

Individual Rights and Rights Modifications

Colorado Department of Health Care Policy & Financing

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Presented for providers and case managers

Trainer Introductions



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Training Objectives

1. Provide a refresher on the Home and Community Based Services Final Rule
2. Recap individual rights
3. Outline the rights modifications process and introduce the state's template
4. Provide answers to common questions



Agenda

1. Refresher on the HCBS Rule
2. Individual Rights
3. Person Centered Planning Skills
4. Individual Rights Modifications
 1. Template for documenting required information
 2. Answers to common questions
5. Supporting Individuals Engaging in Self Advocacy
6. Informed Choice
7. Resources



Refresher on the HCBS Final Rule

Background

How is the CMS HCBS Settings Final Rule often referred to?

The Final Rule or the Settings Rule

What is the official title of the published rule?

Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice (Section 1915(k) of the Act) Home and Community-Based Services (HCBS) Waivers (Section 1915(c) of the Act)

When was the Final Rule published?

The Final Home and Community-Based Settings Final Rule was published by CMS in 2014

When was the effective date of the Final Rule”

March 17, 2014 – however, there is a transition period, which we are still in



Overview of the HCBS Settings Final Rule



To “ensure that individuals receiving services through HCBS programs have **full access to the benefits of community living.**”



To “further expand the opportunities for meaningful community integration in support of the goals of the **ADA and the Supreme Court decision in Olmstead.**”



"To enhance the quality of HCBS and **provide protections** to individuals receiving services."

Colorado Home- and Community-Based Services Settings Final Rule

Colorado is working on adopting a state version of the federal rule.

These rules identify individual rights that are protected at settings where people with disabilities live or receive HCBS. They also set out a process for modifying these rights as needed in individual cases.

You can participate in this process. When the State is ready to put this rule forward, they will publish a notice saying how people can get a copy to review and provide comments.



Individual Rights

What are Disability Rights?

Examples of the rights that people with disabilities have:

- Be treated as equals
- Be treated with respect
- Choose where they live
- Make choices about their lives
- Go to school and choose where they go to school
- Work
- Get married and have children
- Vote
- Claim their human rights



What are HCBS rights?

The HCBS Rule reinforces these rights for people with disabilities:

- Live and interact in the community with people without disabilities
- Choose where to live and where to receive services
- Choose what supports they want and who provides them
- Be in control of their life
- Have respect and privacy
- Not be restrained or secluded



What are HCBS rights? (continued)

In most cases, people with disabilities have these additional rights:

- Be protected against eviction, like other tenants
- Have a private place to store their things (lock their room, have a locker at day program)
- Choose their roommates
- Decorate their room how they like
- Be able to physically access all parts of their home
- Control their daily schedule
- Have visitors and use their own phone/tablet at any time
- Eat at any time



Person-Centered Planning

Person-Centered Planning Requirements



The Final Rule requires a person-centered support plan for each individual receiving services.



The person-centered service plan must be developed through a person-centered planning process that is driven by the individual.



Person-Centered Planning Requirements

The HCBS Final Rule establishes the following requirements for Person-Centered Service Planning:

Directed by the individual to the maximum extent possible.

Planning teams consist of people chosen by the individual.

Occurs at least annually and at the times/locations that are convenient for the individual.

Reviews/revised when circumstances change or at request of the individual.



Dignity of Risk

People with disabilities have the right to make a choice even if it could have negative consequences for them.

- There is a balance between safety and risk.
- A good life includes making choices with some risk. If things turn out poorly, we learn from that.
- Informed choice is a process to ask questions, gather information, and understand any potential consequences before you make a decision.



Individual Rights Modifications

Rights Modifications

Sometimes it can be risky to exercise rights. If the risk makes you or someone else unsafe, you may want to limit how much you exercise that right.

- Getting help to be safe sometimes changes your rights.
- Rights can only be modified if other ways to help were already tried.
- Rights can only be modified for one person, not for a group
- Any modifications to rights need to be documented in the person-centered plan.



Modifications

Modifications to any of the additional standards must be made on a case-by-case basis, and they must be documented in the person-centered service plan.

- A specific and individualized assessed need.
- Positive interventions and supports used prior to any modification(s).
- Less intrusive methods of meeting the need that have been tried but did not work.
- Clear description of the condition(s) that is directly proportionate to the specific assessed need.



Modifications (continued)

Modifications must be documented in the person-centered service plan.

- Determine how staff will mitigate the individual having a right modified
- Established time limits for periodic reviews to determine if the modification(s) is still necessary or can be terminated.
- Informed consent of the individual supported.
- An assurance that interventions and supports will cause no harm to the individual.
- Review data to measure the ongoing effectiveness of the modification(s).



Here is an example of a rights modification

Anna has a disability. Anna gets HCBS in a group home. Her provider owns the group home.

Anna's disability makes her always hungry, no matter how much she eats. Anna would get sick if she ate each time that she was hungry. She likes doing other things besides eating. Eating interferes with the other things she wants to do like going to work.

The HCBS Rule says people can eat whenever they want. This does not work well for Anna.



Here is an example of a rights modification (continued)

Anna works with support staff to eat at certain times. This does not work. Anna still eats too much and gets sick. Anna decides she needs help to stop eating so much.

Anna gathers her person-centered planning team to have a meeting. Anna and her planning team decide that she can only eat at certain times.

This gets put into Anna's person-centered plan. Anna is happy that she will not get sick and can do other things with her day.



