
July 31, 2026

Dr. Mehmet Oz
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

*Submitted via regulations.gov*

**RE: Medicaid Program; Community Engagement Requirement for Certain Individuals (CMS-2454-IFC)**

Dear Administrator Oz:

Autism Speaks is a national non-profit organization dedicated to creating an inclusive world for people with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care for autistic individuals and their families.

Autism Speaks appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services' interim final rule (IFR) implementing Medicaid community engagement requirements for certain individuals. Medicaid is a critical source of health care coverage and long-term services and supports for autistic individuals across the lifespan. It finances essential health care, behavioral health services, home and community-based services, employment supports, residential services, and other disability-related supports that help autistic individuals live, work, and participate in their communities.

Autism Speaks is concerned that the interim final rule does not adequately account for the needs and circumstances of autistic individuals and their families. In particular, we are concerned that the rule narrows the statutory medical frailty protections established by Congress and adopts verification, documentation, and reverification requirements that may create unnecessary barriers for autistic individuals and their families. These barriers may increase the risk of coverage loss for individuals who remain eligible for Medicaid and who should not be subject to community engagement requirements.

As currently structured, the rule imposes additional policy and administrative requirements that may make it harder for eligible individuals to maintain coverage. These risks are especially significant for autistic individuals whose support needs may not be fully reflected through traditional disability-based Medicaid eligibility pathways or through records that were not designed to measure an individual's ability to satisfy a monthly community engagement requirement. Autism Speaks remains committed to protecting access to the Medicaid-covered services and supports that are essential to autistic individuals and their families.

For the reasons discussed below, **Autism Speaks respectfully urges CMS to withdraw the interim final rule and issue a substantially revised proposal that more faithfully implements the statutory medical frailty protections enacted by Congress, preserves the verification flexibility Congress provided to states, minimizes administrative burden, protects continuity of coverage, and safeguards access to Medicaid-funded services for autistic individuals and their families**.

## The Critical Role of Medicaid for the Autism Community

For many individuals on the autism spectrum, Medicaid is the primary public source of access to essential health care, behavioral therapies, and community-based services. Without this coverage, families often face impossible choices between financial stability and meeting critical care needs. Medicaid is a critical source of support across the lifespan. Approximately 600,000 autistic individuals rely on Medicaid for medical care as well as residential, vocational, and day programs, illustrating the program's central role in supporting health, independence, employment, and community participation. [i] Medicaid also provides access to diagnostic services, therapies that support communication and daily living skills, and lifespan services such as employment support, assistive technology, and respite care.

Medicaid is especially important because autistic individuals access coverage through multiple eligibility pathways. 2020 data show that 4.7 percent of autistic Medicaid beneficiaries were enrolled through the Medicaid expansion population, while 57 percent qualified through disability-related eligibility categories. [ii] Autistic adolescents and young adults also disproportionately rely on Medicaid through autism-specific and developmental disability waiver programs. While some individuals may become eligible for Medicare through Social Security Disability Insurance as they transition to adulthood, Medicaid often remains critical for accessing community-based services and supports. Research has found that both dual Medicare-Medicaid enrollment and participation in Medicaid waiver programs are associated with greater use of community mental health services among autistic adolescents and young adults, underscoring the important role Medicaid plays in maintaining continuity of care and access to essential supports across systems.[iii]

For many autistic adults with co-occurring intellectual and developmental disabilities, Medicaid may be the only public funding source that enables them to live and work in their communities. These individuals often require specialized, person-centered care that accounts for sensory, communication, and support needs. Medicaid-funded services are particularly critical for those who rely on consistent medical, behavioral, personal care, or community-based supports to successfully participate in their communities.

## Medical Frailty Exemption Framework

**CMS should implement the medical frailty exclusion in a manner that fully recognizes the diverse support needs and circumstances of autistic individuals and ensures that individuals Congress intended to protect are not inappropriately subjected to community engagement requirements.**

Public Law 119-21 identifies several categories of individuals who qualify as medically frail or otherwise have special medical needs, including individuals who are blind or disabled, individuals with a substance use disorder, individuals with a disabling mental disorder, individuals with a physical, intellectual, or developmental disability that significantly impairs their ability to perform one or more activities of daily living, and individuals with a serious or complex medical condition. These categories reflect Congress's recognition that certain individuals have health conditions, disabilities, and support needs that make application of community engagement requirements inappropriate.

