The Arc New York

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Centers for Medicare & Medicaid Services
Department of Health and Human Services

Re: CMS-2454-IFC; RIN 0938-AV98; Medicaid Program; Community Engagement Requirement for Certain Individuals

Dear Administrator Oz:

The Arc New York appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services' interim final rule implementing the Medicaid community engagement requirement. The Arc New York is the state's largest network of community-based providers and advocates for people with intellectual and developmental disabilities (IDD). Our 33 local chapters serve more than 60,000 New Yorkers with IDD and their families in every county of the state, supported by a workforce of more than 30,000 direct support professionals and staff.

The Arc New York strongly urges CMS to revise the interim final rule to prevent eligible people with disabilities, family caregivers, and people using home and community-based services (HCBS) from losing Medicaid coverage because of administrative barriers. In New York, Medicaid is the foundation of the state's entire system of services for people with IDD, funding HCBS waiver services, day habilitation, supported employment, residential supports, service coordination, and behavioral health care administered through the Office for People with Developmental Disabilities (OPWDD). Nonprofit provider agencies funded by OPWDD employ nearly 100,000 direct support professionals and deliver 85% of services to approximately 140,000 New Yorkers with IDD. Any Medicaid coverage losses caused by this rule's paperwork and verification burdens will fall directly on a system already stretched thin, jeopardizing both the people who rely on these services and the workforce that delivers them.

A 2023 federal analysis of a similarly structured Medicaid work-reporting proposal estimated that more than 2.3 million New Yorkers ages 19 to 55 were enrolled in Medicaid outside of disability, parent/caretaker, or pregnancy related eligibility pathways. While the current rule differs in its specifics, that analysis illustrates the scale of New Yorkers whose ongoing coverage could turn on whether the state can correctly and promptly identify who is exempt. Nationally, research from the only state to have fully implemented Medicaid work requirements found that nearly one in four adults subject to the policy lost coverage, even though more than 95% either

already met the requirement or should have qualified for an exemption, they lost coverage because they could not navigate the reporting process, not because they were ineligible.[1] The Arc New York is deeply concerned that New York will see the same result.

The rule makes Congress' protections for people with disabilities, medically frail individuals, family caregivers, and direct support professionals too dependent on complex state verification systems, documentation rules, and functional tests that do not reflect the lives of people with IDD and those who support them.

I. CMS should remove the "ability to comply" requirement

CMS's rule goes beyond the statute by requiring states to verify not only that a person has a qualifying disability or medical condition, but also that the condition "significantly impairs" their ability to comply with the community engagement requirement. This two-part test creates a new disability-related determination that Congress did not require, and one that independent analysts have found lacks clear standards for states to apply, leaving New York and other states to develop their own inconsistent, unguided methods for measuring "ability to work."[2] Many people with IDD in New York work successfully with the help of Medicaid-funded supported employment and job coaching, but that same support does not mean they can reliably complete a complex monthly reporting regime without assistance. CMS should not confuse a person's capacity to work with supports with their capacity to navigate red tape.

New York Attorney General Letitia James has joined a coalition of 24 states and the District of Columbia in suing the administration over this rule, arguing that the "ability to comply" test unlawfully narrows the medically frail exemption beyond what the statute permits and puts New Yorkers with cancer, diabetes, HIV, serious mental illness, and other complex conditions at risk of losing coverage they need to manage those very conditions. The Arc New York shares these concerns and urges CMS to remove this additional test from the rule.

II. CMS should revise the medical frailty standard to include recognition of ADLs

The Arc New York is concerned that the rule limits the IDD-related medical frailty category to people whose disability significantly impairs one or more activities of daily living (ADLs), even though many of the New Yorkers our chapters serve have significant support needs that fall outside that narrow definition, such as needs related to adaptive functioning, communication, behavioral regulation, safety supervision, decision-making, and medication management. CMS should clarify that people with disabilities may qualify as medically frail based on limitations in instrumental activities of daily living adaptive functioning, communication, behavioral support needs, supervision for safety, decision-making, medication management, transportation, or the need for ongoing assistance to navigate health care and public benefit

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[1] Sommers BD, Goldman AL, Blendon RJ, Orav EJ, Epstein AM, "Medicaid Work Requirements — Results from the First Year in Arkansas," *New England Journal of Medicine* 2019;381(11):1073-1082, https://www.nejm.org/doi/full/10.1056/NEJMsr1901772

[2] KFF, "The Medical Frailty Exemption from Medicaid Work Requirements: Key Takeaways from the CMS Interim Final Rule," June 23, 2026, https://www.kff.org/medicaid/the-medical-frailty-exemption-from-medicaid-work-requirements-key-takeaways-from-the-cms-interim-final-rule/

systems. The final rule should not require an ADL limitation as the only functional pathway for people with developmental disabilities, many of whom can independently perform basic self-care tasks while still needing extensive support to manage the rest of daily life.

