April 18, 2025

Drew Snyder
Deputy Administrator and Director
Center for Medicaid and CHIP Services
Centers for Medicare & Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244-1850

SUBMITTED ELECTRONICALLY AND BY POST MAIL

Re: Supporting The Home and Community-Based Services (HCBS) Rule (the "Settings Rule")

Dear Deputy Administrator Snyder:

We write on behalf of the 56 undersigned national disability and aging organizations committed to the continued successful implementation of the 2014 Medicaid Home and Community-Based Services (HCBS) Settings Rule. Over the past decade, states, under the guidance of the Centers for Medicare & Medicaid Services (CMS), have invested significant effort and resources to improve the quality of their Medicaid HCBS programs and to operationalize a foundational set of criteria to apply where HCBS services are provided. We respectfully urge you and your team to continue to support the progress that has been made, and we oppose any attempts to dilute or dismantle any of the federal HCBS Settings Rule's provisions.

Congress established the HCBS program under section 1915 of the Social Security Act in acknowledgement of the increased health benefits and cost savings of supporting people with disabilities and older adults in their own homes, family homes or other community settings. This statute established the parameters by which states may fund and provide Medicaid-funded HCBS in community-based settings, separate and distinct from the Medicaid long-term services and supports already authorized and provided in institutional settings.

The HCBS Settings Rule was born out of a need to ensure that Medicaid funding for community-based services is delivered in settings that provide access to the full benefits of community living rather than an institution-like experience under another name. By providing clear standards for all HCBS settings, the Settings Rule ensures the integrity of HCBS programs and that institution-like settings are appropriately regulated under Medicaid's institutional rules.

The multi-year effort to create the HCBS Settings Rule incorporated extensive stakeholder input from states, a wide range of providers, advocacy organizations, individuals, and others.

The final Settings Rule set basic standards for the provision of community-based services. Among these basic standards, the Rule requires that individuals receiving HCBS have:

- privacy, dignity, respect, and freedom from coercion in the settings where they receive services;
- autonomy in making life choices, including selecting their HCBS provider and their daily activities; and
- support to fully access opportunities in the greater community, including options for employment in competitive integrated settings if desired, to receive services in the community, and to fulfill goals and activities in the community as they have selected in their person-centered plan.

The basic expectations laid out in the Settings Rule are neither onerous nor unreasonable. The overall effect of the Rule is to make sure people have choices in services that support their health, social, and other needs. A decade of states' experiences implementing the HCBS Settings Rule has shown that the Rule carefully balances individuals' basic rights across the full range of functional support needs for HCBS recipients. The Rule recognizes that people receiving HCBS have varying needs, and allows for individual modifications where necessary to ensure an individual's safety, but is designed to ensure such modifications are appropriately justified and has protections to prevent those modifications from being abused for the convenience of providers or other parties.[1]

Now over a decade after implementation began, the Settings Rule has become embedded in states' HCBS laws, regulations, and policies and in the expectations of people with disabilities themselves. States and providers spent years bolstering their person-centered planning systems and adjusting their programs to meet the Rule's requirements. Medicaid HCBS recipients and their advocates have embraced the fundamental protections that the Rule

[1] One example illustrates how the Settings Rule's modification process effectively balances basic rights and freedoms across the range of individual needs. Historically, food is highly regimented in institutional settings, with little choice over what or when a person may eat and limited access to food outside of a strict meal rotation. In contrast, a person living outside an institution typically shops for their own groceries, has ready access to food in their kitchen, and has input on what they eat every day. In the rulemaking for the Settings Rule, CMS set as the goal that there is choice and access to food, but recognized that some people, due to their disabilities or health conditions, may need more restricted access to food. Therefore, although the Rule requires provider-owned or controlled HCBS settings to provide access to food at any time, this requirement can be modified for an individual who has a specific need, such as diabetes or pica, to either have limited access or access to only certain foods at any time. The Rule seeks to provide choice and a home-like experience to the extent possible, recognizing there may be a need for restrictions as long as they are individualized and reviewed periodically so that if a person's status changes, the restrictions will change with them.

provides. It is now a foundation for states' HCBS systems, promoting the principles of full access to community living, autonomy, and integration into broader society.

