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Achieve with us.

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For people with intellectual and developmental disabilities

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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 of Massachusetts appreciates the opportunity to comment on the Centers for Medicare and Medicaid Services' Interim Final Rule regarding Medicaid community engagement requirements.

The Arc of Massachusetts represents more than 250,000 people with intellectual and developmental disabilities (IDD), including autism, and their families across Massachusetts. We are also informed by our seventeen local chapters, who provide direct services to individuals across the state. Everyday, we work alongside individuals with disabilities, family caregivers, providers, and community partners to advance inclusion and protect access to the supports that make independent community living possible.

Medicaid, known as MassHealth in Massachusetts, is the foundation that thousands of people with IDD rely on to live fulfilling lives. In Massachusetts, over 2 million people are enrolled in MassHealth. MassHealth pays for preventive and primary health care, behavioral health services, prescription medications, durable medical equipment, home-and community-based services (HCBS), personal care attendants, employment supports, transportation, and other essential services that allow people to live, work, and participate in their communities rather than being forced into institutional settings. For our community, access to home-and-community based services are particularly crucial.

The Arc of Massachusetts is deeply concerned that the proposed Interim Final Rule places eligible individuals at significant risk of losing Medicaid coverage—not because they fail to meet the statutory eligibility requirements, but because they cannot successfully navigate complicated reporting systems, documentation requirements, and verification processes. According to the Urban Institute, 10 million people could lose Medicaid coverage in 2028 due to these work requirements and more frequent eligibility checks. Medicaid work reporting requirements result primarily in eligible people losing coverage due to administrative barriers—not because they are unwilling to work.

Our community members often share stories of what losing Medicaid—through unnecessarily strict work requirements or other reasons—could mean for their families. The following are just a few examples out of hundreds of stories.

- *My daughter depends on Medicaid for healthcare, her day habilitation program, and her residential placement. Losing these services would be devastating.*
- *We rely on Medicaid for our son's medications, shared living supports, transportation, employment assistance, and community activities. Without these supports, one parent would have to stop working, and our family's quality of life would be significantly impacted.*
- *[My daughter] would take a significant step backward and have to move back to our home. She could lose her sense of independence, her connection with friends, and caring staff. She could lose having a meaningful life, participating in the culinary program.*

These stories are just a few examples of how critical Medicaid is for our community. Any changes to eligibility that potentially narrows this population's ability to participate in the program would be devastating.

The loss of Medicaid-funded supports does not affect only the individual receiving services—it has far-reaching consequences for entire families. Without these essential supports, family members are often forced to reduce their work hours or leave their jobs to provide care for their loved ones, resulting in financial hardships and increased caregiver burden. These effects ripple beyond individual households, creating broader economic consequences for communities.

Massachusetts has co-led a lawsuit alongside a coalition of 26 states challenging provisions of this interim final rule. The Arc of Massachusetts shares these concerns about how the interim final rule will negatively impact people with disabilities. We are submitting the following comments for the public record.

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

The rule requires states to determine not only whether an individual has a disability or is medically frail, but also whether that condition significantly impairs the person's ability to comply with community engagement requirements. This additional test goes beyond the protections established by Congress and creates a new functional determination that is unnecessary and likely to be applied inconsistently.

With Medicaid, many people with IDD work successfully because they receive substantial supports, including job coaching, transportation assistance, benefits counseling, and ongoing supervision often supplied by Medicaid. The ability to participate in employment should not be interpreted as evidence that someone does not require Medicaid protections or can independently navigate complex administrative reporting systems.

CMS should revise the final rule so that disability-related medical frailty is established by disability, medical condition, or functional support needs—not as an assumption about whether someone can independently comply with administrative processes.

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

The Interim Final Rule relies heavily on limitations in Activities of Daily Living (ADLs). While ADLs are important, they fail to capture the realities experienced by many individuals with IDD. Many people with IDD or autism independently bathe, dress, and eat, yet still require extensive daily support to safely live and work in the community. They may need assistance with communication, decision-making, medication management, transportation, behavioral supports, and more. These are legitimate disability-related support needs that directly affect an individual's ability to navigate Medicaid reporting systems and maintain coverage.

CMS should explicitly recognize Instrumental Activities of Daily Living (IADLs), adaptive functioning, communication supports, supervision for safety, behavioral support needs, cognitive limitations, and ongoing assistance with community living as qualifying indicators of medical frailty.

III. CMS should allow long-term and accessible verification

For many people in this population, having an intellectual and developmental disability is a lifelong diagnosis. Individuals should not be required to repeatedly document diagnoses that have already been established and will not meaningfully change. Requiring repeated certifications places unnecessary burdens on individuals, families, providers, and state agencies while increasing the likelihood that eligible people lose coverage because documentation cannot be obtained quickly enough.

CMS should establish a strong presumption of medical frailty for individuals with lifelong developmental disabilities and permit states to rely on existing records when possible. When electronic verification is unavailable, CMS should allow self-attestation, caregiver attestation, authorized representative attestation, and provider attestation to satisfy documentation requirements.

IV. CMS should strengthen the caregiver exclusion

The Arc of Massachusetts appreciates CMS's recognition that parents, guardians, caretaker relatives, and family caregivers of disabled individuals may qualify for exemptions, but the definition of caregiving should be expanded to reflect the realities experienced by families of people with disabilities.

Family caregivers frequently provide medication management, transportation, behavioral supports, communication assistance, supervision, care coordination, appointment scheduling, help navigating the benefit systems and more. Many parents and family members provide these supports every day without identifying themselves as "caregivers," making documentation difficult despite the substantial time devoted to supporting their loved ones.

CMS should require states to use screening questions, recognize multiple caregivers within a household when appropriate, and adopt flexible documentation standards.

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

The Arc of Massachusetts 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. Medicaid supports employment with services that are specifically designed to help people with disabilities obtain and maintain competitive integrated employment. These services present meaningful community engagement and should independently satisfy the work requirements.

Failing to recognize Medicaid-funded employment supports creates a contradiction, resulting in requiring individuals to prove that they are participating in work while simultaneously disregarding the very services Medicaid provides to make employment possible.

The Arc of Massachusetts urges CMS to revise the interim final rule to ensure that people with intellectual and developmental disabilities, including autism, family caregivers, and direct support professionals do not lose Medicaid because of paperwork, inaccessible systems, or narrow definitions that fail to reflect disability-related support needs.

In Massachusetts, MassHealth has transformed opportunities for people with disabilities by making community living, competitive integrated employment, and independent lives possible. The final rule should preserve these accomplishments by ensuring that eligible individuals remain connected to the health care and services they depend on and not lose coverage because the system failed to recognize their disability or their needs.

Thank you for your consideration of these comments.

Sincerely,

Maura Sullivan
Chief Executive Officer
The Arc of Massachusetts