

Individual Rights and Rights Modifications

Colorado Department of Health Care Policy & Financing

June 2021

Presented for people receiving home and community-based services

Trainer Introductions



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Training Objectives

In this training we will discuss the following:

- The Home and Community-Based Services Rule
- Your rights
- Person Centered Planning
- The process to agree or not agree to limit some of your rights
- Self-advocacy skills
- Resources and words to know



Agenda

This training will consist of three modules:

- Module 1: Overview of the HCBS Final Rule
- Module 2: Individual Rights, Person Centered Planning, and Modifications
- Module 3: Self Advocacy Skills and Resources



Module One: Overview of the Home and Community-Based Services Rule

What are Home and Community-Based Services?

Medicaid is the biggest health care program in the United States. Every state has its own Medicaid program.

Providers are people or places that give you health care or services. Some types of providers are doctors, hospitals, or job coaches.



What are Home and Community-Based Services?

Medicaid pays for **long-term services and supports (LTSS)**.

LTSS are services that help people with disabilities

When people get LTSS in their community, it is called **home and community-based services (HCBS)**.



What is the Home and Community Based Services (HCBS) Rule?

The HCBS Rule says **which services are HCBS**. It also says **which services are not HCBS**.

The HCBS Rule helps us live in our community, get the kind of services we want, and make sure places that say they provide HCBS actually provide HCBS.



Why does the HCBS Rule matter to me?

The HCBS Rule reinforces:

1. Important rights
2. Person-centered planning requirements
3. Rules that providers and staff need to follow



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 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 we are ready to put our rule forward, we will publish a notice saying how you can get a copy to review and how you can provide your comments.



Module Two: Individual Rights, Person Centered Planning, and Modifications

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 my HCBS rights?

If you get HCBS, the HCBS Rule reinforces these rights:

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



What are my HCBS rights? (continued)

In most cases, you also have these additional rights:

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



Person-Centered Planning

Person-Centered Planning Requirements

The HCBS Rule requires you to have a person-centered support plan.

The person-centered support plan must be developed through a person-centered planning process that is driven by you.



Person-Centered Planning Requirements

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

Directed by you to the maximum extent possible.

Planning teams consist of people chosen by you.

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

Reviewed/revised when circumstances change or at your request.



Dignity of Risk

You have the right to make a choice even if it could have negative consequences for you.

- 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.



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
- ✓ You 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



Module Three: Self Advocacy Skills and Resources

Self-Advocacy

What is self-advocacy?

Self-advocacy is the ability to understand and express your needs and make informed decisions about the support necessary to meet those needs.

Knowledge leads to self-advocacy:

- ✓ Know your rights
- ✓ Know who you are
- ✓ Know what you need
- ✓ Make informed decisions



Steps to Self-Advocacy

1. Learn about the HCBS Rule
2. Think about your life and your services
3. Advocate for the community life you want
4. Find organizations that can help



Adapted from Your Right to a Community Life: A Guide to Home and Community Based Services Advocacy. The Boggs Center on Developmental Disabilities, New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service, in collaboration with CQL | The Council on Quality and Leadership and the Illinois Council on Developmental Disabilities.

Informed Choice

Informed choice is a process to ask questions, gather information, and understand what you are agreeing to.

Five key questions to support informed choice:

- Who provides my paid supports?
- Where do I live?
- Who do I live with?
- What do I do with my time and do I want a paid job (or a different one)?
- What do I do with my resources?



More Specific Informed Choice Questions to Explore

1. Do you get to do the activities you like to do?
2. Do you make decisions about what you want to do, when and where you go, and who you see?
3. Do you get to run errands independently or with a support staff if needed?
4. Did you choose the place you live?

More Specific Informed Choice Questions to Explore (continued)

1. If you are unhappy with staff, do you feel safe enough to tell someone?
2. Can you make calls and open your mail in private?
3. Are you able to eat what you want and at the time you want?
4. When you go to your planning meeting are the people who you want present?
5. Do you feel that your support plan includes things that are important to you?

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>

➤ **CMS HCBS Final Rule**

<https://www.medicaid.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 my rights are”
 - c. “Because of this training, I understand the process that might lead to my rights being changed or limited”
 - d. “Because of this training, I understand self-advocacy skills”
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?

Words to Know

Words to Know

Word	Meaning
Community living	Living in the same place as people without disabilities
CMS	Centers for Medicare & Medicaid Services. This is the federal government agency that runs Medicaid.
HCBS	Home- and community-based services. This is when people get long-term services and supports in their community.
HCBS Rule	A rule that CMS made. It helps people with disabilities get the services they want in their communities. It also ensures that institutions do not get HCBS money.
HCBS transition plan	A plan states make that says how they will follow the HCBS Rule.

Adapted from the Autistic Self Advocacy Network

Words to Know

Word	Meaning
Informed Choice	Process to understand what you are agreeing to
Institutions	Larger residences where more people with disabilities live together and may have more limitations on their rights compared to people living in the community.
LTSS	Long-term services and supports. Services that help people with disabilities live their everyday lives. Some kinds of LTSS are job coaches, transportation, or an in-home helper.
Medicaid	A program the government made to help people with disabilities and other kinds of health-care needs. Medicaid gives people health care.

Adapted from the Autistic Self Advocacy Network

Words to Know

Word	Meaning
Person-Centered Support Plan	A document that says what kind of services and supports you get.
Providers	People or places that give people health care. Some types of providers are doctors, hospitals, and in-home helpers.
Restraint	When someone stops someone else from moving around.
Seclusion	When someone locks someone else in an empty room.
Self-Advocacy	The ability to understand and express your needs and make informed decisions about the support necessary to meet those needs.

Adapted from the Autistic Self Advocacy Network

Thank You!



Solutions that Matter