HCBS Settings Final Rule
Rights Modification Stakeholder Workgroup – Meeting #5
Meeting Minutes

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

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I. Meeting objectives

Summary: participants agreed on the following objectives for the meeting:

A. Review group members' training suggestions for possible inclusion in a future HCBS Settings Final Rule training plan;
B. Identify policies and guidance to be included on a standardized template for obtaining informed consent;
C. Share best practices for obtaining informed consent for various rights modifications, or determining that rights modifications are not needed; and
D. Identify remaining action items to finalize draft rule and prepare for its release for public comment.

II. Training Development

Summary: in past meetings, participants indicated interest in the development of trainings related to the HCBS Settings Final Rule. The purpose of this part of the meeting was to review the topics of interest for those trainings and discuss how the trainings should be developed and presented.

A. Review of Suggested Training Topics and Discussion
   a. Participants in the fourth rights modification stakeholder workgroup suggested and voted on training topics. For the fifth meeting, the Department consolidated similar topics and updated some wording for clarity. The topics are listed below in approximate order of popularity, keeping in mind that with the now-consolidated topics, participants may have voted for one or both of the original topics.

Training Topic Suggestion
Differences between rights suspensions, restrictive procedures, and safety control procedures; comparison to federal requirement of informed consent for any rights modification
Individual rights under a lease/residential agreement, landlord-tenant law, property rights, etc. + explaining these rights to individuals
Informed consent
Different roles of CMAs (CCBs + SEPs) vs. providers (PASAs and other providers)
Rights modification process and best practices for people who don't consent
Dignity of risk
Supported decision making
Role of guardians
Rulemaking process/Administrative Procedures Act
Rule of law
Supervisor guidance

   b. General discussion of training topics
      i. Comment: these training topics are spot-on. It is clear what needs to be clarified and trained on. Also, it is good to have a PowerPoint in front of each person and also have dialogue time at the end of the meeting, as that real-life discussion can be more valuable than the actual training.
      ii. Suggestion: Consider different audiences for trainings, especially self-advocates and family members.

1. Response: Agreed. This discussion is not just about training for providers/staff and case managers. (PCG.)

iii. Question: How will the training on the differences between rights suspensions, restrictive procedures, and safety control procedures work if rights suspensions and restrictive procedures are going away—how does it make sense to train on them?
   1. Response: The training for this topic would not be a "how to" for the older concepts, but rather would explain how the older concepts worked compared to how things will work moving forward in accordance with the Final Rule. (HCPF.)

iv. Comment: Supported decision making should be among the top priorities. It is a strong, protective method to use before individuals even need to get to guardianship. There should be training on this alternative to guardianship.

v. Comment: The Colorado Developmental Disabilities Council has resources in English and Spanish on supported decision making, which can be found here (English: http://www.coddc.org/Documents/SDM%20Web%20Version.pdf, Spanish: http://www.coddc.org/Documents/SDM%20Spanish%20Web%20version.pdf)
   1. Question: Do these materials include a legal definition of supported decision making? There are trainings on this topic that do not include a legal definition.
      a. Response: When there is state legislation, the term is defined on that basis. Colorado does not currently have a statute defining supported decision making. (Bob Lawhead, Colorado Developmental Disabilities Council.)
      b. Comment: The National Resource Center for Supported Decision-Making, http://www.supporteddecisionmaking.org, is an excellent resource for states that have adopted legal definitions and plans for supported decision making.

c. Suggestion: Create a training review workgroup to assess training materials prior to dissemination. The training review workgroup should include service providers, advocates (including self-advocates), family members, and individuals receiving services. It is especially important to include individuals and families. The Colorado Developmental Disabilities Council has published guidance for the creation of training materials to ensure that that they are accessible to family members and self-advocates that could be useful in the development of these trainings. In addition to conducting this review process before dissemination to a broader audience, it can be helpful to include graphics.

i. Response: This is a helpful idea. The Department invites volunteers/suggestions regarding people who might be involved in this process. (HCPF and PCG)

ii. Comment: The Department should consider including Speaking for Ourselves Colorado, the state's self-advocacy group, in the training development process.