The interim final rule substantially narrows this protection by requiring medical frailty determinations to consider not only whether an individual falls within one of the statutory categories, but also whether the individual's condition significantly impairs their ability to satisfy the community engagement requirement. In practice, this

approach risks turning what Congress established as a protection for medically frail individuals into a more burdensome individualized assessment tied to work capacity, community engagement, and monthly compliance.

Autism Speaks is particularly concerned that this framework may fail to protect autistic individuals who should qualify for exclusion from community engagement requirements under the statutory protections enacted by Congress. For some autistic individuals, barriers related to employment, community engagement, transportation, communication, reporting requirements, and other administrative processes may create challenges in satisfying community engagement requirements and related verification obligations.

These barriers may not always be fully reflected in diagnosis codes, claims data, or standard medical documentation. Existing records may appropriately identify individuals who fall within statutory categories established by Congress. However, those records often do not capture the practical barriers that may affect an individual's ability to satisfy or document compliance with community engagement requirements. As a result, autistic individuals who Congress intended to protect may nevertheless face significant difficulty navigating the IFR's additional functional assessment and verification framework.

This is especially concerning for autistic adults who do not qualify through disability-based Medicaid eligibility pathways but receive Medicaid through expansion-related categories or section 1115 demonstrations. Some of these individuals may have support needs and barriers relevant to community engagement, even if they are not enrolled through a traditional disability eligibility category.

**CMS should revise the rule to remove the requirement that individuals classified as medically frail must separately demonstrate that their condition significantly impairs their ability to satisfy the community engagement requirement.** The statutory medical frailty categories already reflect Congress's judgment regarding the individuals who should be protected from application of the community engagement requirement. By imposing a separate functional assessment tied to compliance with the community engagement requirement, the IFR narrows protections that Congress established for individuals with disabilities, serious health conditions, and other significant support needs.

Even apart from concerns regarding the medical frailty exclusion, Autism Speaks is concerned about the impact of community engagement requirements on autistic individuals who remain subject to the requirement.

**Medicaid Coverage Supports Health, Employment, and Community Participation for Autistic Individuals**

**CMS should ensure that any community engagement requirements are implemented in a manner that protects autistic individuals from unnecessary coverage loss and disruptions in care.** Medicaid coverage often supports the very health, stability, and disability-related services that make employment and community participation possible.

For many autistic adults, Medicaid-covered health care, behavioral health treatment, and community-based services are essential to managing co-occurring conditions, such as anxiety and depression, and maintaining stability in daily life and employment. Research has found that autistic individuals enrolled in Medicaid waiver programs are more likely to utilize mental health services, underscoring the role Medicaid plays in connecting individuals to needed care. [iv] These services can help support the health and stability necessary for employment and community participation. Loss of coverage may therefore disrupt not only access to health care and services, but also the supports that help some autistic individuals pursue or maintain employment.

For autistic individuals who are employed, maintaining 80 hours of qualifying activity each month may not always be feasible. Employment outcomes among autistic adults continue to reflect significant barriers to workforce participation. Research has found that nearly 42 percent of autistic adults never worked for pay during their early 20s.[v] Even among autistic adults who participate in the workforce, employment is often part-time or

limited in scope. Survey data indicate that 75 percent of employed autistic adults enrolled in Medicaid work part-time rather than full-time, and nearly half report annual earnings of only $10,000.[vi] These findings suggest that many autistic workers have limited or fluctuating attachment to the labor force and may be particularly vulnerable to losing coverage if they are unable to consistently meet monthly work-hour requirements.

**CMS should revise the rule and issue comprehensive guidance to states to account for barriers to sustained employment, fluctuating support needs, and complex health circumstances that many autistic individuals experience.** That guidance should make clear that temporary or periodic participation in qualifying employment or employment-related activities does not disqualify an individual from later qualifying as medically frail. A disabled person's ability to work, volunteer, participate in training, or engage in community activities may vary from month to month, and participation often depends on the availability of supports.

**CMS Should Clarify Qualifying Activities for Autistic Individuals Participating in Employment Supports**

**To the extent autistic individuals remain subject to community engagement requirements, CMS should ensure that disability-related employment and vocational supports are recognized appropriately.** Many autistic individuals participate in vocational rehabilitation (VR) services, supported employment, job coaching, career exploration, skill-building, and other employment-related activities intended to help them obtain and maintain work.

