federal rule by itself could mean any of several things, including no modifications for the rights in *Draft Rule AAA*. A workgroup participant drew the Department's attention to the following states.
   i. Utah was told by CMS that if it was going to allow restraints, it had to handle them as a rights modification, with documentation of informed consent and all the other rights modification criteria. In its regulations, Utah classifies restraints as Level II/III interventions, which can only be used in Behavior Support Plans, which in turn can only be implemented based on informed consent and approval by a specialized committee, which is not a rubber stamp lay committee. (*Utah Administrative Code Rule R539-4. Behavior Interventions.*)
   ii. Oregon provides that when restraints are going to be used, an "individually based limitation," which means a rights modification that includes informed consent, must be in place. *(OAR 411-004-0020 and 0040;* see also *OAR 411-051-0105.)*
   iii. Minnesota does not allow restraints at all. The providers there have figured out a way to safely serve people without restraints. If Minnesota can operate without restraints altogether, it is hard to see why limiting the use of restraints as the Department is proposing to do in Colorado would be the end of the world. (*CMS, Initial Approval Letter to Minnesota, June 2, 2017.)*
   iv. Tennessee has rules for certain provider types that prohibit admitting or retaining residents who require physical or chemical restraints, which effectively prohibits any planned use of restraints. For their programs serving people with IDD, restraints are included within behavioral safety interventions, and these need to be outlined in behavioral support plans,

which the HRCs review for informed consent (among other things). Restrictions may not be imposed without informed consent. *(Rules of Tennessee Department of Finance and Administration, Bureau of TennCare, Chapter 1200-13-01, TennCare Long-Term Care Programs; DIDD Provider Manual; FAQ on Human Rights.)*

v. Alaska allows restraints and restrictive interventions only as described in the person's care plan, which requires the person's informed consent. This is the only state under review where consent to the care plan is enough, as opposed to the other states that require some kind of separate, specific consent to the modification or the behavioral support plan providing for the use of restraints. *(7 AAC 130.229.)*
    1. Question: If CMS intended for the *Draft Rule AAA* rights to follow the same rights modification process, how did Alaska get approved?
    2. Department's response: The Department does not have insight into CMS's analysis of Alaska's statewide compliance. The Department has noted that there are several possible interpretations of the federal rule. It has also explained that even if its approach is not required by the federal rule, it is allowed by it and is supported by strong policy considerations.

vi. This analysis looks only at the informed consent part of the rights modification process; some states have other requirements, like the involvement of a medical provider, that are not captured here. This summary also focuses on planned uses of restraints, as distinct from unanticipated emergencies or crises, where everyone appears to be in agreement. Additionally, this analysis looks only at state regulations, but much of this process is also dictated by what each state has said in Appendix G of its waivers. Some states' waivers disallow any use of restraints in HCBS settings, even if that bar is not in the regulations, so there could be additional barriers to the use of restraints than what is presented here. In Colorado, some waivers are more restrictive than others on that front.

vii. The team from Public Consulting Group that is consulting with the Department is comprised of people who have held leadership and policy positions in state government as well as people who have operated service agencies. They have reviewed the Department's materials and presentations on rights modifications and informed consent and found them to be consistent with the CMS requirements and those that are being used by other states.

viii. The bottom line is that Colorado is well in line with the federal rule and with what other states have done in saying that providers can do what they need to do to keep people safe during a crisis, but after that, they need to get the person's buy-in as to how they are going to be treated going forward, including specifically getting their consent to any planned use of restraints through the full rights modification process.

IV. Development of Work Product Related to Informed Consent

Summary: in past meetings, participants indicated interest in the development of a template for an informed consent form to be used across all settings. The purpose of this part of the meeting was to determine current interest in the development of this template and what the process of development should look like.

A. Discussion
    a. Comment and question: IDD providers already use an informed consent form, but it would be useful to have some sort of guidelines for the Single Entry Point (SEP) entities and for non-IDD folks that do not currently utilize anything. Would it be useful for providers that already have informed consent forms to send their forms to the State to help develop a format that would work for everyone?

i. Response: This would be helpful. If participants want to send in informed consent forms already in use, the Department would appreciate it. The email to send in the informed consent forms is hcpf_stp.publiccomment@state.co.us. (HCPF.)

b. Comment: At our provider, we have the informed consent form attached to the modification itself, so the 8 bullet points that need to be a part of the rights modification are in the document, and at the bottom of it is a section on whether or not they agree to the modification. It has a signature for the client, guardian, and case manager.

c. Comment: A standardized consent form would be beneficial for everyone. From an advocacy standpoint, from a guardian standpoint, and from an HRC committee member standpoint, sometimes it is very difficult to maneuver through every agency's informed consent. A standardized form would be very helpful and it would also help identify whether an independent advocate has been involved in the process to help the person understand what they are consenting to.

d. Two additional comments that a standardized consent form across all settings would be useful.