iii. Question: Are there going to be separate workgroups for training development vs. review, materials for some audiences vs. others, etc.??
   1. Response: There is not a charter or program for training development workgroup(s) yet, but there should be room for individuals to participate at any level they feel comfortable. If workgroup members want to give input on the training development process, indicate their level of interest in participating, or provide examples of trainings or other relevant work product, please submit it to hcpf_stp.publiccomment@state.co.us. (HCPF and PCG.)

iv. Individuals that expressed interest in participating in training development during the meeting were noted and are listed below.
   1. Bob Lawhead
   2. Regina DiPadova

3. Jen Martinez
4. Travis Wilson
5. Brandi Griffiths
6. Anaya Robinson
7. Kari Easterly

v. Individuals that expressed interest in participating in training development after the meeting are listed below.
1. Michelle Gaumond
2. Jan Rasmussen
3. Caitlin Looney

B. Next steps
a. The Department will be developing a training plan. There was more interest for the items that are higher on the list than those than are lower, although the vote tallies are not exact. This list is not a strict mandate, as the Department may need to add or subtract topics. For example, as Nonresidential providers complete their Provider Transition Plans (PTPs), the Department may identify a need for more compliance-oriented trainings targeted at frequently seen compliance issues. But the Department does value seeing the workgroup's overall priorities and will going forward with this list in mind. Again, if participants have presented or attended good trainings on these topics, please share those materials for reference.

III. Informed Consent Draft Template and Guidance

Summary: in past meetings, participants indicated interest in the development of a template for informed consent forms. The purpose of this part of the meeting was to review and obtain participants' feedback on a draft informed consent template with built-in guidance developed by the Colorado Department of Public Health & Environment (CDPHE), with input from HCPF, based the two departments' experiences in reviewing (a) templates currently in use as well as (b) commonly seen best practices and pitfalls in filling out such forms. The draft template/guidance displayed on-screen during the meeting was sent to workgroup participants after the meeting, on June 11.

A. General guidance on use of the draft template, presented by CDPHE
a. Before the form is filled out and a rights modification is made, there should be a thorough conversation regarding why a certain behavior or need constitutes a basis for a rights modification.
b. The draft template includes detailed guidance in italics on how the form should be filled out. When using the template, the guidance in italics should be removed.
c. The form must be filled out accurately and completely. After it is filled out, the case manager and the individual as well as any guardian, advocate, or other legally authorized representative need to take a close look at the form to ensure its completion and accuracy.
i. Question: How do you define "other authorized representative" in regard to giving consent?
1. Response: The informed consent form is a legal document. There is a unique statute pertaining to people with intellectual and developmental disabilities that allows for an authorized representative to assist with accessing and managing certain services. While that representative would likely be part of the process and help with explaining the rights modification to the individual, they do not have the legal authority to sign the informed consent form. (CDPHE.)

d. The form should clearly, thoroughly, and respectfully outline every step of the rights modification process. The form should be in plain language.
e. There is no need to cite statutes or regulations except if that is requested by the advocate, individual, or case manager.
f. Rights modifications need to be reviewed at least every year, if not more often. If the review must be at least every six months, as under certain waivers, say that on the form. This is not just a form; it is also a guidance tool for review of the rights modification. The review process needs to be tailored to the individual. There should be continuing conversations about why the right was restricted and evaluation of the interim steps to restore rights that are outlined in the plan. It should be made clear that if the individual consents to the rights modification, they have the right to withdraw their consent at any time.
g. The case manager, individual, and guardian or legal representative (if applicable) must sign the informed consent form. The provider does not sign the form or include information about staff training or staff requirements for implementing the rights modification, as this type of information is handled separately.
h. The informed consent form is intended to be aligned with the person-centered service plan (currently in the Benefits Utilization System (BUS), eventually in Aerial). The Department is aware of the need for the information collected on the form to correlate to the fields in which the case manager will type the summary. It is keeping track of this issue in case changes are needed. (HCPF.)

