

What Difference Will the HCBS Final Rule Make?

John O'Brien

Organizations funded by HCBS Waivers can't ignore the *Final Rule*¹ –states must assure CMS of compliance in order to use waiver funds. The difference the rule will make in the experience of people who rely on long-term support depends on how organizations choose to receive the provisions that define eligible settings and require person centered planning. The *Rule* will make a bigger difference to people assisted by organizations that actively pursue opportunities to develop capabilities that promote the *Rule's* purpose than it will to organizations that see little distance between their current reality and the *Rule's* purpose and so have no reason to invest in deeper change.

CMS intends these regulations to assist states to meet their obligations under the ADA and the US Supreme Court's *Olmstead* decision. It aims to move CMS toward defining home and community based settings by *the nature and quality of individual's experiences*.² These two items identify some of the experiences the *Rule* intends to increase:

A Home & Community Based setting is integrated in & supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment & work in competitive integrated settings, engage in community life, control personal resources, & receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS. §441.301 (4)(i)

Facilitates individual choice regarding services and supports, and who provides them. §441.301 (4)(v)

The table identifies four ways an organization could read and respond to the *Rule*.



FEDERAL REGISTER

Vol. 79 Thursday,
No. 11 January 16, 2014

Part II

Department of Health and Human Services
Centers for Medicare and Medicaid Services
42 CFR Part 430, 433, et al.
Medicaid Program; State Plan Home and Community-Based Services,
5-Year Period for Waivers, Provider Payment Reassignment, and Home
and Community-Based Setting Requirements for Community First Choice
and Home and Community-Based Services (HCBS) Waivers; Final Rule

Intended Experiences

- Access to community.
- Opportunities to work in integrated settings.
- Engagement in community life.
- Control of personal resources
- Same access to community resources as those not receiving HCBS services.
- Choice of services & supports & who provides them.

	Strategy	Action	Intention	Critical Boundary
1.0	Comply	Sufficient compliance to minimize the impact of external demand from the state	Continuity of current practices & structures	Organization/ MA compliance mechanisms
2.0	Adjust	Adjust practices within current structure & mindset	Better fit between person & practice	Person centered planners/ DSPs & their managers.
3.0	Adopt <i>Best Practice(s)</i>	Modify practice & structure in line with best practice model(s)	Add capability defined by chosen model(s)	Model/ Management – Staff– People who participate, (Family)
4.0	Transform through social innovation	Co-create new capabilities	Disrupt & recreate relationship to source > mindset > structure to increase person's control & inclusion	Relationship to others: people, allies, community Relationship to self

Three ideas help make sense of the options available in response to the *Rule*.



I. Organization as a system. Imagine an organization as a system in which **what we see** –for example, very few people in integrated employment– is produced by the interaction of **patterns of practice** –training for work readiness rather than customizing employment; **structures** –contract work and classes on job finding skills in an organization’s facility; **mindset** –limiting assumptions about employer expectations and people’s ability to make an economic contribution; and **source** – staff-client roles that turn action inward to group activities defined by the facility. A common way to visualize this is to think of the organization as an iceberg. Impact and difficulty of change increases with depth.

II. Critical boundary. Each strategy draws attention and energy to the boundary that matters most to realizing its intention. Attention creates and limits the pathway for change.

III. How might we...? borrowed from Design Thinking as a way to frame a search for innovative ways to create meaningful change when direction is clear but the path remains to be discovered and resources need to be found along the way.

How might we...

The Rule can be accurately read as a list of requirements necessary to pass inspection and avoid penalty. It’s stated purpose can also be read as a set of design questions aimed a producing more desired experiences.

A Home & Community Based setting is integrated in & supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment & work in competitive integrated settings, engage in community life, control personal resources, & receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

–HCBS Final Rule

Opportunities

How might we offer people the option to live in their own home with the individualized support they need?

How might we support people’s engagement in valued roles in community life?

How might we offer people the option to do a paid job in the community?

How might we use person centered plans to increase people’s influence on the supports they need to live a community life & access the same community resources as other citizens do?

This interpretation recognizes that the whole field, and any organization in it, has much more to learn in supporting the experiences that the *Rule* values. The *how might we* statements define the direction and purpose of a continuing

search. For example, extending opportunities for integrated employment only ends with entry level jobs for the most capable people if an organization decides to stop there. Deciding to reach toward what more is possible and support people with even more substantial needs for assistance to reach for even better jobs energizes a continuing journey.

1.0 Comply

An organization that chooses to comply sees little opportunity for development in the *Rule*. In some situations this will be because the organization sees little difference between its current reality and what the *Rule* requires. Language and documentation may need updating: *We have always done person centered planning; we just didn't call it that. Our group homes are fully integrated in the community.* Some new practices may be required: implementing computer based assessments and reports of plans, establishing tenancy agreements and installing door locks for qualified residents. In other situations, programs might face heightened scrutiny for institutional qualities and person centered plans may need to justify maintaining people's current placements.