e. Comment: If HCPF and the State of Colorado want to have a case system practice and wants to limit liability, it will have to be way more than a form. There will be nuanced training and there will be legal guidance about who can consent, and what the independent advocate does. It is blackmail for a provider agency to say that if the person does not consent to a rights modification, it will stop serving them. That is coercive. The commenter has concerns about the whole framework.

f. Comment: The process for developing the informed consent form should start from the basics of clearly defining the concept, then outline specific requirements (relating back to the settings rule and CMS) while considering the Department's training from one year and four months ago, and considering that there is already a definition of informed consent within regulations for HRCs as it relates to psychotropic medication, which is very different from this new definition. There certainly is a need for more streamlined work to ensure consistency and development of a standardized form for all providers to utilize. However, there needs to be a level of flexibility in any standardized form to meet the person's needs and level of understanding. There has been a wide degree of variance on the forms coming through the HRC; some include words, some pictures, some are more plain language, and some are very complex. A standardized form would need to address the person where they are, at their level of understanding. The commenter would like to help with the development effort as part of a small workgroup.

g. Additional comment expressing interest in participating in an informed consent workgroup.

B. Decision

a. There is interest in the development of a proposed or draft informed consent form, and the workgroup will revisit this topic in the next meeting. Workgroup participants were asked to submit informed consent forms currently in use, identification of any meaningful differences between forms (for participants dealing with multiple agencies' forms), and any current policies and procedures on how the forms should be completed.

V. Training Development

Summary: in past meetings, participants indicated interest in the development of trainings related to the Final Rule. The purpose of this part of the meeting was to determine current interest in topics for the trainings, the audience for the trainings, approaches for formatting/presenting each training, and how the trainings should be developed.

A. Discussion
   a. Several participants submitted training development worksheets from the last meeting. These are being reviewed, and participants that did not submit previously are encouraged to send their worksheets to hcpf_stp.publiccomment@state.co.us. The discussion on training development will continue in the next meeting.
   b. Participants were polled on their interest in the following training topics, which were suggested by workgroup participants, with the below results:

Training Topic Suggestion	Votes	Percent of Votes
Informed Consent	38	86%
Rights Modification Process and Best Practices for People Who Don't Consent	30	68%
Notice of Suspensions	23	52%
Dignity of Risk	23	52%
Training for CCB vs. PASA Roles	21	48%
Explaining to Individuals their Rights Under a Lease or Residential Agreement	20	45%
The Differences Between Suspension of Rights, Restrictive Procedures, and Safety Control Procedures	18	41%
Supported Decision-making	18	41%
CCB vs. SEP vs. CMA Roles	13	30%
Role of Guardians	13	30%
Landlord Tenant Law	10	23%
Property Rights	8	18%
Rule Making Process/Administrative Procedures Act	8	18%
Rule of Law	5	11%
Supervisor Guidance	3	7%

   c. Question: I am confused by the topic of training around rights suspensions, rights restrictions, and safety control procedures. Are these not all rights modifications now? Are the previous terminologies still going to be used? (The Department addressed this question at the following meeting.)
   d. Comment: Training on informed consent should cover the full spectrum of consent across different areas (i.e., rights and the use of psychotropic medications).
   e. Comment: Training on the required elements for informed consent would be useful.
   f. Comment: The Department should convene a training development group that includes self-advocates from Speaking for Ourselves Colorado and the Colorado Developmental Disabilities Council to develop and pilot training for people with intellectual disabilities who are currently receiving services. The training should be available in English and Spanish and should not be made available online. A good organization to work with would be AbleLink Smart Living Technologies in Colorado Springs. This is an organization that makes software more accessible to people who have visual disabilities.
   g. Additional comment suggesting that Speaking for Ourselves be included in the development of training materials.

h. Comment: There should be training for the people whose rights are going to be modified, including on supported decision-making The Colorado Developmental Disabilities Council has a guide about supported decision-making and will send that to the Department. Also, the informed consent process should be elevated in importance and not handled as a routine or administrative matter.
i. Comment: Case management agencies and providers need to be trained together on the requirements. And the training(s) should reinforce that the case manager is the one who collects the informed consent.
j. For the next meeting, participants were asked to bring their thoughts about what the trainings should look like for the top-ranked topics, such as ideas about the key points to be covered and any variations based on the audience for the training.

VI. Closing Remarks

A. The Department acknowledges and appreciates everyone's commentary on the Draft Rule and participation in the workgroup. Some participants have asked why we are still doing this while everyone is dealing with COVID-19; the reason is that CMS has not extended the deadline for coming into compliance with the Final Rule, and these rights are important to people. A day of delay is a day that they do not necessarily have all their rights respected. It is important to the Department and to the waiver participants that we keep moving forward. We are really grateful that everyone made the time to join this meeting.
B. Comment: Suggestion to use Adobe Connect so that participants do not have to use both the phone and the computer.
C. Comment: Adobe Connect or Microsoft Teams would be a much better platform. This one feels very outdated and keeps everyone separated.
   a. Response: These comments were noted, and for the next and final meeting, the chat box will be viewable by all participants.

VII. 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 #5) will take place on Wednesday, June 10, 2020 from 12:00 to 2:00 p.m. MT.