B. Informed Consent Guide: *Section 1. Description of your proposed Rights Modification*
   a. Rights modifications must be highly individualized in approach.
   b. This section must clearly outline how the right will be modified. For example: "your right to privacy will be modified in that you will not lock your bedroom door, in case staff need to come in to help you during a seizure. Unless there is concern that you are having a seizure, staff will always knock and ask permission before entering your room."
C. Informed Consent Template: *Section 2. The reason for your Rights Modification, based on your assessed needs*
   a. Rights modifications should only be implemented for assessed needs. For example, it is not appropriate to complete a rights modification because an individual's family has requested it if there is no assessed need for the modification. As another example, it is not appropriate to use a rights modification to address something that was a concern once, 15 years ago, in the absence of evidence that the concern is still present.
   b. The reason for the rights modification must be clearly outlined. For example: "you have used the internet to interact inappropriately with strangers."
   c. The rights modification outlined in the form must be proportionate to the concern. For example, if there is a concern that someone will get up during the night, they might need an alarm on their door during the night, but not all the time.
D. Informed Consent Template: *Section 3. Other ways you have been supported that have not worked on their own*
   a. This section must document positive interventions and supports that have been implemented before the rights modification needs to be put in place. The interventions and supports are not leading to the needed result. For example: "you have tried to practice self-monitoring techniques for making healthy food choices."
E. Informed Consent Template: *Section 4. These are things you can do to have your rights restored, and how your service provider will support you and track how you are doing.*

   a. This section should outline interim steps and goals with clear guidance on how an individual can have their rights restored. Instead of an all-or-nothing approach, explain how the individual can start to get some more control. Every step should have individual input. For example, if an individual has Prader-Willi syndrome, instead of simply saying that they will have this condition forever and therefore they can only ever have carrots and celery sticks available, ask what food they would like to be available to them for an interim step to full access to all foods.

F. Informed Consent Template: *Section 5. This is how the Rights Modification will affect your daily life, and how your staff will support you to avoid harm and discomfort because of the modification.*
   a. There is inherent harm when you are taking away people's rights. This section should outline accommodations that providers make to be flexible about taking away rights. There should be reassurance that the rights will not be totally taken away. For example: "Since you will not be allowed to watch some types of shows on TV, you will get to choose from other appropriate options."

G. Informed Consent Template: *Section 6. You do not have to consent to this proposed Rights Modification. Here are some other options*
   a. This section should clearly explain alternatives to the rights modification that are available, including significant likely consequences that accompany those alternatives. For example: "if you do not agree to this restriction on your internet access and you continue to communicate inappropriately with strangers, you might get in trouble with the law."
   b. If it is relevant, state that the service provider might seek to terminate services for the individual, and that the individual may arrange to receive services from a different provider or at a different setting. The case manager must help the individual understand these options.
      i. This statement should be carefully considered and applied only on an individual basis. The provider should not preprint a standard, blanket statement that says, "if you do not consent, you will not receive our services anymore."

H. Feedback on the informed consent template
   a. Comment: This form is very well done. Thank you!
   b. Comment: I love the guide components and the person-centered language and approach.
   c. Comment: I would appreciate consideration of how to communicate these things to non-readers, such as expanded graphics, photographs, and perhaps the presence of people who know how the person communicates.
      i. Response: State staff have researched this issue and will include guidance in a training and/or the template itself. (CDPHE)
   d. Comment: Sometimes parents sign these kinds of forms for individuals even though they do not have legal guardianship. The training and form should address who is able to consent or sign off on the form.
   e. Comment: A persistent issue is the rights modification itself may make sense, but it goes on for an unreasonably long time. This issue should be addressed in training.
      i. Response: Agreed. There are two questions about duration: (1) how long should the rights modification last, and (2) how often should it be reviewed. (CDPHE.)
   f. Question: Are there other models from other states that implemented rights modification that we can look at?
      i. Comment: This site (http://supporteddecisionmaking.org/events) has a lot of great information and downloadable presentations from national boards and different states.
      ii. General guidelines from other states include making sure that there is enough justification for the rights modification and that there is a solid plan at the outset for getting the

restriction lifted. The review of the rights modification should not be a one-time process; if the person starts to demonstrate improved skills during the year, there should be an objective metric and trigger to roll back the rights modification before the end of the year. Additionally, every step of the rights modification process should be based on person-centered planning. (PCG.)

g. Question: Will this informed consent template with guidance be shared with the workgroup?
    i. Answer: Yes, and participants are invited to send comments to hcpf_stp.publiccomment@state.co.us. (CDPHE, HCPF, and PCG.)

I. There is no need to redo informed consent forms if they already contain the required information. This proposed template is for use going forward.

