

National Leadership Consortium **Bulletin**

Realizing HCBS in
Everyday Leadership

**NATIONAL
LEADERSHIP
CONSORTIUM**



ON DEVELOPMENTAL DISABILITIES

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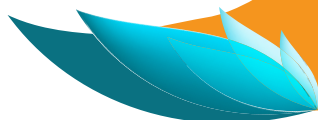
About the Bulletin

The National Leadership Consortium Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin will serve as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

About the National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.



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If you would like to contribute a reflection, strategy, position piece, or research to the Bulletin please contact us at bulletin@natleadership.org. Even if you have not written for publication before, the team at the Bulletin would love to help you develop your ideas.

Introduction: Realizing HCBS in Everyday Leadership

On March 17, 2023, states were required to comply with the Home and Community Based Services (HCBS) Settings Rule, a monumental regulatory win for the inclusion and person-direction of people with disabilities. The Final Rule mandates that people with disabilities who use Home and Community Based Services be supported in their chosen communities, choose where and with whom they live, have full control over their lives, and maintain their homes or jobs if they change service providers. The HCBS Settings Rule has impacted the work of every leader in the disabilities service sector in the United States. And while this Rule certainly isn't new (issued in 2014, originally set to go into effect in 2019, and delayed several times), it is complex to implement. Leaders have had to make challenging and multilayered decisions to adapt state regulations and funding, transform service models and settings, change advocacy approaches, restructure organizations, train and support staff, and more.

For this issue of the National Leadership Consortium Bulletin, we reached out to leaders and experts with a lot of knowledge about the creation and rollout of the regulations. We asked state and national systems leaders, advocate leaders, and organizational leaders to share their perspectives about practices, innovations, and strategies related to the development, advocacy, and implementation of the HCBS Settings Rule. Of course, the Settings Rule is a United States-specific federal regulation; however, there are lessons for our international readers around how systems, organizational, and advocate leaders ensure that people with disabilities have access to inclusive and person-directed services.

We feature perspectives from experts Steve Eidelman, Sharon Lewis, and Mary Sowers about the development and adaptation of the Rule. This issue also includes articles written about systems-level approaches, including Erin Prangle's description of how Developmental Disabilities Council priorities support the implementation of the Final Rule, featured strategies from state agency leaders, Heidi Hamilton (MN), Kristin Ahrens (PA), and Leslie Thompson (MD) and a research brief outlining trends in state services related to the HCBS Final Rule from Cory Gilden. This issue also highlights practices of organizations, including an innovation spotlight from Troy Allen of SRVS and a Feature article from families and people with disabilities, Barbara Parks, Teresa Parks, and Santa Perez, who share some of the benefits and obstacles related to the HCBS Settings Rule. Two final pieces, one offering resources and tools and another from Amanda Rich diving into the research we have and need to support leaders in understanding and enacting the Rule, round out this fall Bulletin Issue.

Also noteworthy, we did not intend to devote an entire issue of the Bulletin to the HCBS Settings Rule until you (people who read the Bulletin and responded to our annual evaluation) requested it! So, we want to take a quick moment to thank you for your feedback; your input helps us make the Bulletin better and more relevant to leaders in this field!

Caitlin Bailey

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History of the HCBS Settings Rule

By Steven Eidelman, Mary Sowers, and Sharon Lewis

To understand the implications of the HCBS Final Rule, it is helpful to understand how it came to be. We asked field experts in designing, regulating, and supporting public policy, such as the HCBS Regulations, to share their knowledge about the factors that led to the HCBS Regulations as well as the process. Steven Eidelman, Co-Founder of the National Leadership Consortium, outlines historical policy decisions, beginning in the 1970s, that led to the Final Rule's rollout. Mary Sowers, Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), shares how the decision to create the HCBS Regulations came about and how people most impacted by services provided input. And Sharon Lewis, a co-founder and former Principal Deputy of the Administration for Community Living at the U.S. Department of Health and Human Services (HHS) and one of the leaders who worked to promulgate the HCBS Final Rule, discusses how much we have learned about the disability service system as the HCBS Regulations were created and mandated.

- The HCBS Final Settings Rule is a set of rules made to ensure that there is a consistent standard for the meaning of community inclusion within Medicaid programs and that people with disabilities who use Medicaid waiver programs are treated fairly.
- Though the HCBS Final Settings Rule was made on March 17, 2014, many organizations are still working to find ways to follow them.
- Through the hard work of the advocates of the HCBS Final Settings Rule, the policy is improving services and supports, and advancing the human rights of people with disabilities.

How We Got to the HCBS Settings Rule

Steven Eidelman

Medicaid is actually four separate programs:

1. Health insurance for low-income families without health insurance
2. Support for elderly people who need help with medical care (some people are “dually eligible” and enrolled in both Medicaid and Medicare)
3. Older adults with disabilities who need long-term care — disproportionately nursing home care
4. People who have disabilities and are not elderly who need health care and long-term care

Advocates for people with intellectual disabilities advocated for the Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR) program that came into being in December 1971, PL 92-223, and went into effect on January 1, 1972. Regulations were issued in 1974. Advocates saw ICF/MR as a way to get federal funding and staffing standards into state institutions, while states saw it as a way to get federal funding to support their institutions.

The first Waiver Program (1915c) was placed in a bill to control Medicaid costs the Omnibus Budget Reconciliation Act of 1981 (OBRA). OBRA 1981 contained a provision (Section 2176) that allowed states to support people in non-ICF programs with non-medical services if they were eligible for ICF services, had an individualized plan of care, offered people a choice of community or institution and, in the aggregate, cost less than the institutional costs in a state.

State HCBS Waiver programs must:

- Demonstrate that providing waiver services will not cost more than providing these services in an institution
- Ensure the protection of people's health and welfare
- Provide adequate and reasonable provider standards to meet the needs of the target population
- Ensure that services follow an individualized and person-centered plan of care

There is a range of meanings and actions, by state, in what happens “on the ground” relative to these four assurances. In 1999, Title II of the Americans with Disabilities Act (ADA) led to a Supreme Court ruling in *Olmstead v. L.C.*, the *Olmstead Decision*, that strengthened the case for community-based supports and providing those supports to institutionalized people who wish to leave.



The New Freedom Initiative executive order by President George W. Bush, signed in June 2001, was designed to remove barriers and promote community inclusion. That legislation led to the Real Choice System Change Grants, beginning in 2001, where all 50 states and Washington D.C. over a nine-year period focused on promising practices and infrastructure building.

Person Centered practices enshrined into federal law and regulations according to CMS, prior to the Settings Rule:

- **Person-driven:** The system affords older people and people with disabilities and chronic illness the opportunity to decide where and with whom they live, to have control over the services they receive and who provides the services, to work and earn money, and to include friends and supports to help them participate in community life.
- **Inclusive:** The system encourages and supports people to live where they want to live with access to a full array of quality services and supports in the community.
- **Effective and accountable:** The system offers high-quality services that improve quality of life. Accountability and responsibility are shared between public and private partners and include personal accountability and planning for long-term care needs, including greater use and awareness of private sources of funding.
- **Sustainable and efficient:** The system achieves economy and efficiency by coordinating and managing a package of services that are appropriate for the beneficiary and paid for by the appropriate party.
- **Coordinated and transparent:** The system coordinates services from various funding streams to provide a coordinated, seamless package of supports and makes effective use of health information technology to provide transparent information to consumers, providers, and payers.
- **Culturally competent:** The system provides accessible information and services that take into account people's cultural and linguistic needs.

The fidelity to these values varies greatly by state and, in many instances, within states. The Settings Rule was put in motion when policymakers and advocates looked at the totality of waiver programs. While some provided truly excellent inclusive supports for people with disabilities, others were still tied to old-school values and practices. It was felt that sufficient research existed, along with many examples of organizations providing inclusive and person-centered supports. It was time to enshrine them into regulations to move the entire system forward. Under the Settings Rule, promulgated in 2017, a setting that is truly home and community based is one that:

- Is integrated into and supports access to the greater community
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services
- Is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting
 - Person-centered service plans document the options based on the individual’s needs, preferences, and for residential settings, the individual’s resources
- Ensures an individual’s 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 and supports and who provides them



These are strong and powerful statements of national policy. It will be up to all of us to see them implemented everywhere in the United States. For a fuller explanation, see [Home and Community Based Services Rules Q&A](#) and the updated [Frequently Asked Questions: HCBS Settings Regulation Implementation](#) from Medicaid.gov.

