



## A Guide to Home and Community Based Services Advocacy

The Home and Community Based Settings (HCBS) Final Rule is a federal policy change announced by the Centers for Medicare and Medicaid Services (CMS) to make sure that people with disabilities have the kinds of services they need in their communities. The Rule requires that the places where people receive HCBS waiver services offer full access to the benefits of community life. This guide prepares you for HCBS advocacy with information about the Rule and tools to share about your experience receiving services.

# Your Right to a Community Life

As a person who receives Home and Community Based services funded by Medicaid, some changes in federal policy give you new opportunities to have the kind of community services you want and need.

In January 2014, the Centers for Medicare and Medicaid Services (CMS), announced the **Home and Community Based Services (HCBS) Settings Final Rule**. The Rule requires that people receiving services through Medicaid HCBS waiver programs have full access to community life and are able to receive services in the most integrated setting possible.

As part of the Rule, every state was required to submit a **Statewide Transition Plan** to CMS describing how they will make sure that the settings where people receive services enable full access to the benefits of community living. All states must have an approved Statewide Transition Plan in place by March 17, 2019, and the changes proposed in the Statewide Transition Plan must be made by March 17, 2022.

Throughout this process, states should ask you for input about the services you receive, the places where your services are provided, and changes that could be made to help you get the community life you want. This is your chance to share what community life means to you!

This guide prepares you for advocacy with information about the HCBS Settings Final Rule and tools to help you provide input on your experience receiving Home and Community Based Services.



You should ask your family, friends, or others that know you well to help you use this guide if you need it. You can recommend that those helping you to learn about the Rule read *Supporting the Right to a Community Life: Assisting People with Developmental Disabilities to Advocate*.

# How Do I Advocate for the Community Life I Want?

## Step 1: Learn About the HCBS Settings Rule

Before you begin to advocate, you will want to learn more about the HCBS Settings Rule and what it says about how and where Medicaid Home and Community Based Services must be provided.

On **page 3**, you will find information to help you **Learn About the HCBS Settings Final Rule**.

## Step 2: Think About Your Life and Your Services

The Rule is designed to make sure that the services you receive provide opportunities for integration and access to the community, choice, individual rights, and independence.

Descriptions of these concepts and questions to help you think about whether **your services** have these qualities can be found on **page 4**.

## Step 3: Advocate for the Community Life You Want

The Home and Community Based Services (HCBS) Settings Final Rule has created many opportunities to advocate for the community life you want. Information about how you can advocate for your right to a community life begins on **page 7**.

## Step 4: Find Organizations That Can Help

There are organizations you can contact if you feel like your right to a community life is not being respected. You can **Find Organizations That Can Help** on **page 10**.

# Step 1: Learn About the HCBS Settings Final Rule

Medicaid is a government program that provides funding for many services that help you and other people with disabilities across the country. Medicaid is the largest source of funding for **Home and Community Based Services (HCBS)** that help people with developmental disabilities live in the community.

Although funding for HCBS waivers has been available for several decades, many people with disabilities still do not have the opportunities they would like to be active and included members of their neighborhoods and local communities alongside people without disabilities.

To make sure that HCBS and the places where they are provided are truly part of the community, the Centers for Medicare and Medicaid Services (CMS) announced the Home and Community Based Service Settings Final Rule. The Rule sets requirements for **where** and **how** Medicaid Home and Community Based Services are provided.

## What the Rule Says About How Medicaid HCBS are Provided

The Rule says that Home and Community Based Service Settings:

- are chosen by the individual from options that include non-disability specific settings
- are integrated in and support access to the greater community
- provide opportunities to seek employment, work in integrated settings, engage in community life, and control personal resources
- make sure that an individual's rights, choices, and independence are respected

## What the Rule Says About Where Medicaid HCBS are Provided

The Rule says that Home and Community Based Service Settings **do not include**:

- Nursing facilities
- Hospitals
- Institutions for individuals with developmental disabilities and/or mental illness
- Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID)

Some places are similar to institutions because of their size, location, or the way they provide services. These places must prove they are truly community-based:

- Places that are part of or right next to a public institution
- Any other places that separate people receiving HCBS from their communities

## Step 2: Think About Your Life and Your Services

The Rule is designed to make sure that the services you receive provide the opportunity for **integration and access to the community**, **choice**, **individual rights**, and **independence**. You will find a description and examples of these important concepts below. Use the questions included to help you think about whether the services you receive have these qualities and if you need to advocate for changes. You may want to ask your family, friends, or others that know you well to help you answer these questions and record your responses.