IV. Draft Rule Wrap-Up

A. Question (early in the meeting): Will there be more time to review the listening log and updated draft rule and provider more comment?
    a. Department's response: Yes. Timelines will be addressed later in the meeting.

B. This series of workgroup meetings and the contract for PCG to facilitate them are coming to an end. However, this is not an end to the conversations about the Draft Rule; there is a plan to hold further meetings throughout the summer to have continuing conversations, as well as a plan to keep adding to the listening log and updating the Draft Rule. An in-progress listening log and a copy of the updated Draft Rule were sent out on June 9 so that participants could see the progress made to date. It took time to have various staff within the Department look at the comments and respond to them. The Department has incorporated some feedback from the group into the Draft Rule and would appreciate reactions to the changes made so far. For example, the Department has added a definition of "age-appropriate" to the Draft Rule. If you would like to send in comments, please send them to hcpf_stp.publiccomment@state.co.us.
    a. There is more to come on this discussion and there are more comments and feedback from the last meeting and from written submissions that need to be incorporated. The next version of the Draft Rule and listening log will address these items and will be shared with people for further review and comment this summer. People will have a chance to see these updates this summer. The Draft Rule is not going straight to the Medical Services Board; the Department intends to do that this fall or winter but first wants to provide updates so that people are able to comment on each iteration.

C. There have been some conversations about whether parts of the Draft Rule are duplicative of provisions in 10 CCR 2505-10 8.600. The Department recognizes this concern but cannot delete the other regulations until the new rule is in place. It is important to have everything laid out in the Draft Rule because the Draft Rule applies to all settings and all waivers. There is a plan to then conform/delete existing regulations as needed.

V. Informed Consent Best Practices

Summary: Some of the comments in the listening log express the idea that "if we ask an individual for their consent to a rights modification that we think is necessary for their health or safety, they will say 'no'." The Department is interested in creative solutions providers and others with experience in this field have come up with to tackle these situations in the past. Participants were asked to share situations in which they thought they could not get consent, but were able to, and/or situations in which they were able to avoid a rights modification altogether.

a. Comment/Questions: Our current model puts a huge responsibility on providers to guarantee individual rights and health and safety. We have real concern for situations in which there is liability for provider agencies for allowing people to not consent to a rights modification and then they experience a negative outcome. Are we willing to allow people to have the same kinds of outcomes that non-HCBS participants would have, regardless of the severity of the outcome? For example, a person who has diabetes but does not want to follow their prescribed diet may die as a result of that. How do we deal with that?
    i. Response: Striking the balance between keeping people safe and maintaining their rights happens in the person-centered planning process and documenting that you have educated the individual and that you have done appropriate staff training. (PCG.)
    ii. Comment: HCPF should respond. Providers will be accused of allowing people to make dangerous decisions that they should have prevented with more restrictive practices.
    iii. The Department cannot tell providers what their comfort level or liability is. The Department can say what it can and cannot pay for through the Medicaid program. The federal rule is clear that the individual decides what kind of risk and how much risk to accept and how they want the provider to support them in mitigating that risk. The only situation in which it is not up to the individual is if there is a guardian appointed by the court, and as some workgroup participants have pointed out, guardianship is not the be-all, end-all, and alternatives like supported decisionmaking should be considered. In the end, if the provider does not agree with the individual about what risks are acceptable, the door is still open for the provider to say that it is not comfortable serving the individual anymore and to initiate the process for terminating services. (HCPF.)
    iv. Comment: Providers have had person-centered thinking training. The assumptions of not being educated on this topic, not being on the same page as the Department's values or not willing to be creative are frankly offensive. We have lots of issues with who can consent, what they understand, how we fully support dignity of risk without getting sued, and "terminating" someone when we are uncomfortable.
b. Comment: Providers are used to focusing on health and safety, and the rules have historically put a big responsibility on providers to do that. When individuals have a right to take risks, there can be a bad outcome. This is a new world for providers.
c. Comment: We are trying to find a way to spread the potential legal liability among other people. For years, we have focused on health and safety instead of the amount of risk the individuals are willing to take. We could develop a procedure to follow if an individual wants to make a decision that could be risky to their health. That may involve incorporating an ombudsman, advocate, or human rights committees in the process to spread the review around, so the provider agency is not solely responsible for allowing people to make their own decisions.
d. Comment: Although the suggestion about bringing in an ombudsman/advocate is good, this is not just a matter of legal liability. The issue is whether we are ready to go all-in on supporting individuals' rights to make their own decisions. There is a whole set of choice-making that we have as people that carries greater risk for negative outcomes. We have to be prepared to make these decisions and understand what that means for an individual. We do not want to give people a take-it-or-leave it false choice of having to consent to the rights modification or stop getting our supports. We need a safer option. We have to commit to saying that we are going to support that person even though they are going to make decisions with negative outcomes. We need help with the decisionmaking process, to help them understand the risks and benefits and make good decisions.