Essential Beginnings of the HCBS Regulations

Mary Sowers

In 2007, thanks to the work of strong advocates across the country, several concerning trends caught the attention of federal policymakers, prompting a long process of regulation development. First, although people were being served in “community” settings, they were often subjected to rigid practices in places that were supposed to be their homes. These practices had a distinctly institutional feel, governing who and when people could interact with friends and family, when they could eat, where they could go, when they had to go to bed, – and the list goes on. Second, several previously certified institutional settings began to “flip their shingle” and started representing themselves as community settings while changing nothing about the experiences of the people who lived there. This spotlighted the essential need for the federal government to overtly identify the qualities of home and community-based settings to ensure that people receiving these supports and services have the same liberties as anyone else. While there is always a lot of bureaucracy that goes along with regulations, at the very basic level, this multi-year effort aimed to make sure that people needing Home and Community Based Services (HCBS) to live and thrive did not need to compromise their civil rights. I had the benefit of being a Centers for Medicare and Medicaid Services (CMS) staff person during the early years of this effort – and the importance could not have been clearer.

Regulations take a long time under ordinary circumstances. These took even longer because of their importance and reach. CMS first issued a white paper to explore the issue with advocates and system partners, while the Administration on Community Living (ACL) convened a group of people with lived experience to advise the process before the regulation development even started. This prompted the issuance of an “RFI” (Request for Information) to give CMS even more perspectives to consider. Both

efforts solidified the resolve that new rules were needed to make sure the “home and community” in HCBS had real meaning. CMS issued several proposed regulations, finalizing the regulation on March 17, 2014. In addition to describing the characteristics of the settings where HCBS must be delivered, the regulations solidified expectations for person-centeredness in HCBS – making sure the person is truly in control of their supports and services. The regulation included a transition plan to give states time to achieve compliance with the new regulations.

Since that time, progress and setbacks have occurred. While many states have met the milestone of compliance, many are still working toward that goal. A pandemic, an unprecedented workforce crisis, and some proponents of the status quo have stymied fast and effective movement, but efforts continue, and as states imbed the principles into their day-to-day efforts, the rule becomes more of a reality in the lives of people with disabilities.

While the road has been long, I firmly believe the HCBS regulation will change the experiences of people receiving HCBS for the next generation. Mindfully ensuring that people have relationships, as well as opportunities for joy, work, and love, will have lasting impacts. I optimistically believe it will change systems and cultures to envision the possibilities for every person.

Creating and Rolling Out the HCBS Final Rule: What We Learned

Sharon Lewis

Back in 2009, when the first version of the Home and Community Based Services (HCBS) Final Settings Rule was published, few of us could have imagined an implementation horizon spanning more than 15 years. After all, at that point, we had nearly three decades of state Medicaid HCBS waiver experience, nearly 20 years had passed since the Americans with Disabilities Act was signed into law, and we were celebrating ten years since the Olmstead Decision.

When the Final Rule was enacted in 2014, we (naively) thought three years was a generous transition timeframe for providers and states. Really, how long could it, or should it, take to make sure people could access food, lock their bedroom doors, associate with people they choose, and be supported to be fully participating community members? Yet, as things unfolded across the country, we heard stories of visitor restrictions, harsh curfews, highly structured days with little choice, locked-up kitchens, segregated and isolated environments, limited opportunities to work, coercion to elucidate behavior, lack of privacy, “silly house rules” (e.g., No wearing pajamas outside your bedroom! No eating pizza in the living room! Everyone gets up at 5 am in this house!) representing some deeply rooted paternalism and very system-oriented and provider-centric approaches. Culture and systems change have gradually taken root and grown, and while the evolution has taken longer than we hoped and we still have more to do, the Final Rule has caused expansive, positive movement in policy and practice across the HCBS ecosystem.

For me, this is both professional and deeply personal. My daughter moved from childhood into adulthood as the Rule implementation unfolded. While there are many factors influencing her quality of life, the federal regulation has created a foundation that allows us, as a family, to hold the system, our community, and her providers

“Throughout it all, we have seen continuous expansion of the fundamental belief that people with disabilities should not have to forgo their rights, freedoms, and community integration opportunities to access the services and supports they need.”

to high expectations. As a result, she is able to pursue and achieve her goals – working in competitive integrated employment, singing karaoke in a bar on the weekends, playing in an adult kickball league, using public transportation to go where she wants, developing friendships and relationships outside of her family, and being valued as a contributor in her local neighborhood – all while staying healthy and safe.

We are grateful that the heart of the Rule that requires Medicaid HCBS to facilitate real and meaningful community living remains steadfastly supported by people with disabilities, families, advocates, and professional allies (e.g., providers, state staff, policymakers) who believe in the primacy of human and civil rights for all. The vigilance and optimism of so many continue to move implementation forward in the face of workforce shortages, resource and capacity constraints, outdated attitudes about people with the most significant medical and behavioral support needs, transportation limitations, a worldwide pandemic, and myriad other obstacles. Throughout it all, we have seen continuous expansion of the fundamental belief that people with disabilities should not have to forgo their rights, freedoms, and community integration opportunities to access the services and supports they need.

While the Rule is now fully in effect, with states finishing out their final corrective action plans and beginning the ongoing process of oversight monitoring, the work will not be completely done until each of the millions of people who rely upon Medicaid HCBS has the support they need, to live the lives they want.

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State Perspectives of the HCBS Settings Rule

By Leslie Thompson, Leah Zoladkiewicz, and Kristin Ahrens

State leaders who are using innovative and person-directed approaches in implementing, supporting, and regulating the HCBS Final Rule were asked to share some of the strategies that have worked. This article includes perspectives and actions taken by state agencies and leaders in Maryland, Minnesota, and Pennsylvania.

- Working together with state and federal agencies can help to make sure there is compliance with and oversight of the HCBS Final Settings Rule.
- Cooperation between state agencies and provider agencies through advisory groups, outreach, person-centered organization change, development of guides/toolkits, and one-to-one support can help with making the HCBS Final Settings Rule happen.
- Changing state policies, service definitions, and how services are paid for to include HCBS standards can help with making the HCBS Final Settings Rule happen in states.

Maryland

Leslie Thompson, the Assistant Director of Programs with the Maryland Department of Health, Developmental Disabilities Administration, gives her insights about work in Maryland related to the HCBS Settings Rule:

Collaboration is Key! The Maryland Department of Health's Office of Long Term Supports and Services (OLTSS) is the Medicaid authority in Maryland, and because of its role, the Developmental Disabilities Administration (DDA) recognized early on during the Community Settings Rule (CSR) compliance journey that collaboration with OLTSS would be key in order to successfully meet the initial compliance deadline, as well as to maintain ongoing compliance in the years to follow. OLTSS took the lead and were truly the conduit between Maryland and CMS in regard to obtaining final approval for our State Plan. DDA and OLTSS also met regularly leading up to the initial compliance deadline to monitor progress and troubleshoot any areas where providers may have been struggling. OLTSS also took the lead in communicating to our providers whether they were compliant or non-compliant and detailing the next steps. Additionally, we took a collaborative approach in regard to technical assistance with providers in order to address any non-compliance concerns. As a result, we were able to achieve 100% compliance across all sites ahead of the deadline.

Collaboration continues to be our approach in regard to ongoing compliance monitoring. We are utilizing what is called the [Community Settings Questionnaire \(CSQ\)](#), which is a tool that allows us to hear directly from the person being supported on what they are experiencing in all matters related to the Community Settings Rule. Our case managers complete the CSQ with the person annually (at a minimum) and enter the results into our LTSSMaryland system. On a biweekly basis, a CSQ Compliance Committee, made up of DDA team members from various regions and departments, meets to review the non-compliant CSQ and determine the next steps. We've found great success in reviewing the non-



compliant CSQ regularly and communicating directly with the provider on what steps can and should be taken to remediate any concerns. Should we not be able to resolve outstanding issues at the regional level, we enlist the assistance of OLTSS to help with technical assistance and support for our providers.

It is through a teamwork approach that we were able to achieve initial compliance success, and that same approach continues to serve us well as we work to ensure all people in Maryland services are able to live their own vision of a good life.

Minnesota

Leah Zoladkiewicz, an HCBS policy consultant with the Minnesota Department of Human Services, Disability Services Division, provides information about how Minnesota has supported and mandated agencies to comply with the HCBS Regulations:

Minnesota learned throughout the implementation of the HCBS regulations that partnership-focused relationships with our stakeholders lead to increased trust and outcomes.

We used a variety of strategies to engage our partners, including advisory groups, targeted outreach, person-centered organization change, development of provider practice guides/toolkits, and provision of in-person, one-to-one support to providers focused on improving service quality and overcoming barriers. During the initial approval of Minnesota's statewide transition plan, we conducted on-site visits to select settings to explore best practices. The insights gained from these visits informed strategies to validate compliance and supported the development of service standards and provider practice expectations.

Minnesota used a multilayered validation strategy to ensure all identified HCBS settings complied with the HCBS final rule requirements; strategies included [provider attestation](#), desk audits of provider-submitted documentation, provider transition plans, and onsite visits.

