



Tracking Progress and Success of Implementation of the HCBS Settings Rule: Potential Outcomes and Measurements

The HCBS Advocacy Coalition is dedicated to the successful implementation of the HCBS Settings Rule. If implemented well, the Rule has the potential to -- and should -- improve the quality of Medicaid-funded home and community-based service systems at all levels: systemically at the state level, at the provider level, and at the individual participant level. As states are implementing the Rule, it is critical that states, together with stakeholders, engage in conversations about how to best benchmark where their systems currently are and how to measure progress. We believe this is a critical piece of the ongoing monitoring requirements of the Rule and of successful system reform more generally.

The HCBS Advocacy Coalition brought together a working group of national subject matter experts on quality measures and available data sets. The expert members of the working group include: the Community Living Policy Center,¹ National Association of State Directors of Developmental Disabilities Services (NASDDDS), Human Services Research Institute (HSRI), The Council on Quality Leadership (CQL), Coleman Institute for Cognitive Disabilities at University of Colorado, and Institute for Community Inclusion at UMass Boston, and the Institute for Community Integration at the University of Minnesota. Representatives from the HCBS Advocacy Coalition include the Center for Public

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Representation, Autistic Self Advocacy Network, and National Health Law Program, participate in the working group.

The initial focus of this working group was to identify data sources and tools currently being used by states that relate to specific requirements of the Rule. Given the robust data sets and tools in use in state systems for intellectual and developmental disabilities (IDD), the group decided to start there, with the goal of using it as a model for expanding the work to other disability populations and to aging services.

The main goal of this working group was to develop a set of recommendations around outcomes and metrics related to the HCBS Settings Rule that can be used for several purposes: (1) for individuals receiving HCBS, their families, and providers to use in conversations with their state around ongoing monitoring and quality improvement; (2) for states to consider as part of their efforts to develop benchmarks, a process for ongoing monitoring of the Rule, and general quality improvement; and (3) for CMS to consider sharing as part of its technical assistance around good practices. Our work is focused specifically on the HCBS Settings Rule and its requirements; it is intended to complement (but not supplant) the work that CMS and other stakeholders (including several in the working group) are engaged in around HCBS outcome measures more generally.

Below is a summary of the five major areas that the working group identified as critical to implementation of the HCBS Settings Rule, with the relevant language from the Rule. For each area, the group identified three to four recommended outcomes. Attached in Appendix 1 is a matrix with potential metrics and/or benchmarks from existing data sources and tools that could be used for each of these outcomes. For each of the five major areas, the group suggested measurement at the individual participant, provider, and state/systemic levels.

There are a few items to note about the preliminary outcomes discussed below. These broad outcomes encompass an array of items that may be applicable at the individual, provider or systems levels. In the attached matrix, the working group identified potential sources of data that may help provide useful information for each of the broad outcomes at these various levels. We note that not all data sets are available within each state and, if available, may be varied in its applicability to the noted outcomes. This document is intended to facilitate a conversation among individuals, families, providers, advocates and states about a process for assessing the landscape within their state to determine what tools and/or data may be

available to gauge progress in implementing the HCBS Settings Rule and ultimately towards increasing community integration.

Area 1: Community access and integration

Rule Requirements: The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community ... to the same degree of access as individuals not receiving Medicaid HCBS.

Recommended Outcomes:

- Increased number of HCBS participants deciding what to do and with whom
- Increased number of HCBS participants having relationships with community members who are not paid to provide support or services.
- Increased number of HCBS participants having access to transportation or other support to access to community activities of choice

Area 2: Residential options

Rule Requirements: The setting 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. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

Recommended outcomes:

- Increased number of HCBS participants living in their own homes
- Increased number of people living in smaller settings
- Increased number of HCBS participants choosing the people they live with
- Increased number of HCBS participants choosing where they live (location)

Area 3: Day options (Competitive Integrated Employment (CIE) focus)

Rule Requirements: The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including

opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

Recommended outcomes:

- Increased number of HCBS participants spending their days in ways that are important to them as defined by the individual
- Increased number of HCBS participants in CIE
- Increased number of HCBS participants engaged in community life or activities aimed at improving community engagement
- Decreased number of HCBS participants in congregate care/day habilitation services

Area 4: Individual control in settings/individual rights

Rule Requirements: Facilitates individual choice regarding services and supports, and who provides them. The setting optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact. The setting ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

In addition, in a provider-owned or controlled residential setting, each individual has privacy in their sleeping or living unit; units have entrance doors lockable by the individual, with only appropriate staff having keys to doors; individuals sharing units have a choice of roommates in that setting; individuals have the freedom to furnish and decorate their sleeping or living units; and individuals have the freedom and support to control their own schedules and activities, and have access to food at any time; individuals are able to have visitors of their choosing at any time.

Recommended outcomes:

- Increased number of HCBS participants whose rights are fully protected in accordance with the Rule
- Decreased number of HCBS participants with rights restrictions; any rights restrictions conform with the requirements of the rule

Area 5: Self-determination (person-centered planning and self-direction)

Rule Requirements: The setting facilitates individual choice regarding services and supports, and who provides them.

Recommended outcomes:

- Increased number of HCBS participants who have choices about providers and services
- Increased number of HCBS participants who are given a choice to self-direct
- Increased number of HCBS participants who use person-centered planning to describe what they want and need to bring purpose and meaning to their life

The HCBS Advocacy Coalition

The HCBS Advocacy Coalition is a coalition of national disability and aging organizations that work together to support the full inclusion of people with disabilities and older adults in all aspects of community life. For more information: www.hcbsadvocacy.org

Community Living Policy Center

The Community Living Policy Center, housed at the Lurie Institute for Disability Policy at Brandeis University, aims to improve policies and practices that promote community living outcomes for individuals with disabilities through research and knowledge translation activities. For more information: www.communitylivingpolicy.org