III. CMS should allow long-term and accessible verification

Many of the New Yorkers The Arc New York supports have lifelong IDD diagnoses that will not change from one annual verification to the next. Yet the rule still requires states to reverify medical frailty status at least every 12 months for everyone, including people with lifelong, unchanging conditions, and generally limits self-attestation to a single use per enrollment period beginning in 2028.

Given New York's ongoing direct support workforce shortage and the documented delays New Yorkers already face in obtaining specialist appointments and updated documentation, repeated proof requirements for lifelong diagnoses will create unnecessary administrative burden and coverage loss, not program integrity. CMS should create a strong presumption of medical frailty for people with lifelong developmental disability diagnoses or records demonstrating longstanding disability. CMS should also allow self-attestation, caregiver attestation, authorized representative attestation, and provider attestation whenever ex parte claims data are unavailable or incomplete, which is a common scenario since claims data alone often cannot capture a person's functional status, ability to perform activities of daily living, or overall frailty.[3]

This concern is especially urgent for New Yorkers with IDD who are in the process of applying for Supplemental Security Income (SSI). SSI's own five-step disability determination process currently takes an average of 184 days, with roughly 862,000 applicants nationwide awaiting an initial decision as of May 2026. Because New York has adopted the ACA Medicaid expansion, a large share of new SSI enrollees are covered through the expansion pathway before their SSI approval. Until their SSI claim is approved, these New Yorkers remain subject to the community engagement requirement and must separately prove medical frailty on a much faster Medicaid timeline with renewals every six months and only 30 days to respond to a notice of noncompliance, using different criteria than the Social Security Administration applies to their disability claim. CMS should ensure that a pending SSI application, standing alone, is sufficient to establish an exemption from the work requirement while that application is under review.

IV. CMS should strengthen the caregiver exclusion

The Arc New York supports CMS's recognition that parents, guardians, caretaker relatives, and family caregivers of people with disabilities may be excluded from the work requirement. The final rule should make clear that caregiving includes assistance with ADLs, supervision, cueing, communication support, behavioral support, transportation, medication management, appointment scheduling, care coordination, crisis prevention, and help navigating education, employment, and public benefit systems.

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[3] KFF, "What Could Medicaid Work Requirements Mean for SSI Applicants?" July 29, 2026, https://www.kff.org/medicaid/what-could-medicaid-work-requirements-mean-for-ssi-applicants/

Many New York family caregivers who provide this kind of daily, essential support do not think of themselves as "caregivers" in a formal sense, and as a result may struggle to document their role using rigid, unfamiliar criteria. CMS should require states to use plain-language screening questions to identify caregivers, consistent with The Arc's own plain-language guidance to help families navigate this rule.[4] CMS should also recognize that multiple caregivers frequently share responsibility for the same individual within a single household, and should not limit the exclusion to a single designated caregiver.

V. CMS should allow Medicaid-supported employment and HCBS employment services to count toward compliance

The Arc New York urges CMS to permit Medicaid-covered supported employment services provided through 1915(c) waivers or 1915(i) state plan services to independently satisfy the work-program pathway. For New Yorkers with IDD, supported employment, job coaching, prevocational services, benefits counseling, transportation training, and other HCBS employment supports are often the very services that make competitive integrated employment possible in the first place. Counting participation in these Medicaid-funded services toward compliance would align the rule with its stated purpose of promoting work, rather than creating a second, disconnected reporting burden on top of services New York already administers and verifies.

Conclusion

The Arc New York urges CMS to pause and revise the interim final rule to ensure that people with intellectual, developmental, and other disabilities, family caregivers, and direct support professionals in New York do not lose Medicaid because of paperwork, inaccessible systems, or narrow definitions that fail to reflect disability-related support needs. Medicaid is the backbone of health care, independence, employment, and community living for more than 60,000 New Yorkers with IDD served by The Arc New York's chapters alone. CMS should implement the statute as Congress intended in a way that protects coverage, minimizes administrative burden, and ensures that people with disabilities and their families are not harmed by systems that cannot accurately recognize their needs.

Respectfully Submitted,

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The Arc New York

[4] The Arc, "New Medicaid Work Rules: What People With Disabilities and Families Should Know," July 16, 2026, https://thearc.org/blog/new-medicaid-work-rules-what-people-with-disabilities-and-families-should-know/.