At a systems level, we aligned state licensing requirements and provider standards with the HCBS regulations to ensure ongoing compliance. Using oversight and regulatory mechanisms already in place created some efficiencies; however, developing and maintaining short-term and long-term IT system structures proved to be our biggest challenge.

“At a systems level, we aligned state licensing requirements and provider standards with the HCBS regulations to ensure ongoing compliance.”

To meet the HCBS regulations more fully, Minnesota developed several new services and chose to set higher or “tiered” standards for what constitutes an acceptable HCBS setting for designated new settings. In Minnesota, we define tiered standards as limits on access (by location, age, and time) for some services or settings that more fully address the HCBS standards’ intent to support community-inclusive service models for people with disabilities.

We have supported organizations to adopt and adhere to the regulations in a variety of ways. Minnesota developed an [HCBS provider toolkit](#), which contains frequently asked questions, promising practice examples, and resources (our video campaign was highlighted in national news). Since October 2019, we have provided one-to-one support to providers focused on improving



service quality and overcoming barriers related to community integration, promoting competitive employment, and person-centered planning.

Minnesota gained an in-depth understanding of provider practices by working intensively with providers to implement the HCBS regulations. We are committed to this continued partnership to ensure people are supported to have the highest possible quality of life.

Pennsylvania

Kristin Ahrens, the Deputy Secretary of the Office of Developmental Programs within Pennsylvania's Department of Human Services, gives her insights about work in Pennsylvania related to the HCBS Settings Rule:

Two key strategies have promoted success in the implementation of Pennsylvania's IDD program. First, Pennsylvania approached the HCBS Settings Rule by embedding the requirements into our own licensing and program regulations. In some cases, this simply codified past practice or policy into regulation. For example, Pennsylvania had long-established rules about residential setting size and proximity to other human service settings that are now in regulation.

By using this approach, it not only enshrined the settings rule requirements into state regulation but also supported enforcement by establishing measurable standards and leveraging existing oversight mechanisms (i.e., licensing and PA's Quality Assessment and Improvement process) to ensure routine systematic evaluation of those standards.

Second, for the areas in which Pennsylvania had the greatest challenges in meeting the requirements of the federal HCBS Settings Rule, day habilitation and prevocational services, we took an approach aimed at transformation. Pennsylvania had approximately 19,000 people in traditional day programs, so great care was needed to ensure the continuity of services for these individuals. Pennsylvania crafted service definitions that included minimum requirements for providers to support individuals in community settings (defined by both setting and number of people with disabilities participating). The fee schedule for these services was modified to support this transformational approach. Pennsylvania also continues to implement a comprehensive Employment First plan that includes training and technical assistance to prevocational providers to assist in converting to providing supported employment.



“Implementation of and compliance with the Rule is not and should not be an endpoint for any state's efforts to support people with disabilities and being both in and of their communities. Each of the strategies shared above exemplifies how leaders throughout state agencies are promoting meaningful community inclusion and choice and control, using the HCBS Regulations as a starting point. The strategies that show themselves to be successful in implementing the HCBS Final Rule will help create a clear path for more effective and ethical support in short- and long-term efforts.”

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The Role of State Councils on Developmental Disabilities in Improving Access to HCBS

By Erin Prangley

- DD Councils empower people with disabilities and their families with knowledge and tools to be informed about issues, build skills, speak for themselves, and be strong advocates for their HCBS supports.
- DD Councils build capacity by providing grants to organizations working to advance community living.
- DD Council members advocate for change through building strong relationships with state governors, legislators, and state agencies.

People with intellectual and developmental disabilities (IDD) have the expectation and right to live in the community. The Americans with Disabilities Act's (ADA) integration mandated and the creation of the Home and Community Based Services (HCBS) waiver program provided a pathway for people with IDD to escape the isolation and historically dangerous conditions of institutional settings and instead, live in the community with peers with and without disabilities. The Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) helped define how institutionalization can be a form of discrimination against people with disabilities, including the practice of unnecessary segregation, and upholds that the ADA requires the state to provide access to HCBS options. Still, not all people with disabilities who want to live in the community have access to services they need to live independent and self-determined lives.

State Councils on Developmental Disabilities (DD Councils) work within state systems to empower people with IDD to expand the use of Medicaid waivers and end the wait list for HCBS services through advocacy, systems change, and capacity building. [DD Councils are federally funded, self-governing organizations](#) deeply embedded in the state government with the unique role of advocating for self-determination and inclusion for people with IDD in all aspects of community living (including housing, education, employment, and other aspects).¹ DD Councils are often at the center of systems changes to improve access to HCBS for people with IDD because they bring lived experience, policy expertise, and federal resources in the form of grants to support innovative programs addressing HCBS needs for each state.

Self-Advocacy

DD Councils are made up of voluntary members appointed by the state's governor. By law, most members must have a developmental disability or be a family member to a person with it. The DD Council members are some of the most powerful state actors with IDD who are charged with significant responsibilities to promote community living for everyone. Community living is where all people, regardless of age or

“People with developmental disabilities need to lead advocacy efforts to improve policies and programs that affect their lives,” said Rachel London, Executive Director of the Maryland Developmental Disabilities Council. “Making investments in organizations led by people with IDD, like People on the Go, ensures more people have the resources and knowledge they need to be strong leaders and advocates who can talk about what they need and want and bring about change. It is the best way to make sure HCBS advocacy is authentic and effective.”

disability, live independently and participate fully in their communities. It includes the right to make choices and to control the decisions in and about their lives (also known as self-determination). HCBS is critical for some people with IDD to be able to access community living. DD Councils do not provide direct services to people with IDD; instead, they focus on creating programs and advocating for policies that empower people with IDD to advocate for HCBS that makes community living possible for many people with IDD.

The Partners in Policymaking program is one example of how DD Councils promote advocacy, developed by the Minnesota Governor's Council on Developmental Disabilities in 1987 to empower people with developmental disabilities and their family members to become leaders and advocates. The program has been replicated in several states. Tens of thousands of people with IDD and their families learned the skills to advocate before policymakers for HCBS and other programs to support their lives in the community.



[People on the Go of Maryland](#) (POG) is a statewide self-advocacy group led by people with developmental disabilities. With support from the Council and the Maryland Center for Developmental Disabilities, POG educates and advocates for change with state agencies, the state legislature, and the community. POG also provides training, assistance, and support to a network of local self-advocacy groups. This helps them be informed about issues, build skills, speak for themselves, and be strong advocates. POG priorities include closing institutions, supporting direct support workers, ending waitlists for HCBS, and supporting HCBS in the state budget.

“People with developmental disabilities need to lead advocacy efforts to improve policies and programs that affect their lives,” said Rachel London, Executive Director of the Maryland Developmental Disabilities Council. “Making investments in organizations led by people with IDD, like People on the Go, ensures more people have the resources and knowledge they need to be strong leaders and advocates who can talk about what they need and want and bring about change. It is the best way to make sure HCBS advocacy is authentic and effective.”

Capacity Building

DD Councils build capacity by providing grants to organizations working to advance community living. DD Councils can customize their grants and programs to meet the unique needs of their state. This process leads to innovative projects that can often continue after the DD Council grant period, thereby building networks of organizations and individuals who carry out systems change.

Central to HCBS is the importance of person-centered planning. Person-centered planning is an approach to the planning and coordination of a person's services and supports based on individual aspirations, needs, preferences, and values. DD Councils support training people with IDD to be empowered to express their needs in HCBS plans and communications. For example, [“Expectations Matter: My Choice, My Needs, My Plan”](#) is a program created by and for people with disabilities and their families through a grant funded by the West Virginia Developmental Disabilities Council. The program has trained hundreds of people with disabilities and family members in multiple states to understand person-centered planning for the HCBS, the support available through the process of planning, how to develop a plan and make it work, and expectations for timelines and accountability of providers. The program is so successful that the grantee has expanded this training to other states.

HCBS are used in various settings, including employment. However, states struggle to meet the need for supported employment and other services for people with IDD in the workforce. To build capacity and raise awareness of the need for HCBS employment services, the Pennsylvania Developmental Disabilities Council invested in “Empowerment through Employment Grants” to promote the capacities of people with IDD and to increase demand for supported employment services statewide. One of their grantees, Community Options, Inc., plans to identify and publicize stories by and about people with intellectual and developmental disabilities in competitive and integrated employment, higher education, vocational training, or other meaningful community activities. Their stories will promote self-determination and choice and make clear the importance of HCBS for their state employment systems. In Nebraska, the DD Council partnered with Nebraska Public Media and others to create a film and website focusing on how supported employment programs and job coaches can assist individuals as they learn work tasks.

