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Emerging Needs

The HCBS Settings Rule & The Developmental Disabilities Act

What is addressed in this Tip Sheet?

As University Centers for Excellence in Developmental Disabilities (UCEDD) we are authorized by and support the findings and purpose of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in several ways including:

- Increasing the ability of people with disabilities to exercise greater choice, self-determination, and engage in leadership activities in their communities;
- Enhancing the capabilities of families in assisting individuals with developmental disabilities to achieve their maximum potential;
- Promote systemic change that ensures the active and meaningful participation of people with disabilities in their communities
- Ensure the protection of the legal and human rights of individuals with developmental disabilities.

These key responsibilities align with the purpose and goals of the Home and Community Based Services Settings (HCBS) Rule (The Rule) which serves to assure that those receiving HCBS “have full access to the benefits of community living and the

opportunity to receive services in the most integrated setting appropriate.” The Rule includes requirements that people receiving HCBS must be supported in settings that:

- Ensures that the person receives services in the community to the same degree of access as individuals not receiving HCBS (e.g. to the same degree as people without disabilities)
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Are selected from among a variety of options including non-disability settings and have the option for a private unit within a residential setting.
- Ensures individual rights of privacy dignity, respect, and freedom from coercion and restraint.
- Optimizes individual initiative, autonomy, and independence in making life choices
- Facilitates individual choice regarding services, supports, and who provides them.

UCEDDs can contribute to the authentic implementation of The Rule and collaborate with people with disabilities, families, providers, and state systems to assure ongoing compliance in a number of ways. Many UCEDDs do work in service to the HCBS Settings Rule in efforts that support the realization of the values of DD Act. UCEDDs can further support implementation of The Rule within the context of the core functions.

“How do we fund this?” is a common question asked of any need to be addressed or idea put forth. UCEDDs can use various funding opportunities to support efforts related to the HCBS Settings Rule, these include but are not limited to: grants from organizations such as State Developmental Disabilities Councils or foundations promoting community integration and engagement of people with disabilities; state systems partners looking for assistance with implementation; and UCEDD Core Grants.

UCEDDs Can Promote HCBS & Settings Rule Through Core Function

Interdisciplinary Pre-Service Training

Incorporate into Course Curricula – UCEDDs with faculty that teach undergraduate and graduate students can build information about HCBS and the Settings Rule into course content. Courses that provide an Overview of Disability, address Disability Policy, and/or discuss Human Service Organization Practices often provide the best opportunities to educate the next generation of professionals about community inclusion and regulations that reinforce the importance.

Build into LEND or Disability Studies Programs – UCEDDs that also have LEND or Disabilities Studies programs can also consider ways to incorporate information about Medicaid HCBS and The Rule into the curricula. Discussion can fit nicely within the context of disability policy, service funding strategies, community inclusion, and considerations related to the transition to adulthood.

Include in Post-Secondary Programs – Advocacy is often a core focus of Post-Secondary and Career Studies programs coordinated at Universities by UCEDDs for students with disabilities. As students learn and grow through taking classes, career exploration, job skill development, and social opportunities, it’s important that they understand the rights they have with the services they receive. These students may rely on HCBS throughout their education and beyond and it is essential that they know their rights and be empowered to advocate for full inclusion in all life activities.

Community Services/Training & Technical Assistance

Technical Assistance to State Systems – UCEDDs can provide TA to state systems in a few ways including with the development of Statewide Transition Plans, sharing opportunities for stakeholders to give public comment, feedback about or development/implementation of provider self-assessments, system assessments, and related informational materials. UCEDDs may also serve a consultative role to state systems leaders and other staff conducting assessments.

Training – It is important that all HCBS stakeholders understand The Rule and what it means for them and the expectations they should have for service providers. UCEDDs can help to share this information by developing and conducting training that focuses key tenants of The Rule, strategies to assure successful implementation, build systems capacity, and support and educate advocates.

Coordinate/Collaborate to establish Peer Groups of People with Lived Experience – Few things are as important as peer-to-peer interactions that support people with disabilities to understand policy and how it impacts their lives. UCEDDs can support these initiatives by collaborating with “self-advocacy” organizations or enlisting people with disabilities, supporting the development of agendas and coordination of activities that incorporate information about the Rule, and supporting the facilitation of these activities by people with disabilities.

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Information Dissemination

Develop a Media Campaign – More and more often, people are getting their information through online media. UCEDDs can collaborate with people with disabilities to create videos and other media to introduce The Rule and share the importance of various aspects of community life. Disseminate the media via websites, email distribution, and social media. Some may even want to create an Instagram or other social media campaign encouraging others to share the importance of HCBS and community integration.

Create Social Stories – Social stories are an effective way to explain social situations to people with autism or intellectual disabilities. They can also be useful to describe how policy influences real life. UCEDDs can develop social stories or other materials that blend pictures and plain language text to help educate people about The Rule and their rights. Such products can be distributed using a variety of methods including websites, social media, and print.

