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#MEAction Urges HHS to Exempt ME/CFS and Long COVID Communities from Medicaid Work Requirements

HHS Headquarters, WASHINGTON, D.C. – On May 12th, the ME/CFS and Long COVID community are **gathering outside the Department of Health and Human Services** to call on HHS policymakers to intervene before tens of thousands of people with the debilitating diseases of ME/CFS and Long COVID lose access to the healthcare they need to survive.

New federal Medicaid work requirements are expected to cause approximately 10 million Americans to lose Medicaid coverage. People with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) and Long COVID are among the most vulnerable, and among the most likely to fall through the cracks, because our communities are often not recognized as officially disabled, even though the majority of our community are too sick and disabled to work.

The majority of people with ME/CFS who access Medicaid do so because of poverty, not because they have been formally recognized as disabled, leaving them without protected status when work requirements take effect.

Federal law includes a "medically frail" exemption designed to protect people with serious medical conditions from work requirements. But states have broad flexibility to define who qualifies, and ME/CFS and Long COVID are not automatically included. Nebraska, the first state to release its work requirement policy, does not currently include ME/CFS or Long COVID on its list of automatically exempted conditions, despite direct advocacy from #MEAction at the state level.

HHS has final sign-off authority on state recommendations regarding medical frailty definitions. That means HHS can act right now to ensure that ME/CFS and Long COVID are recognized as the serious, complex medical conditions they are, and that people living with these diseases are protected. HHS is required by law to issue an interim final rule on Medicaid work requirements by June 1, 2026.

HHS Event Details: #MEAction - a grassroots non-profit - will host an art installation and educational gathering for HHS policymakers on the southwest sidewalk outside HHS headquarters from 12 p.m. to 2 p.m. on Tuesday, May 12, 2026.

The stakes could not be higher.

ME/CFS is more disabling on average than multiple sclerosis, congestive heart failure, and end-stage renal disease. Only one in four people with ME/CFS is able to work. Core symptoms make sustained employment not just difficult but medically dangerous:

- Post-exertional malaise causes a severe worsening of symptoms following even minimal physical, cognitive, or emotional exertion
- Orthostatic intolerance makes sitting or standing upright for extended periods impossible for many patients
- Cognitive dysfunction, sometimes called "brain fog," severely impairs thinking, memory, and organization

For people with ME/CFS and Long COVID, whose energy is already severely limited and whose financial resources are often depleted by years of illness, navigating a complex exemption process is not just burdensome. It can cause serious medical harm.

ME/CFS is the least-funded major disease per capita in the United States relative to its burden, and still not taught about in medical schools, which is precisely why so many policymakers remain unaware of its severity. #MEAction is determined to change that.

Quotes:

"My sons are severely disabled by ME. They require 24/7 care and are unable to reach their intellectual potential or live independently. My sons have never broken a curfew because the only places they go are with caregivers. They cannot attend school, have not learned how to drive, cannot socialize with friends, and have never been on a date." — Denise, caregiver to two sons with severe ME

"We simply cannot let this population of people lose access to healthcare. We cannot let anyone with disabilities lose access to their healthcare. It is inhumane and unjust and not the country the vast majority of us want to be. There is an opportunity here to do the right thing, and we are looking to HHS to do that." — Laurie Jones, Executive Director, #MEAction

About #MEAction

#MEAction is a national nonprofit organization dedicated to advocacy, education, and support for people with myalgic encephalomyelitis (ME/CFS), Long COVID, and related infection-associated chronic conditions. #MEAction is a 501(c)(3) organization.

For more information, visit: millionsmissing.org