Two reasons states struggle to serve people through HCBS are (1) there are not enough HCBS slots for the number of people who need them, and (2) there is a workforce shortage of Direct Support Professionals (DSPs). DD Councils around the country are working to build capacity in both of these areas. “Meet the Need” is a project led by LAND (Leadership Alliance for Neurodevelopmental Disabilities) and funded by The North Carolina Council on Developmental Disabilities to address the twin issues of its 17,000-person waiting list and the DSP workforce shortage. People on waitlists for Medicaid waivers in other states in the U.S. have an [average wait time of just under four years \(45 months\)](#). In North Carolina, the wait can be up to 12 years or more. The DD Council is [bringing together groups and individuals working with a common agenda](#) to meet the service and support needs of individuals with IDD. NCCDD has also developed a film called [Unmet](#). The film brings audiences into the homes of individuals with disabilities experiencing these two long-term crises.

Two reasons states struggle to serve people through HCBS are (1) there are not enough HCBS slots for the number of people who need them, and (2) there is a workforce shortage of Direct Support Professionals (DSPs).

In partnership with the Florida Developmental Disabilities Council, Mathematica, Inc. is identifying best practices and shared competencies for case management professionals. The team is piloting a tool to assess the competency of these professionals, with the goal of increasing the uniformity and quality of HCBS provided to people with IDD and their caregivers.

Systems Change

DD Councils are uniquely positioned to affect systems change because of their strong relationships with state governors, legislators, and state agencies. As governor appointees, DD Council Members can access state resources that help them with their HCBS advocacy. DD Council Members and staff are called on as experts in state policies concerning HCBS and people with lived experience in the HCBS system. DD Councils provide expertise and testimony before legislators, organize advocacy days to educate policymakers, participate in state task forces on HCBS, and advise state agencies on the importance of Medicaid waivers to meet the needs of people with IDD.



Systems change requires educating policymakers that people with IDD are capable and competent to be full members of our community. One way DD Councils educate is through the publication of stories and reports. The Maryland Council on Developmental Disabilities published a 2009 report, [“What’s Possible,”](#) telling the stories of nine people who now call the community home after living at the state’s largest institution, Rosewood, for decades. After successfully advocating for the institution’s closure, the DD Council followed up with former residents and their families to see how their concerns about living outside the institution were addressed. Many feared they would be left alone and unable to provide for their safety, social, and physical needs because of their disability. However, these former residents thrived. Their stories show what is possible when people are given new opportunities and the community supports they need. “What’s Possible” is still cited today by advocates looking to close institutions.

Another example of systems change is DD Council use of legislative advocacy days. The Georgia Council on Developmental Disabilities hosts multiple advocacy days during each state legislative session, where self-advocates are trained to educate and make recommendations to legislators. In 2023, advocates were trained and sent to legislative offices to push for more action on access to HCBS waivers (ending wait lists), higher wages for direct service workers providing HCBS, and advancing supported employment instead of sheltered workshops. In many meetings, advocates still encountered institutional bias from well-meaning legislators.



“Our self-advocates change hearts and minds during our advocacy days,” said D’Arcy Robb, Executive Director of the Georgia Developmental Disabilities Council. “In an attempt to be helpful, a state legislator once recommended a day-center to one of our advocates. Our advocate politely declined, saying that he had been to that day-center, but he liked going to his job better. The state legislator became a true believer in competitive integrated employment.”

Systems change also requires participating in the state and federal regulatory processes, including monitoring current state waivers and advocacy in favor of new HCBS settings rules that would improve access and provide meaningful standards for providers who receive HCBS Medicaid funding. Several DD Councils advocate for state systems that include the broadest participation in the Medicaid waiver program so that more people can receive services. The Wisconsin Board for People with Developmental Disabilities (BPDD) is actively engaged on all home and community-based waivers in their state and routinely engages with the Department of Health Services on systemic challenges families and people with disabilities face within the HCBS systems. The Board also makes policy, budget, and operational recommendations to improve the programs. BPDD also leads Wisconsin’s Living Well project, a national demonstration grant from the Administration on Community Living that seeks to improve the health, safety, independence, and community participation of people with disabilities and improve community monitoring to prevent abuse, neglect, and exploitation.

“DD Councils are working closely with their state developmental disabilities agencies, state Medicaid directors, legislators, and others to make sure people with IDD are included in discussions concerning their unmet HCBS needs,” said Brett Williams, NACDD (National Association of Councils on Developmental Disabilities) Public Policy Committee Chair and Public Policy Analyst for the Michigan Developmental Disabilities Council. “We’ll keep at it until everyone is receiving the HCBS that they need to live their lives in the community.”

DD Councils' work in expanding community living through HCBS continues to evolve. During the COVID-19 public health emergency, DD Councils responded quickly to advocate for emergency HCBS waivers known as "Appendix K" waivers. [Appendix K](#) allows temporary changes including eligibility, covering more services (including services delivered by telehealth); provider settings and qualifications, such as allowing family members and legal guardians to provide personal care services; increasing provider rates and making retainer payments to certain providers; and more. DD Councils became key advocates for these waivers and worked with their state developmental disabilities agencies to make the case for expanding access to HCBS through these waivers. As these waivers are set to expire in November 2023, DD Councils have already worked with their states to maintain some of these waivers even after the public health crisis has ended.

DD Councils play a vital role in the ongoing struggle to end the institutional bias of state systems and replace them with community-based long-term supports and services. DD Councils advocate for access to the broadest possible Medicaid home and community-based services (HCBS) waiver programs because these services keep people out of institutions and in the community where they can lead their best self-determined lives. DD Councils will continue to focus on finding solutions to systemic failures where states still fall short when it comes to providing services for people in need of HCBS.

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Self-Advocate and Family Member Perspectives on the HCBS Settings Rule

By Teresa Parks, Santa Perez, and Barbara Pritchard

The National Leadership Consortium reached out to self-advocates and family members to hear their experiences with HCBS. They shared their perspectives, success stories, and hopes for the future regarding home and community based supports. Teresa Parks shares how the HCBS rule has and can continue to help her son, Nathan, live a great life. Santa Perez discusses dignity of risk and the imperative to use the HCBS Rule to support people to take risks. Finally, Barbara Pritchard defined and shared a vision for meaningfully experiencing home, community, and support as a person with disabilities and talked about the challenges that people with disabilities face in living fully included lives.

- The HCBS Final Settings Rule offers people with disabilities more options for living where they feel comfortable, an essential part of living a full life.
- The HCBS Final Settings Rule is a big challenge for many organizations but will ultimately expand possibilities for people with disabilities to live the lives they choose.
- The HCBS Final Settings Rules demands more customized supports from service providers and offers the opportunity to build more natural supports in the community.

How Home and Community Based Supports Help Nathan Live a Remarkable Life

Teresa Parks

As the parent of a young adult with disabilities, I am excited to see the full implementation of the HCBS Settings Rule. When my son Nathan was born, it became my mantra to help him live his fullest life with the same opportunities as any of us enjoy. I advocated for him to be included in general curriculum classrooms, to enjoy inclusive leisure activities based on his choices and interests, to gain community employment, to experience the outcomes of his own autonomy, and to enjoy basic human rights, all of which he has acquired to date. As we are now on the cusp of working through his living arrangements, it is my ultimate hope that the life that he has created for himself will continue into the future and with his living arrangements. Currently, Nathan is living at home with his family as he enjoys the home-like setting, living with his small family versus a group of individuals and having the services of a personal assistant come to his home, albeit for a limited number of hours. He maintains two part-time jobs in the community and enjoys a host of outside activities with a variety of family and friends. The concept of Supported Living is of particular interest to Nathan and us as it represents the life Nathan currently enjoys. With Supported Living, Nathan could continue to live at home, but he would receive as many hours of support as needed, given the various changes in his life.



The HCBS Rule has the potential to offer a range of living and service options for persons with disabilities in a way that best meets individual needs, choices, and interests. The implementation of the HCBS Rule could better promote inclusive community living arrangements, community employment, more autonomy, and enhanced rights protections. Through person-centered planning, the HCBS Rule could allow persons with disabilities to live the lives they want to live.

However, there are challenges that could jeopardize and delay the full implementation of the HCBS Rule. Such challenges include adequate funding, creative problem-solving when issues arise, and overcoming existing service structures. Ultimately, the greatest challenge is attitudinal in recognizing that persons with disabilities can determine their own futures absent control of families, service providers, and funding limitations.

Nathan has built a remarkable life for himself that he truly enjoys. The implementation of the HCBS Rule could facilitate the continuation of his beautiful life, his dreams, his future.

How We Support People with Disabilities to Take Risks Under the HCBS Final Rule

Santa Perez

The HCBS Rule is finally a reality, but what does that mean to people with developmental disabilities and intellectual disabilities (IDD)? Are people prepared for that change in mindset, and are we, as providers, prepared to let them take the lead? For some people with IDD, this shift is going to be easy because they have always been ready. But for the others, they are going to need time and experience.