### Integration and Access to the Community

**Integration and access to the community** means that you have the same chances to be an active and included member of your neighborhood and community as someone without disabilities. You should have opportunities to:

- find competitive employment working alongside people without disabilities
- participate in local activities
- access services in the community just like people without disabilities

#### Think about your life...

Do you spend time in places where other people living in your community go? (examples: stores, restaurants, bank, house of worship)



☐ Yes



☐ No

Do your service providers support you to do what you want in your community? (examples: go to a gym, visit the library, take a class)

☐ Yes

☐ No

Do you receive services in the same places as people without disabilities?

☐ Yes

☐ No

Do you get to do as much as you want in your community?

☐ Yes

☐ No

If you answered “no,” what changes should be made so the services you receive provide the opportunities you want to access and be part of your community?



## Step 2: Think About Your Life and Your Services

### Choice

**Choice** means that you can select the services and supports that you need, as well as who provides them and where you receive them. You should have options to live and receive services in places that are for people with and without disabilities.

#### Think about your life...

Did you choose where your services are provided?  
(for example: group home, own home, day program)

Did you choose the services you receive?

Did you choose who provides your services?

Did you choose where you live?

Did you choose who you live with?



☐ Yes



☐ No

☐ Yes

☐ No

☐ Yes

☐ No

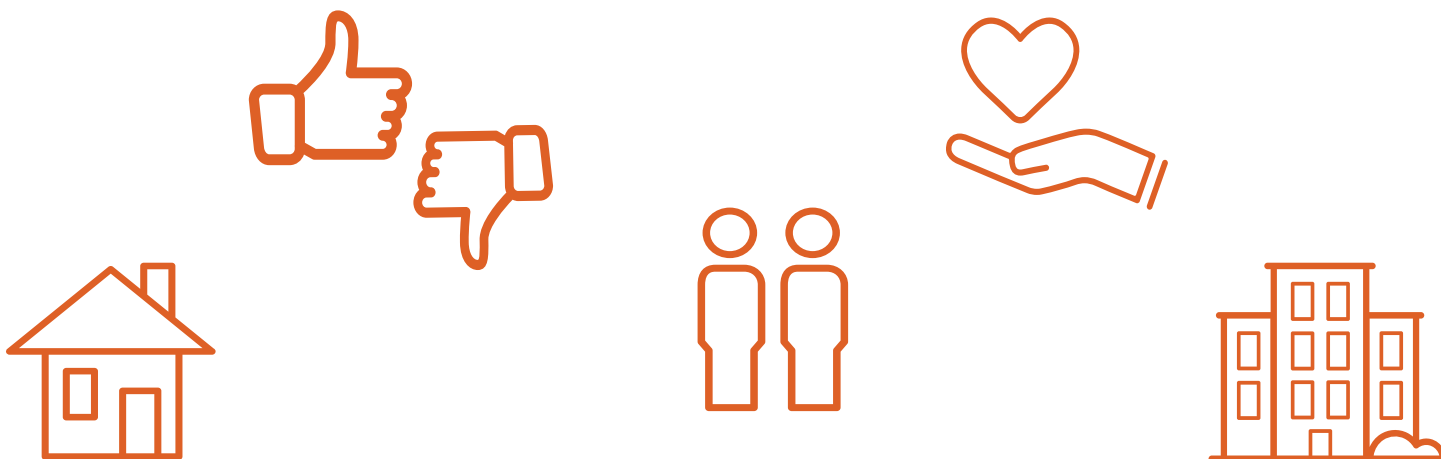
☐ Yes

☐ No

☐ Yes

☐ No

If you answered “no,” what changes would you make to your services or living arrangement?



