

Getting the Community Life You Want

A Guide to Home and Community Based Services Advocacy



Introduction

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

In January 2014, the Centers for Medicare and Medicaid Services (CMS), announced the **Home and Community Based Services (HCBS) Settings Final Rule**.¹ 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.

To make sure this vision is upheld, it is important for people with developmental disabilities and their families to give input about the services they currently receive, the services they would like to receive, and any changes that could be made to help them get the community lives they want.

This guide provides:

- Information to learn about the **Rule**
- Important ideas and questions to think about **your life and your services**
- A worksheet to help you **provide input about the services you receive and how they can change to help you get the community life you want**

¹ [Federal Register – Final Rule \(2014\)](#)

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Learn About the HCBS 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 most significant source of funding for **Home and Community Based Services (HCBS)** that help people with developmental disabilities live in the community. In New Jersey, Home and Community Based Services are available through one of two Medicaid Waiver programs, the **Community Care Waiver (CCW)** and the emerging **Supports Program**. New Jersey's Division of Developmental Disabilities depends on Medicaid funding to make services, which are typically delivered by provider agencies, available.

Although funding for Home and Community Based Services Waivers started nationally in 1978, 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 Home and Community Based Services 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 (HCB) waiver services are provided.

With this Rule, CMS is working to make sure that Home and Community Based Services (HCBS) focus on the experiences of the person and the difference services make in their lives – what are called **outcomes**.

The goal of this rule is to “maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting.”²

The Rule says **Home and Community Based Service Settings**:

- are selected by the individual from options that include non-disability specific settings and an option for a private unit;
- 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; and
- give the same degree of access to services in the community as those not receiving HCBS.³

Additional resources to learn more about the HCBS Settings Final Rule can be found on page 10 of this guide.

² [Fact Sheet: Summary of Key Provisions of the HCBS Settings Final Rule](#), CMS (2014)

³ [CMS Presentation Slides – Final Rule: Medicaid HCBS](#)

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Your Life and Your Services

This 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.**

This part of the guide describes the important ideas found in the rule for people with developmental disabilities.

As you go through the guide, here are some things to think about:

- Where you receive services, the services you receive, and who provides them
- Whether the services you receive have the qualities described in the following pages
- What changes should be made so that your services give you more opportunity to be included in your community

Integration and Access to the Community

Integration and access to the community means that you have chances to: find competitive employment working alongside people without disabilities, participate in local activities, control your own budget, and access services in the community just like people without disabilities.

“Everywhere I go I’m always meeting new people, and then I get to know who they are, and they get to know who I am.”

– *Barbara*



“Everybody should be working because that’s the way you’re going to meet different people. I meet a lot of different people at my job. If I didn’t have a job or get a paycheck I would be bored. I wouldn’t know what to do.”

– *Myrta*

“I actually do a lot of community services within the church. My parents always want me to be active and in my family everybody’s active. Nobody’s at home doing nothing.”

– *Ryan*



“Sometimes I like to go home with my family, and spend some time with my nieces and my brother-in-law. I see my great niece and I’ll spend some time and play games with her.”

– *Josephine*

Think about your life...

What does being a part of your community mean to you?

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.



“It’s like being your own boss. You get to have choices of what you want to do and making your own decisions without anyone else doing it for you.”

– *Barbara*

“This is the kind of home that I like. I can invite people to come here. I talk the most to my roommate. We laugh, we talk together, we do things together like a sister.”

– *Annie*



Think about your life...

What is important to you about choosing the supports and services you need?

Individual Rights

Individual rights include privacy, dignity and respect, and freedom from coercion and restraint.

“What it’s like to me is being more out in the community. You have your own keys. You can go out the door whenever you feel like it.”

– *Josephine*



“A home in the community means a lot because, I live in an apartment and I get to come and go as I please. What a home in the community means to me is, like, having your freedom.”

– *Barbara*

“In your own apartment you got the freedom you want. You’re capable of coming and going as you please. You do what you want. Nobody’s following you around. The way it should be.”

– *Myrta*



“I actually have privacy for myself and my loved one. My neighbors, they’re very friendly. It makes me feel good when you have the positive vibe, you socialize and you connect.”

– *Ryan*

Think about your life...

What does having rights mean to you?

Independence

Independence means that you are in charge of making decisions about your life and what you want to do. These decisions include, but are not limited to, your daily activities, your surroundings, and the people you interact with.



“In your own home you get to pick whatever meal you want, cook what you want to eat, what time you want to eat, what time you want to go to bed. [You] have the choice to have a snack... choose the clothes you want to wear... when you want to go out, too. That’s having your own choice out in the community.”

– *Barbara*

“Each day is something different. I love it. I like to do different things every day because you don’t get bored of doing the same things.”

– *Myrta*



“In my community around here I like to go shopping, travel back and forth to work every day with transportation on my own.”

– *Annie*

“One of the choices I make in the community is setting my schedule. Whether it be going to the gym or reading books and meeting up with friends.”

– *Henry*



Think about your life...

What is important to you about making your own decisions?

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Providing Your Input on Home and Community Based Services

Sharing your thoughts will help your support coordinator and service providers to learn more about what you want from the Home and Community Based Services you receive. Your ideas will help them to make changes so your services give you the opportunities you want to be included in your community. You may want to ask your family, friends, or others that care about you to help you answer these questions and record your responses.

This is your chance to share what community life means to you! You can use this worksheet to give input about **integration and access to the community**, **choice**, **individual rights**, and **independence**.

Integration and Access to the Community



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

Yes

No

Do you have a chance to find a paid job in the community?

Yes

No

Do you choose how you spend your money?

Yes

No

Do you spend time with the people you want to?

Yes

No

What changes should be made so the services you receive provide the opportunities you want to access and be part of your community?

Choice



Did you choose where your services are provided?
(for example- group home, own home/apartment, day program, etc.)

Yes

No

Did you choose the services you receive?

Yes

No

Did you choose who provides your services?

Yes

No

What changes should be made to make sure you have these choices?

Individual Rights



Do you have the privacy you want?

Yes

No

(for example- do you have time alone, can you lock your doors, can you use the phone and computer when you want, etc.?)

Are you able to come and go as you please?

Yes

No

Are you able to turn down activities that you don't want to participate in?

Yes

No

What changes should be made to ensure your individual rights are respected?

Independence



Do you have the chance to set your own schedule?

Yes

No

Do you choose when and what to eat?

Yes

No

Do you choose what you do for fun?

Yes

No

Do you get to make decisions about your appearance?

Yes

No

(for example- hairstyle, make-up, clothing)

What changes should be made so the services you receive promote your independence?

Discussing with Your Support Coordinator and Service Providers

Use your responses from the questions above to discuss with your support coordinator and service providers:

- how you think your current services provide you with opportunities for integration and access to the community, choice, individual rights, and independence
- where you would like more opportunities for integration and access to the community, choice, individual rights, and independence
- changes that should be made so the services you receive help you to get the community life you want

Resources to Learn More

Medicaid.gov Home and Community Based Services:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>

New Jersey Department of Human Services:

http://www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html

HCBS Advocacy:

<http://hcbsadvocacy.org/>

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

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