The dignity of risk is the right to fail, and to fail is the right to live. With these new rules comes new responsibilities for providers. They have the unconventional task of *unteaching* decades of compliance and saying “Yes” to be compliant. This can be challenging when people they support don’t want, need, or desire these changes. People with IDD need the practice of life experience and advocacy. This is learned through a lifetime of community experiences and learning what is right for them, through good and bad experiences. Teaching must start at a young age and continue throughout the lifespan. This does not happen overnight, nor is it a one-time training — it is continuous. It needs to start small by having choices to build into self-advocacy and self-determination. Even the task of choosing to have orange juice or apple juice can lead to self-advocacy. The key is to keep building skills and for providers and families to encourage and respect their choices, even when they conflict with our own beliefs. Yes, we have the obligation to protect the people we serve, but at what cost?

Today, we can visualize a more inclusive community through the media. We can see ourselves like never before. People with IDD can identify with someone else and be introduced to a fully inclusive society. People with IDD can now expect to plan their future with no historical boundaries. They can take untraditional roles in society. They can become movie stars, wives, teachers, politicians, etc., as they want.

Change is always a battle! Providers have the task of preparing people with IDD to be leaders in their lives. Providers and families need to start building toolboxes for people to use. This process will be slow and hard, but together, we can do great things.

Home and Community-Based Supports – What Should They Be?

Barbara Pritchard

HCBS includes “home,” “community-based,” and “supports.” I will discuss each component separately, based on what I know and have heard from many self-advocates over the years.

Home

What is “home”? For most of us, we choose where we live. We choose the city or town and what type of house we live in. We choose when we move, who we live with, and how many people we live with. We are well acquainted with the people we share our home with. Schools, stores, and amenities nearby are things we were able to evaluate before moving in. Most of us would never choose to go back to college “dorm life,” and we can barely fathom how much worse “congregate living” would be.



“Homes” that many people with disabilities live in are not really homes that most of us would recognize. They are called group homes, with a bed, a space, or a slot. These are very impersonal terms for what could be a very impersonal and unfamiliar setting. Many of these group “homes” are operated by providers that offer housing only to people with disabilities who want to live “in the community.” A provider buys a house and works with an organization that knows people with disabilities looking for housing.

If you, the reader, had a disability, your “home” might be in a town you have never even heard of, away from all the friends, family, and services you know. You might be placed in a very large dwelling shared by four to 16 individuals whom you probably did not even know before someone else chose to put you together. You might even share a bedroom with one or more other people who you may not have met before. If you were a person with a disability, this is one of the very few options society offers you, with little to no input from you. You would be expected to accept it, like it, and be grateful for it.

Community-based

What is “community”? Most of us live in a community, and we are part of that community. We have friends from work, the neighborhood, and church. We have neighbors who share our hobbies and interests. We are even on the same sports teams. We know local business owners and their establishments, and their employees recognize us. When we come into a community, there are many circles of people that we can readily join. Additionally, we may create new circles, like a book club, that reflect our own interests. We personalize our community. We are part of our community, and our community is a part of us.

What is “community-based”? People with disabilities might be entering a community where their new neighbors have fought hard not to have them there at all. Residents and their many housemates are isolated in a bubble and are often very dependent on their staff. Residents typically spend a lot of time getting their basic daily needs met, and staff help with that. People with disabilities are usually out of the residence during the weekday, either with a few hours of paid employment or learning life skills at a provider-run location. This minimizes the hours per day when staff are required to be in the residence in an effort to lower costs.

Many residents in a group home do not know their neighbors. For residents with little extra time or energy, getting to know their neighbors and neighborhood can take a long time. When you live with a number of people, you often do not get individualized or personalized support. The group may vote on

food for dinner, and they may vote on where to go for entertainment. Due to short staffing, most often, individuals need to go in a group too large to be accommodated in homes and small venues.

Is “community-based” something that the rest of us would recognize as community? Our goal should be for every one of us to be part of the community, not just being “based” in the community.

Supports

What are “supports”? For most of us, support is all around us. The process of getting started for the day is relatively straightforward and independent. Doors admit us, we sprint up the stairs, we can access every bathroom, and street signs are clear to us. We jump in our cars to go anywhere we like, whenever it is convenient for us. If our car does not start, we hop on a bus, train, or rideshare. Each of the steps of getting a job (hearing about an opportunity, filling out an application, chatting on the phone, and getting ourselves to an interview) is relatively easy for us, and the chance of success is not too bad. Worst case scenario, we have the option of “fallback” employment at a fast-food restaurant or in retail. We take for granted how society revolves around us.

For people with disabilities, none of this is simple or easy. Getting started for the day can be overwhelming when you cannot get yourself out of bed or use the bathroom on your own. If you only have the energy for two things per day, and showering counts as one, what other activity do you choose to do? Is it preparing food? If you cannot read, recipes or following directions from a box are not an option.

For those with disabilities, simply navigating the community can be problematic on many levels; doors do not open, stairs cut off whole sections of the community, lack of sidewalks force you into busy streets, words on street signs do not make sense, you can’t hear sounds that warn you of dangers, and rideshares almost never accommodate wheelchairs. Even when transportation is provided, it might require three days’ notice and still be unreliable.

With a disability, the process of getting a job can seem insurmountable: reading, writing, understanding, and finding out about jobs are all barriers to employment before you can even apply. Once you know about a job, can you understand what is required? Can you fill out an application? Can you call to ask questions? Can you get to the interview? Will you need support to learn the job or to do it on an ongoing basis? And, after all of that effort, you might be dismissed the moment they see you.

Supports must be customized to each unique individual. No matter their abilities and level of understanding, the person being supported can and should be at the center of all decisions. The support person needs to listen, truly understand, encourage, and offer options and choices. If someone has not been exposed to different things in society, it may be the job of the support worker to introduce the individual to shopping at a store or going to the library for the very first time – all at a rate that works for the individual with a disability. The support person is essential in helping the person figure out who they are, what they like, and what they do not like. This is especially important for people who move from a large facility to a small home in the community. With the right support, it can be a fun and exciting time to learn new things and explore new opportunities.

Folks with and without disabilities need to work together to re-imagine a society that works for and provides opportunities for everyone. It is not just the law but the right thing to do.

Home and Community-Based Supports

My home state of Illinois regularly ranks 47th-51st (behind Puerto Rico!) in community services to persons with disabilities. But, other states have tried various innovations to provide home and community-based supports. [“Home of Your Own”](#) was once offered in Texas, creating a pathway to homeownership for people with disabilities. Kansas created a program of two support staff per individual, allowing individuals with explosive behaviors to live in their own apartments. Oregon has a program where a person with a disability and a support worker live together as roommates. We, as a country, have tried new innovations in HCBS with success. We do not seem to learn from our failures, and we do not expand our successes nationally.

We need to turn our current system upside down. We need to think about moving the system forward so that everyone can live in a true home in a community they can be a part of, with the individualized support they need and want. Folks with and without disabilities need to work together to re-imagine a society that works for and provides opportunities for everyone. It is not just the law but the right thing to do. I challenge all of us to put ourselves in the shoes of people with disabilities and create communities that are naturally all-inclusive.

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Counting What Counts: Current Research on the HCBS Settings Rule

By Amanda Rich

- Most people agree with the values of the HCBS Final Settings Rule that promote inclusion of people with disabilities in the community, even though it has been challenging for many agencies to meet the new standards.
- Research about the HCBS Final Settings Rule has looked at how stakeholders' give input to the policy, how to measure outcomes, and the impact of using definitions of home and community that focus on service users' well-being.
- Shifting services to follow the HCBS Final Settings Rule may require more state support and different evaluation methods in the future.

As other articles from this edition have described, recent changes to Medicaid's Home and Community Based Waiver program were designed to help remove barriers to and promote real community inclusion and belonging for people with disabilities in the United States.

Under the Home and Community Based Services (HCBS) [Final Settings Rule](#), home and community are now defined based on outcomes related to the nature and quality of services users experience with services as opposed to only the physical characteristics or location of the service setting. Even [critics of these rule changes](#) appreciate or acknowledge the values the CMS Final Settings Rule promotes. These [values focus on factors that promote meaningful inclusion in the greater community](#), such as integrated employment, meaningful choice and control over services, resources, and daily life, supporting independence and autonomy, and respect for rights of privacy, dignity, freedom from abuse, coercion, and restraint.

Values can be hard to measure and sometimes it is tempting for those tasked with evaluating sweeping changes to research elements of the changes that are easy to count while missing what matters most. That, however, is not the case for most research related to the HCBS Final Settings Rule.