i. Response: The ideas of expanding supported decisionmaking and/or the ombudsman program are on the Department's radar. Staff are not aware of current initiatives to expand/fund such programs. It seems clear that such expanded programs will not be in place before statewide compliance with the federal rule is required. (HCPF.)

e. Comment/Question: Providers have been able to be creative and have successes. The comments about what to do if a person does not consent to a rights modification come from experiences where there are not successes that we have been able to find. There is an example about pica in the listening log that was not responded to that is a great and pertinent example. Can this example be addressed?
   i. Response: CMS has been clear that pica is a situation where the rights modification process would apply. Have people navigated that situation and gotten consent? If the individual does not consent, how have people navigated that situation? (HCPF.)
   ii. Follow-up comment: Under our current model, providers do not feel supported to make that decision. The Department should tell providers what to do. If someone decides to consume something that will put their life at risk and will not consent to modifications, what would you do?
   iii. Response: These questions and the techniques for dealing with them are not new. We have always had to weigh the risk and balance that risk with the rights these individuals have. We have always had to balance what is important to the individual and what is important for them. The difference is that right now, individuals do not officially have to consent to rights restrictions. We do not have a lot of examples where providers have allowed individuals the dignity of risk and people have made decisions that compromise their health and safety. However, there are providers in Colorado that have always been getting informed consent and individual buy-in, even for rights suspensions that could simply be noticed under the rules. Providers have figured out ways to do this. And other states have done this. It is not necessarily the case that all the other states that have implemented this rule have adopted expanded ombudsman, supported decisionmaking, or other third-party programs. There is a way to figure this out. The Department appreciates that it is a challenge, but we can take a step back and examine past practice in the state and in other states and see that it can be done. (HCPF..)
   iv. Follow-up comment: There is a New Jersey organization that supported a gentleman through some poor decision making for diabetes, and he had to have limbs removed as a result of that decision making. Is that the route we want to go down? I want to be the agency that says "we are going to support you regardless of whether or not you accept the rights modification," but CDPHE is not known for supporting poor outcomes for people. The current model is protecting people from making poor choices. Providers and case managers need to know that these kinds of decisions will be supported by CDPHE.
   v. Question: We do agree that this is an ongoing conversation. What would you currently do in this situation? (HCPF.)
   vi. Response: Currently, if unapproved food is found in the person's apartment, we might remove it, discuss why it needs to be removed, or we might not buy the food that is not on the approved diet. Right now, we are not required to get consent for this. This is in accordance with the model that CDPHE employs; it is a model that protects people from making poor choices. The regulation does not allow for dignity of risk for the individuals served. If we are going to allow people to make choices that may have negative outcomes, the model used by CDPHE needs to change. Regulatory guidance needs to align with the rights modification process and informed consent outlined in the rule.

vii. Response: The commenter is requested to send the Department the citation(s) to the CDPHE regulations that do not allow any negative outcomes to ever occur. (HCPF.)
viii. Comment: It is the state's job to identify these regulations.
ix. Response: The Department created an extensive Systemic Assessment Crosswalk for that purpose, in an effort to analyze what parts of existing regulations and other authorities would have to be changed to create consistency with the federal rule. The crosswalk was put out for public comment. If the Department missed anything, please let us know so that we can take it into account. CDPHE is going to survey according to the rule that is adopted. (HCPF.)
x. Comment: Anyone at CDPHE can identify the rule at issue, which says that group homes may not allow people to be alone or unsupervised at any time. The state agencies have to be aligned. The rule needs to be consistent with rule of law.
xi. Response: There is agreement that the rule needs to be consistent with the rule of law. The Department's Draft Rule is consistent with the rule of law. If we missed a citation that needs to be conformed, we will work to identify and fix it. This task is doable. (HCPF)
xii. Comment (different commenter): The regulation in question is *10 CCR 2505-10 8.076.1.7.c: The Provider, either by omission or commission, is endangering or has endangered the health, safety, or well-being of a program services client or clients.*
xiii. Comment (different commenter, via email): The regulation in question is *6 CCR 1011-1 Chapter 8, 6.6: The administrator shall ensure that there is sufficient trained staff on duty to meet the needs of all residents at all times. A resident may be allowed to remain unsupervised in the facility only when certain criteria are met*.

