



SUPPORTING THE RIGHT TO A COMMUNITY LIFE



Assisting People with Developmental Disabilities to Advocate

The **Home and Community Based Services (HCBS) Settings Final Rule** is a federal policy change announced by the Centers for Medicare and Medicaid Services (CMS) in January 2014 to make sure that people with disabilities have the kinds of services they need in their communities. The Rule sets requirements for **where** and **how** Medicaid HCBS are provided to ensure that people receiving services through Medicaid HCBS waiver programs have full access to community life. This means that services should be provided in the most integrated setting possible, and must provide opportunities for **integration and access to the community, choice, individual rights, and independence.**

Throughout the planning and implementation process to comply with the Rule, states will ask stakeholders for input about the services they receive, the places where services are provided, and changes that could be made to help them get the community lives they want. Some people with developmental disabilities may need assistance to think about how their services could better support them in their communities and to advocate for their right to a community life.

This resource prepares you to assist those you support to advocate for the community lives they want and share their experiences receiving Home and Community Based Services.

Step 1: Learn About the HCBS Settings Final Rule

Before you support someone to advocate, you will want to learn more about the HCBS Settings Rule yourself. A reader-friendly HCBS Settings Rule 3-Part Toolkit was created by the national HCBS Advocacy Coalition. The toolkit covers what you should know about the Rule and provides guidance on how to advocate for truly integrated community settings. The toolkit, along with other national resources, can be accessed on the HCBS Advocacy website:

<https://hcbadvocacy.org/national-resources/>

Step 2: Help Those You Support to Think About Their Lives and Their Services

The Rule is designed to make sure that HCBS services provide people who receive them with opportunities to participate in the community, make choices, have individual rights, and be independent. You should review the concepts of integration and access to the community, choice, individual rights, and independence with the person you support. Make sure the person you support understands these key concepts by asking them to provide their own definitions and examples, and offering clarification as needed. You can find definitions and examples for each of the concepts to help guide this conversation in *Your Right to a Community Life: A Guide to Home and Community Based Services Advocacy*, available online at the following address:

<http://rwjms.rutgers.edu/boggscenter/RighttoaCommunityLife.html>

In addition to making people aware of their rights, supporters have an important role in helping to determine if these rights are being realized. You should have a conversation to determine whether the services the person receives provide opportunities for inclusion, choice, and independence, and whether advocacy is needed. It's important to ask, listen, and observe to learn what the person you support really wants for their community life. Here are a few tips for having this conversation:

ASK

Ask open-ended questions about **integration and access to the community**, **choice**, **individual rights**, and **independence** to help the person you support determine whether the services they receive comply with the requirements of the Rule, and where advocacy is needed. Before you begin, make sure the person you support knows why you're having this conversation and how the information will be used. Suggestions for questions to help guide this conversation are listed below and on the next page.



Integration and Access to the Community

- What opportunities do you have to spend time in places where other people living in your community go? (examples: stores, restaurants, bank, house of worship)
- What kinds of interactions do you have with people in your community? (examples: visit with neighbors, attend meetings of clubs or religious groups, order food in restaurants)
- How do your service providers support you to do what you want in your community?
- Do you get to do as much as you want in your community? If so, what are the things you are supported to do? If not, what would you like to do that you aren't doing now?

Step 2: Help Those You Support to Think About Their Lives and Their Services (continued)

Choice

- How did you choose where to live and who would live with you? What options did you have to choose from? Do you have your own lease?
- How did you choose where to work? What options did you have to choose from?
- How did you decide who would provide your services?
- Are you happy with where you live, work, and receive services? If not, what changes would you make?

Individual Rights

- What do you know about your rights as someone receiving services?
- Are there things you want but don't have? If so, what are they and why can't you have them?
- Have there been times when you felt you were not being treated fairly? If so, what happened to make you feel this way?
- How do you know if your opinions are valued and respected?

Independence

- What kinds of decisions do you make?
- What kinds of things do you choose to do for fun in your community? How often? Who do you go with?
- What kinds of things do you decide to spend your money on?
- Is there anything that would make it easier for you to get around your home, school, workplace, or community?
- Is there something you wish you could do, but can't? If so, what's the reason?

LISTEN

Listen to the person you support as they respond and probe for more detail by asking for examples of how their services do or do not provide the opportunities they want to be part of their community.



OBSERVE

Keep in mind that the person you support may be telling you what they think you want to hear. Pay attention to signs that might show the person you support feels differently than what they are telling you. This could be through body language or wanting to change the subject quickly. You should reassure the person you support that the information they share will help to inform changes needed to their services and the services of others with developmental disabilities, and will not be used against them.



Step 3: Assist with HCBS Advocacy

The Home and Community Based Services (HCBS) Settings Final Rule has created many opportunities for advocacy. Stakeholders might be asked to provide their input through discussions with service providers and/or support coordinators, by providing public comment, or testifying at hearings. You can assist the person you support to advocate for the community life they want by helping them to:

- prepare for sharing their thoughts at a team planning meeting with service providers, case managers, support coordinators, and others who know them well
- draft testimony to present at public hearings or submit during comment periods
- call an advocacy organization or policymaker
- connect with others interested in HCBS advocacy

Step 4: Find Organizations That Can Help

If the person you support feels their rights are being restricted, or not respected, you should help them determine if they need to talk to the Human Rights Committee for the organization providing services.

There are also organizations you can help the person you support to contact if they feel like their rights are being violated. In each state, there is a **Disability Rights/Protection and Advocacy System** to provide legal representation for individuals with disabilities, a **Developmental Disabilities Council** to work toward change with stakeholders and advocates, and a **University Center for Excellence in Developmental Disabilities (UCEDD)** to provide training, technical assistance, and information. To learn more about these programs and to find contact information for the ones in your state, visit:

<https://www.acl.gov/about-acl/administration-disabilities>

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.

Some items found in this resource were adapted from: The Council on Quality and Leadership (2017). *Personal Outcome Measures®: Measuring Personal Quality of Life*.

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