To review the current HCBS Final Settings rule research, we searched academic research from over 400 databases using several variations of "Home and Community Based Services Final Settings Rule." We ruled out articles that had the words "home," "community," "settings," and "rule" but were not about the Final Settings Rule and then looked at what the research says about why the Final Settings Rule came to be, how it is being implemented and evaluated, what is currently known about its impact, and if there is alignment between the values behind the research and the values of the Rule. We also included information from relevant websites and news sources.

What Does the Research Say?

Drivers of the Final Settings Rule

Medicaid is the largest federal funding source for people with IDD in the U.S. In recent years, most of that funding has come from the [Medicaid Home and Community Based Waiver](#). As the program is jointly funded by Federal and State governments, each state has a lot of [flexibility](#) in how the program is implemented, including who is covered, reimbursement, what services can be provided, and how they are provided. This has resulted in a wide variety in the nature, quality, and eligibility for supports [across states](#). Additionally, although HCBS waiver funding surpasses institutional funding for people with IDD in all states, many people using HCBS waiver services still have difficulty accessing meaningful social inclusion. Some states have struggled to clearly define the difference [between institutions and home and community based services](#). Physical inclusion without social inclusion has been referred to as the “[illusion of inclusion](#)” and is a common experience for people with IDD. Some researchers have cited [stigma and a lack of community infrastructure](#) as reasons for these continued challenges. Both a lack of consistency in services and the unmet value-based objectives of meaningful social inclusion that is thought to be, at least in part, due to a lack of supportive infrastructure, set the foundation for policy change.

A wide variety of disability rights and other advocacy groups support the HCBS Final Settings Rule. Acting Administrator of the Administration for Community Living Alison Barkoff [said](#), “The Rule builds off decades of work by the disability rights movement and furthers the goals of the Americans with Disabilities Act (ADA) and the Supreme Court’s Olmstead decision, holding that community living is a civil right. For example, person-centered planning is at the heart of the Rule, but on the ground, we still hear about people who are not meaningfully engaged in the development of their plans, not asked about their interests, and not given real options when ‘choices’ are offered.”

Engagement and Implementation

As of March 17th, 2023, all states must be in compliance with [most of the Rule’s requirements](#). All but [six](#) have had their plan to transition into compliance with the Rule move into CMS’s “[Final Approval](#)” stage, meaning that requirements for public comment, input, and summary have been met and their plan has provided all necessary information. The remaining six states are in the “[Initial Approval with Milestones and a Resubmission Date](#)” stage, meaning that their public comment, input, and summary requirements have been met, but some of the assessments have yet to be completed.

Voice, choice, and service users’ active engagement in their services and plans for services is a central component of the Final Settings Rule. States were required to take comments and engage stakeholders, including people with disabilities who use services, their families, and providers in their transition plans. However, [a study from 2018](#) found that family members and people with disabilities who used services were largely unaware of the Settings Rule and how it may impact them. The study found that at the time, over 76% of people with intellectual and developmental disabilities surveyed had never heard of the Final Rule Setting or knew very little about it.

Activists, advocates, and researchers developed programs such as “[The Advocates Creating Transformation](#)” to make information about the Settings Rule more accessible to the people it impacts most and support greater policy development, implementation, and engagement. [Research has found](#) that The Advocates Creating Transformation program is effective in increasing people with disabilities, their families, and support workers’ knowledge of the Settings Rule. Meaningful choice and control require stakeholders to have the needed information about decisions that impact them, and this research supports that value.

Additionally, [researchers have noted](#) that the Settings Rule will require more support to ensure service users have informed choices and opportunities for competitive and integrated employment.

The implementation of the Final Settings Rule [was delayed twice](#). First in 2017 and then again during the COVID-19 pandemic. Though states were given more time to implement the changes, the pandemic also underscored the need for meaningful community-based supports as institutions and institution-like facilities [had higher rates of transmission and death](#). Institutions and institution-like facilities were referred to as “[death pits](#)” and “[sites of human tragedy](#).”

The policy change will likely have the most dramatic impact on those using and providing services in isolated, non-inclusive settings. [Recommendations](#) on best practices to identify, evaluate, and remediate these settings include ensuring Rule compliance is embedded into the state licensure and oversight process, having mechanisms to take complaints about rule violations, and engaging in ongoing evaluation through unscheduled visits and observations.

Evaluation and Outcomes

The HCBS Rule is grounded in emphasizing individuals’ right to choice, control, and meaningful inclusion over simply matching people to available services by defining required person-centered approaches. Person-centered approaches involve “[placing a person’s needs and priorities at the center of service planning and delivery](#).”

Measuring the person-centered outcomes associated with the Final Settings Rule is more complicated than measuring the physical location of services. [Some researchers are highlighting a need for better person-centered outcome measures](#). These researchers highlight that there are limitations to the three current measures used, which include [The National Core Indicators](#)[®], [The Council on Quality and Leadership’s Personal Outcome Measures](#)[®], and the [HCBS CAHPS Survey](#). Specifically, they highlight that these measures compare an individual’s experience against a definition of quality that has been defined by someone else and identify a need for stronger measures of person-centered outcomes. Others have noted that even with current measurement limitations, the focus on assessment and evaluation of the Final Settings Rule will help address gaps in research on Medicaid that have often ignored [beneficiaries with intellectual and developmental disabilities](#).

Despite these possible limitations, researchers are exploring methods of measuring [the complexity of person-centered approaches](#) and their effect on service user’s personal outcomes. Elements of person-centeredness can be viewed on the basis of action from case managers as well as broader administrative flexibility within the state systems. Each element has a different impact. However, both are associated with supporting better outcomes related to [social connectedness](#).

Though the Home and Community Based Services Final Setting Rule has only been fully implemented since March of this year, researchers have looked at the [impact of home and community-based setting rule outcomes on health and well-being outcomes for people with Intellectual and Developmental Disabilities](#). They found that the outcomes related to the Settings Rule, such as self-determination, having choice and control, and supports that are person-centered, are associated with lower emergency room visits, lower rates of abuse and neglect, and fewer injuries.

What Does It Mean for the Field?

Research about The Home and Community Based Settings Rule is still limited as it is in its early stages of full implementation. However, the research published so far is well aligned with the values at the heart of the policy. Specifically, it has looked at stakeholders' knowledge of and engagement with the shaping of the policy, how meaningful outcomes and impacts may be measured, and the impact of using an outcomes-based definition of home and community on service users' well-being. New insight is likely to be shared about how specific states are implementing and adapting to the new rule, the barriers they are facing, and the support that is most effective. Additionally, more research on the impact of these changes on people with disabilities and their families' lived experiences is also likely to emerge.

What Does this Mean for Me?

The HCBS Final Settings Rule may impact your day-to-day job differently based on the types of services your organization provides. It is associated with a shift away from funding for [residential habilitation services and sheltered workshops towards supportive living and integrated employment](#) options. It likely will also mean that the state may change the type of documentation they require from you and how they collect it. All change takes work and can be hard! However, it is also likely that this shift will require states to invest more in infrastructure support to aid in the transition to community-based and person-centered supports. It may also better allow you and your organization to walk your talk and live your mission of supporting people with disabilities in living fully connected lives in their chosen communities.

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Tracking HCBS Final Settings Rule Progress

By Cory Gilden

- Results from the NCI®-IDD survey show big differences between how agencies across the nation are performing on certain parts of the HCBS Final Settings Rule.
- There are evaluation methods that agencies can use to help ensure agencies are delivering quality HCBS supports.
- There are statewide and national toolkits and resources to help people with disabilities and their families advocate for HCBS supports and help agencies provide quality services.

What Does the Research Say?

Now that states must fully comply with the HCBS Final Settings Rule requirements to receive Medicaid funding, evaluating progress in key areas associated with the regulation using quality measures becomes an integral part of knowing where improvements need to be made, organizationally, statewide, and nationally.

One such quality measure is the [National Core Indicators® – Intellectual and Developmental Disabilities \(NCI®-IDD\) research from 2021-22](#), a collaborative effort between the Human Service Research Institute (HSRI), state DD systems, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) that monitors the quality of services through in-person interviews of people with disabilities and their families. A recent [Data At A Glance from May 2023](#) that summarized some results of the in-person survey about provider-owned settings questions and questions related to access to preventative health care revealed areas of need across the nation. The NCI®-IDD survey asked people with disabilities if there were rules about having visitors, if they could lock their bedrooms if they wanted, if they could choose or had input in choosing where they lived, and if they could choose or had input on choosing their housemates. There was a large gap between the lowest and highest state responses, often around a 30% difference. [National averages](#) showed that many people with disabilities living in provider-owned settings did not have rules about having visitors (69%), but they had much less choice about who they lived with (44%).