Since the Rule was enacted, states have worked closely with HHS and their stakeholders to implement comprehensive statewide transition plans; update state regulations and policies to assure adoption of the basic criteria set forth in the Rule; build new innovative service delivery models; and strengthen providers' capacity to offer high quality HCBS in the community. To reopen or rescind the HCBS Settings Rule at this time would compromise all of the work completed to date and overwhelm state Medicaid agencies that have put so much into modernizing their HCBS programs over the past decade. States and providers would have to again rewrite policies and reprogram computer systems at huge expense.

Rolling back or weakening these protections would also be a dangerous step backwards for people with disabilities and older adults. It would directly compromise basic rights that all people – including disabled people and older adults – should have. Undermining these basic rights of autonomy, choice, and community integration would likely trigger major pushback from States, service providers, aging and disability advocates, and the public at large.

Contrary to some misinformation about the Settings Rule, it does not and has never specifically prohibited types of settings other than the defined Medicaid institutions. It establishes a process for all other settings to show that they provide a community-based experience. This includes adhering to the relatively few basic protections and principles listed in the Rule. For example, provider-controlled or owned residential settings must provide a written lease or tenancy agreement that provides the tenancy protections afforded to anyone living in that jurisdiction. They must provide units with lockable doors with only appropriate staff having access to keys. They must allow individuals to decorate their living spaces as they choose and support individual's control over their daily schedule and activities. And they must allow residents access to food and visitors at any time. These describe basic minimum rights that anyone living in the community should expect. They should not be controversial, even if the implementation requires thoughtfulness and nuance. Types of settings like gated communities, farmsteads, assisted living facilities, and disability-specific intentional communities have always been able to qualify as HCBS settings, as long as they meet the basic requirements and protections in the Settings Rule. As part of the Rule's balancing process, certain settings that exhibit characteristics or tendencies that are likely to isolate people from the broader community may receive heightened scrutiny as they are reviewed, but the core requirements they need to meet are the same as those for other provider-owned and controlled HCBS settings. Indeed, many of these types of settings have already been approved as Medicaid HCBS settings.

Nor does the Rule regulate or restrict access to nursing facilities, hospitals, institutions for mental diseases (IMD), and intermediate care facilities for individuals with intellectual disabilities (ICF-IID). These institutional settings have their own separate funding streams and regulatory requirements outside of HCBS.

We recognize that improving Medicaid HCBS remains a work in progress. Too many HCBS recipients still do not know their rights or who to contact if they encounter problems. Too many people with disabilities still have too few available options for where to receive services and from whom. HCBS providers are facing a direct care workforce shortage that causes them to decline new program participants. However, revising or rescinding the Settings Rule will not address the HCBS workforce shortage and would result in additional costs to states and HCBS providers.

We look forward to the opportunity to work with you and your CMS colleagues to find real solutions that make more options available and address some of these ongoing challenges. If you have any questions, please contact David Machledt, National Health Law Program (machledt@healthlaw.org).

Sincerely,

Access Ready, Inc.
Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
American Civil Liberties Union (ACLU)
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Therapeutic Recreation Association
The Arc of the United States
Association of People Supporting Employment First (APSE)
Autism Society of America
Autistic Self Advocacy Network (ASAN)
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Caring Across Generations
Center for Medicare Advocacy
Center for Public Representation
CommunicationFIRST
Community Catalyst
Corporation for Supportive Housing
The Council on Quality and Leadership

Disability Rights Education and Defense Fund (DREDF)
Diverse Elders Coalition
Easterseals, Inc.
Epilepsy Foundation of America
Family Voices National
Griffin-Hammis Associates
Human Services Research Institute
IEC (Institute for Exceptional Care)
Justice in Aging
The Kelsey
Lakeshore Foundation
Marc Gold & Associates
Medicare Rights Center
MomsRising
Muscular Dystrophy Association
NASILC - National Association of Statewide Independent Living Councils
National Academy of Elder Law Attorneys (NAELA)
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Consumer Voice for Quality Long-Term Care
National Disability Institute
National Down Syndrome Congress
National Down Syndrome Society
National Health Council
National Health Law Program
National PLAN Alliance (NPA)
National Respite Coalition
National Women's Law Center
New Disabled South
PHI
SPAN Parent Advocacy Network (SPAN)
TASH
United States International Council on Disabilities
Usher Syndrome Coalition
Well Spouse Association