The experience of planning will change as people are supported to take charge of the planning meeting and different questions are discussed. The experience of services, positive or limiting, will very seldom change because of the plan.

In any case, compliance will require substantial effort but the organization's aim is to minimize the impact of the *Rule* on the organization and so maintain continuity with the organization's past. The critical boundary draws attention to the interface with Medicaid reporting, documentation and inspection mechanisms.

2.0 Adjust practices

Organizations that choose to adjust see opportunities for improvement in practices based on better information about what is important to the people they support and better tools for problem solving. This often results in adjustments to routines that benefit people in ways that make support work more meaningful. The use of staff time and talent better matches individual interests and abilities. Initiatives within current structures are celebrated and may serve as good examples of carrying out the intent of the *Rule*.

Adjustment takes place within current structures. This strategy makes what is already available in an organization work better for people and those who assist them. When they are influential, person centered plans lead to more interesting activities, greater attention to individual preferences, and more comfortable care routines.

The critical boundary is internal to the organization and draws attention to the reciprocal influence between person centered planners (including the person and chosen allies) and direct service workers and their managers.

3.0 Adopt Best Practice models

The *Rule* challenges organizations to take account of advances in the design and delivery of support. Assistive technologies, supports to communication and mobility and person centered approaches to challenging behavior open new possibilities for self-direction and community engagement. New ways of supporting employment and community living open valued community roles, such as employee and contributing community member. Available models support people who require all types and levels of assistance with individualized support to live with a person they have chosen in a place they have chosen from the same real estate market as any other citizen with their resources. Many of these forms of individualized support have been captured in well structured models, such as customized employment, paid neighbor arrangements and shared living. Implementing the *Rule* can provide a stimulus for organizational investment in new ways to offer support that affect mindsets and structures.

New approaches to employment or housing might be added on to an organization's offerings or resources can be redirected, as when an organization closes a group home and redirects funds to expand capability for individualized support to community living.

The critical boundary encloses those involved in adopting the model and engages those organization and system functions necessary to attract resources (people, funding, authority, technical assistance).

Organizations that chose the implement best practice see an opportunity to add capability by offering a new form of individualized support. Available models and related technical assistance guide implementation. Person centered plans guide implementation for those who choose to participate by defining individual requirements and preferences, setting and renewing direction and strategy, and providing a forum for real time problem solving and coordinating allies' efforts.

4.0 Transform through social innovation

There is always much more to learn about how to effectively support community engagement and integrated employment and how to offer meaningful life choices. An organization that chooses transformation sees the *Rule* as setting conditions that influence the social innovation they are committed to generate and looks for opportunities to make the best of those conditions.

Co-creation is a necessary condition of the search for new ways. This means that people who rely on long term support and their allies are active as designers and explorers. Person centered planning widens its scope and becomes integral to the organization's process of social innovation.³ Transformation questions, disrupts and reconfigures every aspect of the organization. Power-with relationships that recognize and encourage the agency of people, allies and direct support workers define the source of innovation. The assumptions and beliefs that form familiar mindsets come in for questioning. New structures

emerge for testing and are refined by amplifying what works. Practices develop through a process of action and reflection.

Transformation is both an external process of co-creating new roles and forms of support, one person at a time, and an internal process of discovering how each person's higher purpose connects them to the work of innovation. This internal work is as important for those in staff, professional and management roles as it is for people who rely on support.

The critical boundary brings people who require support together with community relationships and settings that offer valued roles.

An irony

In its purpose and intent the *Rule* seeks experiences for HCBS beneficiaries that typically call for development, either through the adoption of best practices (3.0) or social innovation (4.0). As administered the rule demands that states assure compliance with detailed specifications. This creates an irony: demonstrating compliance competes with the work of development. Satisfying compliance mechanisms distracts attention from developing organizational capabilities to support the experiences the *Rule* intends. This is especially true when auditors have a different understanding of a criterion than innovators do. Co-creation, being a relationship based, individually grounded process, is inherently messy. Auditor's work is most feasible when the edges of boxes are crisp and clear. Failing an audit is punishing, so producing and filing sufficient and accurate documentation to satisfy inspectors draws attention away from possibilities for transformational change. Innovative organizations must struggle to make the space for development.⁴

Endnotes

1 [§441.301 https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf](https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf)

2 <https://www.medicaid.gov/medicaid/hcbs/downloads/hcbs-setting-fact-sheet.pdf>

3 This perspective is developed in John O'Brien & Beth Mount (2015). *Pathfinders: People with developmental disabilities and their allies building communities that work better for everybody*. Toronto: Inclusion Press (inclusion.com)

4 For a multi-perspective reflection on meeting the challenges of transformation see Hanns Meissner (2013) *Creating Blue Space: Fostering innovative support practices for people with developmental disabilities*. Toronto: Inclusion Press (inclusion.com)