**Colorado requires  informed consent
for a rights modification**

Informed Consent

1. Description of your proposed Rights Modification for the period ___/___/___ - ___/___/___
2. The reason for your Rights Modification, based on your assessed needs
3. Other ways you have been supported that have not worked on their own
4. These are things you can do to have your rights restored, and how your service provider will support you and track how you're doing
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
6. You do not have to consent to this proposed Rights Modification. Here are some other options.



Informed Consent – example

1. Description of your proposed Rights Modification for the period 7/1/21 - 12/31/21

Your right to eat at any time you want will be modified in that you will only be able to eat at certain times outlined in your person-centered plan.

2. The reason for your Rights Modification, based on your assessed needs

You have Prader-Willi Syndrome and with free access to food, you have been eating to the point of becoming sick

3. Other ways you have been supported that have not worked on their own

You have tried to practice self-monitoring techniques to only eat at certain times. You tried this for the past 6 months.



Informed Consent – example

4. These are things you can do to have your rights restored, and how your service provider will support you and track how you're doing

You will get to choose some foods to always have available and staff will suggest and help support you to not eat it all at once, and as that improves (meaning that staff observe you are able to stop eating those foods after 1-2 portions in a sitting), more choices will be available.

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

Since you will only be allowed to eat at certain times of the day, you will get to choose which times of the day you want to eat and what you want to eat.

6. You do not have to consent to this proposed Rights Modification. Here are some other options.

If you do not agree to this restriction on your access to food, you can eat whenever you want, and you may experience sickness and uncontrolled weight gain, which has made you uncomfortable in the past, and which could create the following health risks: diabetes, obesity, high blood pressure, poor sleep quality, high cholesterol, and heart disease



Rights Modifications - Key Takeaways

- ✓ Rights should be known
- ✓ People with disabilities should have assistance, support, and knowledge to exercise their rights
- ✓ Any modification must be individualized and supported by a specific assessed need and justified in the person-centered service plan
- ✓ Any rights modification must be documented in the person-centered service plan
- ✓ Any rights modification must have a completed informed consent document



Rights Modifications – Common Questions from Providers and Case Managers

- ✓ This is something I used to handle as a rights suspension. What is changing?
- ✓ This is something I used to handle as a restrictive procedure. What is changing?
- ✓ This is a "medical restriction" that is being implemented under doctor's orders. I never used to treat it as a rights suspension or restrictive procedure. What is changing?
- ✓ I work with individuals covered by the Human Rights Committee. What is changing?



Rights Modifications – Common Questions from Providers and Case Managers

- ✓ I don't work with individuals covered by the Human Rights Committee. What is changing?
- ✓ What if the individual has to follow this restriction because of a court order?
- ✓ What if the individual does not consent?
- ✓ Are there different rules for adults and minors?



Resources

History of Disability Rights

Through the efforts of many people, including ADAPT in Colorado, disability legislation was fueled by the Civil Rights Movement and includes:

- The Rehabilitation Act (1973)
- Education for all Handicapped Children Act (1975) replaced by IDEA
- Individuals with Disabilities Education Act (1990)
- The Americans with Disabilities Act (1990)
- *Olmstead v. L.C.*, 527 U.S. 581 (1999)
- Developmental Disabilities Assistance and Bill of Rights Act (2000)
- HCBS Rule (2014)



Adapted from the New Mexico Department of Health Know Your Rights Campaign <https://www.nmhealth.org/publication/view/presentation/3806/>



Helpful Resources

➤ **Speak Up Colorado**

Speak Up is a class designed to teach people with disabilities to lead their own Person Driven Plan

<https://speakupcolorado.com/>

➤ **The Right Question Institute**

The Right Question Institute makes it possible for all people to learn to ask better questions and participate more effectively in key decisions.

<https://rightquestion.org/>

➤ **Colorado Department of Health Care Policy & Financing**

<https://hcpf.colorado.gov/our-stakeholders>

<https://hcpf.colorado.gov/home-and-community-based-services-settings-final-rule>

<https://hcpf.colorado.gov/sites/hcpf/files/Rights%20Modification%20Training%20for%20Case%20Managers%20and%20Providers-January%202019.pdf>

<https://cohcpf.adobeconnect.com/patwru6v7o0a/>

<https://hcpf.colorado.gov/sites/hcpf/files/Rights%20Modification%20Training%20Webinar%20Transcript-January%2017%202019.pdf>

➤ **CMS HCBS Final Rule**

<https://www.medicare.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html>



Helpful Resources continued

- **The Arc of Colorado**

The Arc Chapters

<https://thearcofco.org/about/the-arc-chapters/>

- **Colorado Cross-Disability Coalition**

<https://www.ccdconline.org/>

- **Colorado Long-Term Care Ombudsman Program**

<https://cdhs.colorado.gov/about-cdhs/performance-outcomes-and-reviews/ombudsman-offices/long-term-care-ombudsman>

- **Colorado Developmental Disabilities Council**

<http://www.coddc.org/>

- **Centers for Independent Living**

<https://coloradosilc.org/colorado-centers-for-independent-living/>



Exit Survey

Please provide feedback on this training:

1. Overall, how satisfied are you with this training? (scale of 1-5)
2. Please rate your level of agreement with this statement:
 - a. “Because of this training, I understand the HCBS Rule”
 - b. “Because of this training, I understand what rights people with disabilities have”
 - c. “Because of this training, I understand the process that might lead to rights being changed or limited”
 - d. “Because of this training, I understand informed choice”
3. What do you feel were the strengths of this training? (open-ended)
4. What do you feel were the weaknesses of this training? (open-ended)
5. Do you have any other feedback for the trainers?

Thank You!



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