Regarding access to preventative health care, the NCI®-IDD asked people with disabilities if they had a physical exam in the past year, had a dental visit in the past year, had a mammogram in the past two years, had a vision test in the past year, and had a pap test in the past three years (if applicable). [National averages](#) revealed that most people with disabilities (85%) surveyed had had a physical in the past year, but much fewer, only nearly half, had more specialized and relevant exams like vision (56%) and pap tests (55%). The variance between high and low state averages shows that there continue to be large differences in how states facilitate services for people with disabilities. The results also highlight the importance of using well-rounded datasets with a variety of indicators to gauge performance and get the full picture of how a state is progressing on the HCBS Final Settings Rule. Now that compliance for community integration, choice and control, autonomy, and person-centered planning are required, future data is even more important as it will tell the story of how providers and states are progressing in their services.



What Does It Mean for Our Field?

There are many measures from nationally recognized sources that organizations and states can use to help gauge their progress with the HCBS Final Rule. The [HCBS Quality Measure Set](#) promoted by CMS aims to support national standardized quality measures to “create opportunities for CMS and states to have comparative quality data on HCBS programs and drive improvement in quality of care and outcomes for people receiving HCBS” as well as reducing the “time and resources expended on identifying, assessing, and implementing measures for use in HCBS programs.” These tools measure waiver assurances and subassurances pertaining to service plans and health and welfare, with the key priority areas of (a) access to resources that support overall wellbeing (e.g., peer support, respite, crisis support, etc.); (b) rebalancing the use of services in home and community-based settings relative to institutional care; and (c) community integration to ensure the “[self-determination, independence, empowerment and full inclusion of children and adults with disabilities and older adults in all parts of society](#).” Currently, the HCBS Quality Measure Set includes measures from [HCBS Consumer Assessment of Healthcare Providers and Systems \(CAHPS\)](#)[®] from the Agency for Healthcare Research and Quality, [National Core Indicators[®]-Intellectual and Developmental Disabilities \(NCI[®]-IDD\)](#) and [National Core Indicators-Aging and Disability \(NCI-AD\)](#)[™] administered by ADvancing States and HSRI, and the [Personal Outcome Measures \(POM\)](#)[®] from The Council on Quality and Leadership (CQL).

While using measures from this set is currently voluntary, CMS highly recommends states use them to promote equity in their HCBS programs. Provider organizations aiming to promote quality and equity in their services need data to back up their claims, track their progress and areas of need, and gauge satisfaction from the people they support. Consistency in services has been lacking during the transition to more community-based support. Now that the standard is set in the legislation, it is up to provider organizations and states to track progress with nationally standardized quality measures to close the gap in services and ensure that all people with disabilities have appropriate supports to direct their lives.

What Does It Mean for Me?

There are [differences between the knowledge](#) providers have about the HCBS Settings Rule and what people with disabilities and their family members know; many people with disabilities and families are unaware of requirements that impact their lives and services. It is important for providers to ensure that the people they support and their families have the tools they need to educate and advocate for their rights pertaining to HCBS. Some tools that are packed with useful information designed for people with disabilities and their families include:

- [Your Right to a Community Life](#) from The Boggs Center on Developmental Disabilities, CQL, and the Illinois Council on Developmental Disabilities
- [HCBS Settings Rule Resources](#) from the Autistic Self Advocacy Network (ASAN)
- [The Medicaid HCBS Settings Rules: What You Should Know!](#) from the HCBS Advocacy Coalition, and
- [HCBS Provider Requirements for Residential Setting](#) and [Rights Restrictions and Modifications](#) videos by CQL

Provider agencies and states can benefit from information found in [webinars from the Administration for Community Living](#) and from resources such as these:

- [Long-Term Services and Support Rebalancing Toolkit](#) from CMS
- [Toolkit for States](#) by CQL
- [The Minnesota Home and Community-Based Services Modules for Person-Centered Organizations](#) from the Minnesota Department of Human Services and the Institute on Community Integration, and
- Various toolkits developed by states, such as the HCBS toolkits from [Illinois](#), [New York](#), [Virginia](#), and [Alabama](#)

As community-based services continue to expand and become more community-based and individualized, education and advocacy for both professionals and the people with disabilities they support will be an ongoing process. For example, [Some states are beginning to provide more remote services](#) to help support people in community settings, but not all states have enabled these supports, so more education and advocacy may be needed by provider agencies in states that have not yet provided their waiver recipients with this choice. While there may continue to be growing pains in the next several years with services catching up to what is mandated in the HCBS Final Settings Rule, it ensures that people with disabilities will be more fully integrated into society and closer to living self-determined lives.

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Transforming Employment Services Toward Competitive Integrated Employment

A Q&A with Troy Allen, Regional Director of SRVS, about how they transformed their services from sheltered workshops to competitive integrated employment

When we reached out to our network to learn about the leaders and organizations that were making important strides to meet the HCBS Regulations, we were connected with SRVS, an agency that offers employment services in Tennessee. Troy Allen, Regional Director, shared with us why their organization decided to transform from sheltered subminimum wage-earning workshops to competitive integrated employment (CIE) services.

- Partnership with state agencies and support from agency employees at all levels is important to providing quality, competitive integrated employment services.
- Using a self-assessment tool can help agencies examine their practices and create a path to better support competitive integrated employment.
- Supports that focus on employment, offering different experiences to make sure informed-choice, and benefits counseling can help the transition to competitive integrated employment.

Please describe your organization and the services it provides.

Shelby Residential and Vocational Services (SRVS) was established in 1962 with a workshop as our flagship model. The agency grew to have three workshops in Memphis with 13 satellite locations throughout West Tennessee. These 16 sites employed over 600 people with disabilities who were paid subminimum wages. Unfortunately, our workshops functioned more like a day habilitation center, and participants often became bored with the repetitious nature of the work. Many yielded checks that were often \$20 or less for a two-week period.

This model is no longer progressive or sustainable. In fact, segregated service delivery systems are fast becoming extinct in mainstream society. In 2013, I reluctantly accepted the role of project manager to transform the organization by closing our workshops and creating integrated services for the people we support. Based on national best practices, community resources, and candid conversations with people in our workshop, I found that most had not been exposed to the options and opportunities outside our four walls. I came to the realization that I was an involuntary yet major part of the problem due to my limited scope and institutional mindset. Through this process, I became an avid supporter of CIE and unfettered community integration.



What helped your organization transform its services?

One of the most significant benefits during the transformation was having at least one “Champion” in state government. Tennessee’s Director of Day and Employment services was a key figure in recruiting providers willing to pilot a transformation effort and was able to garner state resources and partnerships to make it happen. As a result, Tennessee’s Intellectual and Developmental Disability (IDD) and Vocational Rehabilitation programs entered an agreement to work collaboratively in this process. In addition, the state received technical assistance through the Office of Disability Employment Policy (ODEP), which proved quite helpful by sharing national best practices in disability employment. For instance, they highly recommended engaging with a benefits counseling provider early in the process to help alleviate fears and misinformation concerning competitive integrated employment.

Remembering how current staff play a major role in transformation was also key; they must be at the table and considered at every step of the process. We know our Direct Support Professionals have an enormous degree of influence on people receiving services and their families. Reassuring staff that they are valuable members of the team and have a place within the organization has been imperative. Also, proactively providing training on inclusionary practices made a huge difference in perceptions and fostered willing engagement.

It was vitally important that a collective decision was made that moved all stakeholders towards transformation as the desired outcome. We could not allow the new vision to sit on a shelf and gather dust. This shift undoubtedly required a dedicated and diverse group of internal and external stakeholders. SRVS embraced community engagement and CIE and developed a strategic plan for transformation that heavily involved seizing every opportunity to speak to business groups and the media regarding the power of employment. Transformation was exactly what we wanted and continue to want for the people receiving services. When we shared this amazing and life-changing model in a compelling manner, others saw the vision. We supported people who had been restricted to day centers and workshops for years and even decades in some cases. Many were limited by a fixed income with little to no change or gain over long periods of time. Many also dreamt of breaking free of their limitations, branching out into the real world of work, building new relationships, having meaningful jobs, and enjoying more of what life has to offer.

Additionally, using a self-assessment tool helped us take an honest look at our organizational model and determine transformation and CIE readiness. It also helped to seek out subject matter experts to gain a better understanding of national best practices. Finally, using person-centered techniques also helped us minimize our inherent inclination to default to congregate thinking.

Did everyone you support take part in CIE?

No. SRVS developed a robust community service model that gave those exiting the workshop but not interested in CIE opportunities to become valued members of their communities. These successful outcomes were realized through volunteerism, increased social engagement, education, and activities of interest at organizations such as the food bank, faith-based organizations, and senior care facilities.

How has SRVS been successful in shifting its employment services to CIE?