Available data demonstrate vocational rehabilitation services are widely used by autistic individuals and can support employment goals. On average, approximately 80 percent of autistic individuals across states received VR services after being found eligible.[vii]

**CMS should clarify that participation in vocational rehabilitation, supported employment, job coaching, job search assistance, pre-employment training, transition services, and related employment-support activities counts toward the community engagement requirement where an individual is subject to the requirement. CMS should also clarify that participation in these activities does not undercut eligibility for the medical frailty exclusion.** Autistic individuals should not be penalized for attempting to work, train, or build employment skills with the supports available to them.

This point is especially important for autistic youth and young adults in transition. Participation in transition services through an Individualized Education Program, pre-employment transition services, career exploration, work-based learning, or skill-building activities does not necessarily indicate that an individual can consistently satisfy an 80-hour monthly requirement or navigate reporting obligations without support. **CMS should ensure that state implementation does not discourage participation in transition and employment-support programs that are designed to promote long-term independence and community inclusion.**

**HCBS Participants and Individuals Receiving Disability-Related Services Require Clear Protection**

Autism Speaks is also concerned about uncertainty regarding how the interim final rule will apply to individuals receiving home and community-based services and other disability-related supports through Medicaid.

Many autistic individuals rely on Medicaid-funded HCBS to live, work, and fully participate in their communities. These services may include supported employment, residential supports, day services, personal assistance, respite, behavioral supports, and other long-term services and supports that help individuals achieve greater independence and community inclusion. For many individuals, HCBS are not optional services; they are the support system that makes community living possible.

**CMS should provide clear guidance ensuring that individuals receiving HCBS and other disability-related services who meet the statutory criteria for medical frailty are appropriately identified and excluded from**

**community engagement requirements.**

This clarification is necessary to avoid confusion for states, individuals, families, providers, and eligibility workers. It would be inappropriate for individuals receiving substantial disability-related supports through Medicaid to lose coverage because of procedural barriers, documentation failures, or misunderstanding about the interaction between Medicaid eligibility pathways, HCBS authority, and the medical frailty exclusion.

**In revising this rule, CMS should provide detailed implementation guidance to states regarding identification of HCBS participants and individuals receiving disability-related services who qualify for medical frailty protections.** The guidance should direct states to rely on existing Medicaid records, HCBS enrollment information, eligibility files, case records, claims, encounter data, and other reliable information already available to the state wherever possible, rather than requiring individuals and families to submit duplicative documentation. Congress expressly directed states to use reliable information available to the state and, where possible, avoid requiring individuals to submit additional information.

**Verification and Documentation Requirements Should Preserve the Flexibility Congress Provided**

Autism Speaks is deeply concerned that the interim final rule's verification, documentation, reporting, and reverification requirements will produce coverage losses unrelated to actual eligibility.

Autism Speaks recognizes that the statute (Public Law 119-21) requires states to verify compliance with community engagement requirements and to determine whether individuals qualify for exceptions or exclusions. The statute requires states to verify compliance at regular redetermination and allows states to conduct more frequent verifications if they choose. However, Congress also directs states to establish processes and use reliable information available to the state, including payroll data, payments, encounter data, and data on payments for Medicaid-covered services, without requiring additional information from the individual where possible.

**CMS should revise the interim final rule to preserve that statutory flexibility. The rule creates an added verification challenge by requiring states to determine not only whether an individual falls within a statutory medical frailty category, but also whether the individual's condition significantly impairs their ability to satisfy the community engagement requirement.** That additional inquiry is difficult to administer using existing state systems and risks increasing documentation burden on individuals, families, providers, and eligibility workers.

Claims data, diagnosis codes, encounter data, HCBS enrollment records, and existing Medicaid eligibility records may often be sufficient to identify individuals who fall within one of the medical frailty categories established by Congress. However, those data sources generally are not designed to measure an individual's ability to satisfy the community engagement requirement and cannot reliably capture the functional, environmental, and support-related factors that may affect participation in qualifying activities. The challenge is not identifying many individuals with autism and other developmental disabilities. Rather, the challenge arises from the IFR's additional requirement that states determine whether an individual's condition significantly impairs their ability to satisfy the community engagement requirement. Existing claims, diagnosis, encounter, HCBS, and eligibility data were not designed to support that type of determination.

