



PO Box 26853
San Jose, CA 95159

info@ncsautism.org
ncsautism.org

March 17, 2025

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

Re: A New Era of Common Sense About Developmental Disabilities: It's Time to Rescind The CMS Home and Community Based Services Rule ("Settings Rule")

Dear Deputy Administrator Snyder:

I am the president of the National Council on Severe Autism, a national organization advocating for the growing population of Americans disabled by severe and profound forms of autism and related neurodevelopmental disorders.

We are writing in strong support of the March 11, 2025 request by Together for Choice to rescind or amend the Obama-era CMS Home and Community-Based Services Rule (the "Settings Rule"), 42 C.F.R. Sec. 441.301(c). The purpose of the Rule is to define what settings are considered home and community-based settings and therefore what programs qualify for Medicaid waiver funding under Section 1915(c) of the Social Security Act.

Medicaid waiver funding is a lifeline for adults with severe and profound forms of autism. These individuals often suffer severe cognitive impairment with an array of behavioral challenges that can include aggression, self-injury, property destruction, elopement (wandering from supervised safety) and pica (ingestion of inedible objects). They typically require 24/7 supervision and often benefit from amenities such as open space, proprioceptive activities such as swinging and bouncing, safety features such as fences and gates, and when loud vocalizations are involved, some remove from neighboring properties. Daily living skills such as dressing, hygiene and communication are also often a challenge for this population.

The Settings Rule is designed to promote person-centered planning, which is very important, but it subsumes this purported principle within a bureaucratic, ideological, and intrusive framework that has the effect of sharply limiting options, particularly for individuals like those we represent. The rule ignores both practical realities and private, appropriate choices. It places significant burdens on the states in terms of time and expense. It is so vague about both its substantive and procedural contours that its interpretation varies not only state to state but county to county.

In the end, it strongly disincentivizes program development — particularly for those with the most severe developmental disabilities — because local and state bureaucrats can deny HCBS

funding to individuals based on an oceanic amount of discretion. Anything deemed to have the “risk of isolating” an individual, no matter how arbitrary, may result in a denial of services funding. It’s a sword hanging over the heads of every program serving individuals with severe autism and related disabilities.

But this “risk of isolating” is nonsensical as written and applied. The Rule assumes, without evidentiary basis, that an individual living in an apartment with an aide — but having no friends or community activities — is not isolated, while an individual living in a group setting among friends and ample options for site-based and community engagement — is isolated. Personal choice is erased. Appropriate and financially viable solutions succumb to whims of bureaucrats.

We are hearing from families across the country that states are denying new developments based on a vague assertions that the Settings Rule prohibits HCBS funding for disability-specific programs. A father in Southern California was told he could not develop a property to serve his daughter if “too many” other disabled individuals were allowed to live on the site. A mother in New York reports that her developmental disability department refused to fund programming for an autism-specific program. Families in Pennsylvania tell us that virtually no residential options appropriate for adults with severe and profound autism are permitted due to the state’s draconian interpretation of the Settings Rule. The Rule stands in the way of the development and operation of appropriate day and residential programs for America’s most vulnerable citizens — even when based on infusions of private funding.

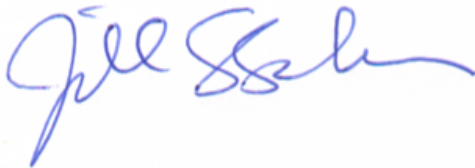
We agree with Together for Choice that CMS should recommend to the Administrator of the Office of Information and Regulatory Affairs that the Settings Rule be rescinded.

However, if CMS prefers to recommend that the Settings Rule be amended, we also endorse the redlined version offered by Together for Choice.

America needs a new era of common sense about autism and developmental disabilities — and this includes axing red tape that is preventing our most severely intellectually disabled Americans from receiving appropriate services while maximizing financial efficiency.

We at NCSA would appreciate the opportunity to meet with you in person or virtually to discuss rescission or amendment of the Settings Rule.

Best regards,



Jill Escher
President
jill.escher@gmail.com
408.314.1655