Make Worksheet Publications – UCEDDs can play a role in helping people to understand The Rule, consider if the services they receive are in compliance, and share what needs to change with their services in order to assure their rights are being upheld and they are supported to be included in their community. UCEDDs can develop online or printed materials that provides information and includes space for people to write down their experiences. These materials can help individuals by serving as a template for public comment, a place to write down what they want to share at a service planning meeting, and/or reporting non-compliance to state entities.

Additional Resources – Additional resources and publications developed by UCEDDs can help move the values of the Rule forward. Guidebooks, manuals, articles, newsletters, and other published resources can help to inform people with disabilities, families, professionals, and policymakers.

Research & Policy

Provide Public Comment – Each state is required to solicit public comment on its Statewide Transition Plan. UCEDDs can take this opportunity to review the plans and provide comments based on best practice further educating policymakers on the possibilities of community inclusion and strategies for achievement. UCEDDs can use resources found on www.hcbsadvocacy.org and the CMS HCBS website to learn more about The Rule, its intent, and key areas of focus.

Statewide Quality Measures – UCEDDs can provide valuable expertise in the implementation of statewide quality measures that address areas found within the HCBS Settings Rule. Through collaboration with national entities like HSRI, UCEDDs can work with their state DD systems to use quality evaluation methods such as [National Core Indicators \(NCI\)](#) to measure system performance, identify areas for improvement, and determine means to create change. NCI was one of a few measures included in the [CMS HCBS Quality Measure Set](#). UCEDD support may include coordination of surveys (e.g. Temple IM4Q), facilitation of meetings to discuss data, creating publications sharing data in user-friendly ways and displaying progress toward the HCBS Settings Rule, developing training/providing TA on topics for which a need is identified, or a variety of other ways.

Personal Outcomes – [The Council on Quality and Leadership's Personal Outcome Measures \(POM\)](#) is a person-centered discovery process, explores the presence, importance, and achievement of outcomes, along with the supports that help people achieve those outcomes. Also, included in the HCBS Quality Measure Set, POM can be used at the individual, provider, and state levels to assess the quality of services in the context of the HCBS Settings Rule. In particular, when used at the individual level, this tool can help providers identify the preferences, needs, and desired outcomes of people they support across life domains and take action to support them to achieve this. UCEDDs can support the use of CQL POM by promoting with state systems leaders and providers; providing TA regarding the benefits of provider accreditation; getting staff certified as POM interviewers and trainers to expand its use in accordance with CQL requirements; and/or reaching out to CQL to learn about potential collaborations.

Collaborating and Cultivating Relationships

The HCBS Setting Rule provides yet another opportunity to collaborate with the disability community within one's state. In particular, it's a great way to expand partnerships with State Developmental Disabilities Councils and Protection and Advocacy Organizations further complementing shared goals consistent with the Developmental Disabilities Act. Fostering a collaborative relationship with the Centers for Independent Living can also be helpful in promoting and educating people about The Rule. In addition to these ACL Aging and Disability Network partners, other collaborators at the state and national level may include:

- Advocacy and Parent Groups
- State Systems
- Service Providers and/or State Provider Associations
- Quality Research & Evaluation Organizations (e.g. CQL, HSRI)
- National Organizations (e.g. AUCD, The Arc of the US, TASH)
- Other UCEDDs with expertise in building inclusive community practices and/or broad national projects (e.g. UMKC Charting the LifeCourse Nexus; Boston UMASS SELN)

Examples of UCEDD Work Supporting the Values of the HCBS Settings Rule

Each UCEDD does work in support of the values of the HCBS Settings Rule through activities that aim to increase the ability of people with disabilities to exercise greater choice and self-determination and promote the active and meaningful participation in their communities. A brief selection of examples is provided below:

Institute for Disability Research, Policy, & Practice, Utah State University – The Center for Employment and Inclusion Training, Resources, and Research

Institute on Community Integration, University of Minnesota – Direct Support Professional Workforce Development Training, Technical Assistance, Research; DirectCourse, [College of Direct Support](#), [College of Direct Support](#); Minnesota DHS Systems Change and Capacity Building

Institute on Disability, University of New Hampshire – Technical Assistance to New Hampshire, Led HCBS Initiative, Convened HCBS Advisory Task Force, consulted providers; Research on Heightened Scrutiny Reviews and ongoing monitoring; Training on HCBS expectations and Heightened Scrutiny Review Process; Collaborated with New Hampshire as CMS HCBS Liaison and Convened Stakeholders Michigan Developmental Disabilities Institute, Wayne State University – Technical Assistance to Michigan; Publications What HCBS Means to Me

Partnership for People with Disabilities, Virginia Commonwealth University – Technical Assistance, Member of Virginia HCBS Advisory Committee

The Boggs Center, Rutgers Robert Wood Johnson Medical School – [Community Life Video Series Right to a Community Life](#); Technical Assistance to NJ DDD re: HCBS and Money Follows the Person Capacity Building

The Institute on Disabilities, Temple University – HCBS Virtual Events, Illustrated Guides, Resources, and [#Inclusion4AllPA Campaign](#)

More Information

[UCEDD Resource Center](#)

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