For the autism community, these requirements create significant risk. Autistic individuals frequently encounter challenges navigating health care systems, coordinating care, communicating with providers, completing administrative processes, responding to documentation requests, and understanding complex notices. These challenges do not reflect a lack of eligibility for Medicaid. They reflect the very barriers that the medical frailty exclusion should account for.

Many individuals may not have recent claims data that adequately reflects their needs. Others may have

conditions that are under-coded, inconsistently documented, or documented in ways that do not speak to their ability to satisfy community engagement requirements. Provider documentation may also be difficult to obtain, particularly where specialists are unavailable, wait times are long, providers are unfamiliar with the required forms, or clinicians are reluctant to make determinations about a patient's ability to work or meet community engagement requirements.

The autism community already navigates complex health care, educational, and social service systems. Burdensome administrative processes can be particularly challenging for individuals with communication differences, executive functioning difficulties, or significant support needs, increasing the likelihood of missed deadlines, incomplete documentation, or other procedural issues that could result in avoidable coverage disruptions.[viii] Research has found that autistic adults experience barriers to health care access at disproportionately high rates compared with individuals with other types of disabilities. These barriers include difficulty identifying providers with appropriate autism expertise, challenges navigating complex health care systems, communication barriers with providers, limited care coordination, transportation obstacles, and inadequate support when accessing services.[ix] In many communities, shortages of qualified providers and long wait times for specialty appointments can further delay access to care and documentation.

These concerns are especially significant for individuals whose exclusion from community engagement requirements is based on autism or another developmental disability. Repeated documentation and annual reverification requirements may impose substantial administrative burden without meaningfully improving program integrity. The relevant question should not be whether an individual continues to have autism, but whether state records already establish that the individual should not be subject to the community engagement requirement. Where existing records establish that status, additional documentation and repeated reverification should not be required.

As a result, otherwise eligible autistic individuals may lose coverage not because they fail to qualify for Medicaid or do not meet an exclusion, but because they miss deadlines, misunderstand reporting requirements, are unable to obtain documentation, or encounter administrative barriers during verification and reverification.

The consequences of even temporary coverage loss can be significant. Medicaid supports access to health care, behavioral health services, therapies, employment supports, HCBS, and care coordination. Interruptions in coverage can destabilize access to services and create additional administrative burdens for individuals, families, providers, and state agencies. Prior Medicaid community engagement demonstrations have shown that beneficiary awareness, clarity of requirements, accessibility of reporting mechanisms, and administrative complexity can influence participation and compliance.

**CMS should revise the verification framework to better align with the flexibility Congress provided and maximize the use of reliable information already available to state Medicaid agencies.** States should be permitted to rely on existing eligibility records, disability determinations, HCBS enrollment information, diagnosis and claims data, encounter data, case records, managed care information, and beneficiary attestations where appropriate rather than requiring additional documentation whenever possible. **CMS should also revise the interim final rule's restrictions on self-attestation for medical frailty and its annual reverification requirements.** For conditions such as autism and other developmental disabilities, repeated documentation and recurring reverification requirements may increase administrative burden without meaningfully improving program integrity.

## Impacts on Family Caregivers

The interim final rule's reporting, documentation, verification, and reverification requirements will also affect family caregivers who frequently assist autistic individuals in navigating Medicaid and other public programs. **CMS should revise the caregiving exclusion framework to adopt the broader statutory caregiver definition**

**established by the RAISE Family Caregivers Act and protect caregivers from burdensome documentation requirements, reporting obligations, and potential coverage loss.**

Autism Speaks is concerned that the interim final rule departs from the broader caregiver definition established by Congress in the RAISE Family Caregivers Act by limiting the exclusion based on criteria related to living arrangements, family relationships, or, for some caregivers, a requirement to demonstrate at least 80 hours of caregiving activities per month. As a result, some individuals who qualify as family caregivers under the RAISE Family Caregivers Act may not qualify for the exclusion and could become subject to community engagement requirements. The interim final rule also requires some caregivers to document and report caregiving activities to demonstrate compliance with the 80-hour threshold. Because much of family caregiving occurs outside formal service settings and may not be easily verified, obtaining and maintaining this documentation may be difficult. Many caregivers already devote substantial time to coordinating medical care, therapies, educational services, waiver programs, employment supports, transportation, and public benefits. Additional obligations to track caregiving hours, gather documentation, complete reporting requirements, and respond to verification requests will increase administrative burden on families, potentially diverting time from caregiving responsibilities and placing caregivers' own coverage at risk.