f. Suggestion: It seems that a lot of concern here is legal and about who can and cannot consent. There should be an informed consent workgroup with people with more legal expertise that can help work out the gray area about who can consent and whether they really understand their options and the risks.
i. Participant comment: That makes a lot of sense because the guidelines should fall within the professional areas of expertise of the people establishing them, and be appropriate to the rule of law.
ii. Response: There is agreement that the rule needs to be consistent with the rule of law. It is consistent with law. In terms of expertise, at least one HCPF staff member in this group is an attorney, and others in this group are lawyers. Other HCPF and CDPHE staff as well as many participants in this workgroup have experience in the field as providers and case managers. (HCPF)

VI. Next Steps and Closing Remarks

A. Rhyann Lubitz is the Case Management and Quality Performance section manager at the Department. The Case Management and Quality Performance section has received recommendations about human rights committee trainings, policy, and procedures, and will be holding stakeholder workgroup meetings in the late summer or early fall. She will send out invitations to the distribution list from the Rights Modification Stakeholder Workgroup. Participants are welcome to attend.
a. Travis Wilson and Chris Lawson expressed interest in participating.
B. The Department thanks everyone for their time and commitment to this important effort, which has been a real challenge, especially with technical issues and COVID-19. Your contributions have been incredibly important to the development of the rule, informed consent forms and related guidance, and a training plan. It has been invaluable to hear all the diverse views, the questions you raised

and the challenges and disagreements with us and with each other that helped us identify gaps in our approach or in explaining our approach to you all. We and most importantly all of our waiver participants will all reap the benefits of this work as we move toward full statewide implementation of the rule, which is the end game here—making all of these rights meaningful, and real, and workable for everyone in this ecosystem.

C. In terms of what participants can expect to see next with all of this work:
   (1) The Department will post the meeting minutes online once we have a full set after this last meeting. The minutes from meeting 4 are still being finalized, as the meeting schedule got compressed at the end.
   (2) Participants can send in comments on the updated Draft Rule shared on June 9, as that is still very much a work in progress—please let us know if we missed anything in the revisions to date (keeping in mind that in some cases we just have not gotten to the comments received in earlier meetings/written submissions—bear with us). Send comments to the STP public comment inbox at hcpf_stp.publiccomment@state.co.us.
   (3) Participants will see an updated version of the rule, along with the more completed listening log. We are planning to host another meeting where you can provide comments again, so if we missed anything in revising the rule by that point, you can let us know. We might host separate meetings for providers, case management agencies, and advocates/other stakeholders, as is currently being done for the Department's weekly COVID-19 webinars, to allow for more robust and candid conversation within those cohorts.
      a. Comment: The online format at times has not felt very transparent. The feedback groups should not be split apart. Regulations are stronger with a robust process, not a segregated process.
      b. Response: That is interesting, and the format for the next series of meetings is not necessarily definite. The main point was that the conversation on the Draft Rule will continue. (HCPF.)
   (4) And then the rule will go to the Medical Services Board for formal public notice and comment in fall/winter. We want to continue engaging and hearing your comments this summer, before the fall/winter.
   (5) Separately, the Department will be working to revise the informed consent form/associated guidance based on the feedback received today and that we hope participants will send to the STP public comment inbox, and we will be putting that out for statewide use.
   (6) The Department will also be working with our contractor to finalize a training plan and present more trainings in the coming months. This work will take into account the ideas and suggestions participants have provided.

D. There is additional time for materials and "homework assignments" sent out to participants to be completed and sent in. The Department welcomes feedback and wants everyone to take the time they need to complete it and send it in whenever they can.