We have had several success stories of CIE for the people we support. For example, a highly regarded restaurant franchise in Tennessee and sixteen other states has been an excellent partner in providing job opportunities to people with disabilities. Disabled job seekers are encouraged to apply for employment at any location without fear of discriminatory or exclusionary practices, and those working at the restaurants are afforded opportunities to advance within the company. One of the people working in CIE received an Employee of the Month recognition for his exceptional job performance. He is very proud of his accomplishments and has vowed to work even harder on the job he loves. Another example is a partnership with Showtime Pictures, an affiliate of Elvis Presley Enterprises, which provides quality pictures of Graceland visitors upon their arrival and during tours of the Graceland Museum and other attractions. Someone SRVS supported had a burning desire to work at Graceland, so we arranged for her to get a job as a greeter to direct guests to photo opportunities that would capture their Graceland experiences. Thanks to positive guest comments, Showtime Picture and Graceland continue to employ people with disabilities today.

SRVS closed our workshop in 2015, and we have gathered data and feedback from people receiving services, their families, and our staff about the shift in services. While three people left the organization in search of facility-based services, all who desired CIE are working, and there has been a 91% retention rate among those in CIE. Additionally, workshop services are no longer referenced or requested. We found that employment-themed support approaches, exposure to different experiences to foster informed choice, and benefits counseling aided the transition to CIE. Keeping complete integration as our only objective has made the transformation successful.

Troy Allen is the Regional Director for SRVS and a National Subject Matter Expert (SME) on "Organizational Transformation." He holds a bachelor's degree in Business Management and has 35 years of service to people with disabilities. He has led multiple employment, day, and residential initiatives in Tennessee and launched new program models for IDD and Managed Care Organizations. Contact Troy at Troy.allen@srvs.org.



Useful HCBS Resources

While the HCBS Settings Rule has the potential to move our system in a direction that better aligns with longstanding values of inclusion and self-determination, it also requires significant development and transformation of priorities, practices, and knowledge in many of our states and organizations. Below is a list of useful resources and information cited throughout this issue that can help leaders in various professional and advocacy roles understand and implement different aspects of the Final Rule.

National-level resources were included, rather than state guidelines and implementation requirements, so this resource would be relevant to as many readers as possible. However, some of the resources below include links to state-specific resources if you hope to do a deeper dive into a state or region.

Resource	Published By	Types of Information					Potential Uses
		General Descriptions	Law & Policy Specific Definitions & Descriptions	Links to State-Level Plans & Information	Practical Guides	Plain Language Materials	
Home and Community Based Services Fact Sheet	Centers for Medicare and Medicaid Services (published in 2014)						For a deeper dive into the Rule as it was originally written and to understand how the Rule relates to different sections of Medicaid law
HCBS Settings Rule Resources	The Autistic Self Advocacy Network						For people with disabilities and families who want to know more about their rights and address violations under the Rule
HCBS Guide: Your Right to a Community Life	The Council on Quality and Leadership						For people with disabilities and families who want to know more about advocating for their rights under the Rule
HCBS Instrument Database	ICI, Rehabilitation Research and Training Center on HCBS Outcome Measurement at UMN						For organizations and systems who want to know which tools can be used to measure implementation of the Rule
HCBS Overview Video	The Council on Quality and Leadership						For people who want a user-friendly and engaging overview of the Rule
Home and Community Based Services Training Series	Medicaid.Gov						For leaders who want to do a deep dive into rules and implementation related to topics and requirements of the Rule
HCBS Advocacy Coalition Information and Resources	HCBS Advocacy Coalition						For leaders who want additional national and state-level information, implementation strategies, and resources about the Rule
HCBS Webinars	Administration for Community Living						For service providers and advocates to strengthen their knowledge and help guide more community-based supports

What We're Reading, Viewing, and Listening To

Title: [The American Workforce Faces Compounding Pressure](#)

Author: [American Psychological Association \(2021\)](#)

Description: APA shares their 2021 Work and Well-Being Survey results, which highlights the impact of working during COVID-19. The survey examines workplace experiences during the pandemic, employee stress related to work, and what employees are looking for from their employers as it related to mental health.

Title: [Ed Roberts: Free Wheeling](#)

Author: [People in Motion Ready to Live](#)

Description: This film is a short documentary about the life and legacy of the father of the Independent Living Movement.

Title: [Changing the World Without Losing Your Mind: Leadership Lessons from Three Decades of Social Entrepreneurship](#)

Author: [Alex Counts \(2019\)](#)

Description: This book focuses on mission driven leadership and finding joy in work and life even in times of crisis and change. It is practical, engaging and provides real-life examples and concrete leadership tips.

Title: [Managing to Change the World: The Nonprofit Manager's Guide to Getting Better Results](#)

Author: [Alison Green and Jerry Hauser \(2012\)](#)

Description: This book is designed to help new and experienced nonprofit leaders to develop new and important skills that are central to effective management. These include setting clear goals, team accountability, creating a result-oriented culture, hiring, onboarding and retaining excellent staff. This book offers important insight and practical strategies to help nonprofit leaders negotiate times of changing context.

Title: [Keeping the Promise: Self Advocates Defining the Meaning of Community Living](#)

Author: [Self Advocates Becoming Empowered, Autistic Self Advocacy Network, and the National Youth Leadership Network \(2011\)](#)

Description: This summary of the views of people with IDD on community living still resonates today, serving as a good reminder of the work left to do. It provides important context for the importance of the HCBS Final Rule.

Title: Forging a Federal State Partnership: A History of Federal Developmental Disability Policy

Author: Robert Gettings (2011)

Description: This is an excellent book that puts community services into the larger policy context of State and Federal developmental disability policy.

Title: Shining A Light: Creating Pathways to Equity, Safety, Healing, and Justice with People with Disabilities

Author: Shirley Paceley (2022)

Description: Shining A Light is a powerful memoir that focuses on women's journey to find healing, justice and safety in community with other people with disabilities. It highlights issues related to sexual violence in the lives of people with disabilities and centers on the importance of access to and inclusion in community.

Upcoming Training Sessions

Consider attending one of our upcoming training sessions! These extended programs are intended to enhance leadership skills, provide relevant and up-to-date information on the disability service sector from leaders in the field, and offer skills and strategies for leaders to make impactful changes in the organizations. Past attendees have shared that *“The Leadership Institute is a wonderful program led by powerful, informative, and innovative professionals in the developmental disabilities field. It was an honor to be here and experience how to make changes within myself and my company. This gave me a jump start to look at how I want my career to grow and how I can make positive changes through my company. The ability to meet other professionals who share the same values and provide insight into how their companies function in their state and being able to have a resource of professionals to reach out is something I really look forward to in my professional career.”*

December 2023

The Leadership, Empowerment, Advancement, and Development (LEAD) Delaware Direct Support Professionals Training is a 9-week program focused on the growth and development of Delaware Direct Support Professionals that begins in December 2023. Each cohort of DSPs will engage in a variety of in-person and virtual sessions and activities aimed at enhancing the confidence, knowledge, and skills of Direct Support Professionals working in the Delaware disability service system. Applications are open now and will close on November 8th. This training is open to all Direct Support Professionals in the state of Delaware. [Click here](#) for more information or to apply.

January 2024

The **Leadership Institute**: This intensive leadership development program is designed for seasoned and emerging leaders. Applicants may work in areas of executive leadership, management, or program leadership in organizations that provide, advocate for, or fund supports for people with intellectual and developmental disabilities and their families. The focus of the Leadership Institute is on supporting participants to determine and set organizational direction to move their organization to a high-performance model and build a lifetime network of peers and leaders to sustain career growth.

The **Winter Leadership Institute** will be held in-person in Radnor, PA January 28th – February 2nd, 2024. Applications are open now. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders. *If you are a leader who works for a state department of developmental disabilities within the United States, a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition, travel, and hotel accommodations!*

The **Canadian Leadership Institute** will be held virtually in January 2024, meeting a few times a week for 4.5 hours a day. Applications are open now. [Click here](#) for more information or to apply. This Institute is open to all Canadian Disability Sector Leaders.

Upcoming Workshops

Join us for one of our upcoming skills-based workshops! The workshops are a great opportunity to network with other leaders and enhance your leadership skills. Past participants of National Leadership Consortium programs have shared, *“You have given me the tools and drive to want to make myself the best leader I can be and also grow my team into the best leaders they can be.”*

November 2023

The **Let’s Talk: The Keys to Successful Communication** workshop is a two-session virtual workshop open to leaders at all levels that will be held on November 8th & 9th, 2023. Learn more about your *communication style* as well as strategies to *enhance your communication skills and engage in challenging conversations* more effectively. [Click here](#) for more information or to register.

December 2023

The **Decision-Making and Planning: Understanding and Strengthening Your Skills** workshop is a two-session virtual workshop open to leaders at all levels that will be held on December 6th & 7th, 2023. Learn more about *skills, techniques, and strategies* that will help you become a *better decision-maker*. [Click here](#) for more information or to register.



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