## Step 2: Think About Your Life and Your Services

### Individual Rights

**Individual rights** include privacy, dignity and respect, and freedom from coercion and restraint. Some of the individual rights you should have are:

- being able to lock your doors
- using the phone when you want
- coming and going as you please
- having time alone when you want

#### Think about your life...

Are you able to have personal space and time alone when receiving services?



☐ Yes



☐ No

Are you able to come and go as you please?

☐ Yes

☐ No

Are you able to have visitors where you live and where you receive services?

☐ Yes

☐ No

Do people listen when you speak up for yourself?

☐ Yes

☐ No

If you answered “no,” what changes should be made so that you are respected?



## Step 2: Think About Your Life and Your Services

### Independence

**Independence** means that you are in charge of making decisions about your life and what you want to do. These decisions include your daily activities, your surroundings, and the people you interact with. Some examples of independence are:

- setting your own schedule
- choosing where you want to go
- controlling your own budget

#### Think about your life...

Are you able to choose your own schedule?



☐ Yes



☐ No

Do you choose what you do for fun?

☐ Yes

☐ No

Do you choose how to spend your money?

☐ Yes

☐ No

Do you have a chance to make decisions about your life and what you want to do?

☐ Yes

☐ No

If you answered “no,” what changes should be made so the services you receive promote your independence?



### Do I need to advocate?

You have the **right** to services that provide opportunities for integration and access to the community, choice, respect for your individual rights, and independence. **If you answered “no” to any of these questions, you need to speak up!** Learn how to advocate in the next section of this guide.

## Step 3: Advocate for the Community Life You Want

The Home and Community Based Services (HCBS) Settings Final Rule has created many opportunities to advocate for the community life you want.

### Discuss with Your Case Manager and Service Providers

You can begin to advocate by sharing your opinions about the services you receive with your case manager, support coordinator, and provider agency. You should discuss where you would like more opportunities for integration and access to the community, choice, individual rights, and independence. Your ideas will help them to make changes so your services give you the opportunities you want to be included in your community.

### Provide Input During Public Comment Periods

#### On the Statewide Transition Plan

There may be several opportunities for you to provide input on the Statewide Transition Plan (STP) your state has developed to come into compliance with the HCBS Settings Final Rule. For example, states are required to ask for **public comments** when they make changes to their STP.

#### During the Settings Assessment Process

As states implement their Transition Plan, they must also take a close look at the places where HCBS are provided to figure out if they are truly community-based. During this process, called **settings assessment**, your state may ask for your thoughts on whether the places where you receive HCBS help you participate in the community, make choices, have individual rights, and be independent.

When you are asked to provide your opinions, it is important to share how you are currently supported to participate in your community, make choices, exercise your rights and be independent, and what your provider agency could do to support you better.

#### On Places that Require Heightened Scrutiny

Some places could segregate people with disabilities from their communities because of their size, location, or the way they provide services. These places require an even closer look, called **heightened scrutiny**, to determine if they are community-based. Your state must provide public notice about settings submitted for heightened scrutiny and a chance to comment on the settings. It's important to advocate during the heightened scrutiny process by sharing:

- information about your own experience or the experiences of others you know who receive services in that setting
- settings that aren't on the heightened scrutiny list that you think should be, like housing developments for people with disabilities only

## Step 3: Advocate for the Community Life You Want

### How do I advocate?

Remember, you have the **right** to services that provide opportunities for integration and access to the community, choice, respect for your individual rights, and independence. **If your services don't offer these opportunities, you need to speak up!**

You can advocate for the community life you want by using your responses to the questions from the **Think About Your Life and Your Services** section beginning on **page 4** to talk with your service providers, provide public comment, or testify at hearings.

You should check regularly with your state office of disabilities services or [hcbadvocacy.org](http://hcbadvocacy.org) to find out when your state is posting plans for comment and where to submit comments.

You don't need to wait for public comment periods to advocate! You can reach out to your policymakers at any time so they know that being in the community and having the supports you need to do this are important to you.

Make sure that you enlist others to join the HCBS advocacy movement. Consider connecting with other advocates and advocacy groups in your area to show how important community is to everyone.