**State Implementation Challenges Increase the Risk of Improper Coverage Loss**

Autism Speaks is deeply concerned about how states will operationalize the medical frailty framework established by the interim final rule. Existing eligibility systems were generally designed to identify diagnoses, eligibility categories, and service utilization – not to make individualized determinations regarding whether a person's condition significantly impairs their ability to satisfy an 80-hour monthly community engagement requirement. As states implement these requirements, autistic individuals may face inconsistent determinations, unnecessary documentation requests, and increased risk of procedural coverage loss. **CMS should revise the rule and provide implementation guidance that prioritizes use of existing records, minimizes administrative burden, and protects eligible individuals from inappropriate disenrollment.**

In particular, **CMS should ensure that states rely on available information whenever possible, avoid unnecessary documentation requests, and implement medical frailty protections in a manner that is understandable and accessible for autistic individuals and their families.**

Prior Medicaid work requirement demonstrations have shown that complex reporting and verification procedures can result in coverage losses that are unrelated to eligibility for coverage.[x] For autistic individuals and others who may already encounter challenges navigating health care and public benefit systems, documentation and reporting requirements may create additional barriers to maintaining coverage. **CMS should revise the IFR to ensure that autistic individuals and their families do not lose access to essential health care services and supports because of documentation requirements, reporting obligations, or other procedural barriers unrelated to eligibility.**

**Conclusion**

The policies established by the interim final rule would increase the risk of unnecessary coverage loss, create additional administrative barriers, and jeopardize access to essential health care services and supports for autistic individuals and their families. Medicaid is a primary source of access to essential health care, behavioral therapies, and community-based services for many autistic individuals. Taken together, the IFR's narrowed medical frailty framework, burdensome documentation and verification obligations, and increased risk of Medicaid disenrollment threaten access to critical services that support health, independence, community participation, and employment opportunities for the autism community.

Congress established medical frailty protections for individuals with disabilities, serious health conditions, and

other significant support needs. CMS's implementation adds a separate inquiry into whether an individual's condition significantly impairs their ability to satisfy the community engagement requirement and then layers verification, documentation, and reverification requirements on top of that inquiry. For autistic individuals, this narrowed framework is especially problematic because autism-related barriers relevant to employment, reporting, documentation, communication, transportation, and systems navigation may not be fully captured by claims data, diagnosis codes, or activities-of-daily-living assessments.

Combined with a verification framework that may limit states' ability to rely on existing records, available state information, beneficiary attestations, and state election not to require individual verification where permitted by statute, the interim final rule creates a significant likelihood of Medicaid coverage losses driven by administrative burden rather than true ineligibility. Such losses would threaten access to HCBS, employment supports, behavioral health services, health care, and other Medicaid-funded services that support health, independence, employment, and community participation.

For these reasons, **Autism Speaks respectfully urges CMS to withdraw the interim final rule and issue a substantially revised proposal that fully implements the statutory medical frailty protections enacted by Congress, preserves state flexibility in verification, minimizes administrative burden, protects continuity of coverage, and safeguards access to Medicaid-funded services for autistic individuals and their families**.

Autism Speaks appreciates the opportunity to provide these comments and welcomes the opportunity to work collaboratively with CMS to design policies that center the experiences and needs of autistic individuals and their families. Should you have any questions, please contact Alyssa Brockington, Director of Public Policy, at alyssa.brockington@autismspeaks.org.

Sincerely,

David Sitcovsky
Vice President, Advocacy
Autism Speaks

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[x]Jennifer Tolbert, Sammy Cervantes, and Gary Claxton, *Different Data Source, But Same Results: Most Adults Subject to Medicaid Work Requirements Are Working or Face Barriers to Work* (San Francisco, CA: KFF, June 25, 2025), https://www.kff.org/medicaid/different-data-source-but-same-results-most-adults-subject-to-medicaid-work-requirements-are-working-or-face-barriers-to-work/.