### What will happen with the information I share?

Your feedback will help service providers, your state, and the federal Centers for Medicare and Medicaid Services learn more about what people with developmental disabilities want from the HCBS they receive.

Your service provider may use the information to make changes to the services you receive so that you have the opportunities you want for integration and access to the community, choice, individual rights, and independence.

States will use the opinions you share during public comment periods to make changes to policies and to determine settings that need to change to comply with the Rule.

### Where can I learn more about how to advocate?

You can learn more about how to advocate for the community life you want by accessing *HCBS Settings Rules: How to Advocate for Truly Integrated Community Settings* created by the HCBS Advocacy Coalition:

<http://www.aucd.org/docs/policy/HCBS/HCBS%20Setting%20Rules%20Settings%20Advocacy%20Final%201%202022%202016.pdf>

## Step 4: Find Organizations That Can Help

The Home and Community Based Services you receive **must** provide you with opportunities for integration and access to the community, choice, individual rights, and independence. If your services don't provide you with these opportunities, you need to speak up!

You can start by sharing your responses from the **Think About Your Life and Your Services** section beginning on **page 4** with your case manager and the organization providing your services.

If you feel that your rights are being **restricted**, or not respected, you should talk to the Human Rights Committee for the organization providing your services.

If you would like more information about your rights as someone receiving Home and Community Based Services, or if you feel like the feedback you have shared is not being listened to, you can contact your state's:

### Disability Rights/Protection and Advocacy (P&A) Systems

Disability Rights organizations provide legal representation to people with disabilities and ensure access to life in the community. You can find your state's Disability Rights organization online through the National Disability Rights Network:

<http://www.ndrn.org/en/ndrn-member-agencies.html>

### Council on Developmental Disabilities (DD Council)

DD Councils empower advocates and work with stakeholders to achieve change. You can find contact information for your state's DD Council online through the National Association of Councils on Developmental Disabilities:

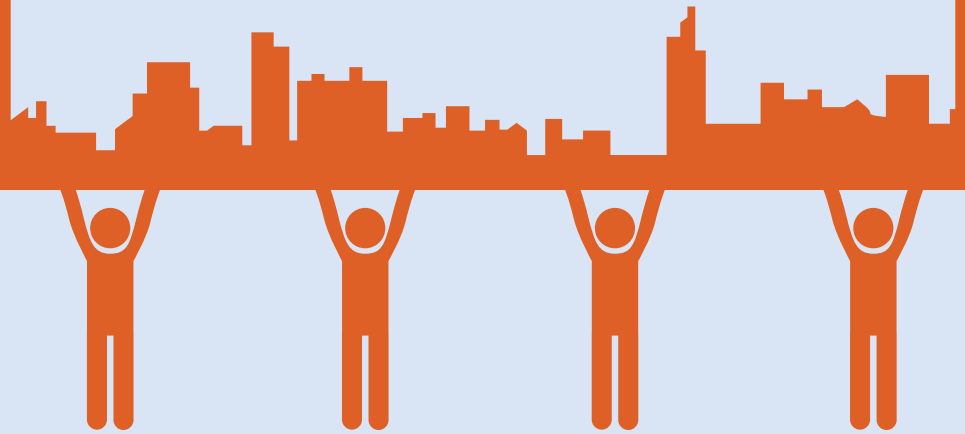
<http://nacdd.org/councils>

### University Center for Excellence in Developmental Disabilities (UCEDD)

UCEDDs provide student training, perform community training and technical assistance, conduct research and evaluations, and disseminate information. You can find your state's UCEDD using AUCD's UCEDD Directory online:

<http://www.aucd.org/directory/directory.cfm?program=UCEDD.LEND>

# Your Right to a Community Life



## A Guide to Home and Community Based Services Advocacy



This resource was developed by 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.

January 2018

**RUTGERS**  
Robert Wood Johnson  
Medical School  
**THE BOGGS CENTER**  
ON DEVELOPMENTAL DISABILITIES

**CQL**<sup>SM</sup>  
CQL | The Council on  
Quality and Leadership

**ICDD**  
Illinois Council on  
Developmental  
Disabilities