March 10, 2026

Emily Ricci, Deputy Commissioner
Alaska Department of Health
3601 C Street, Suite 902,
Anchorage, AK 99503

RE: Medicaid work requirements exemptions for medically frail individuals with ME/CFS, Long COVID, and other infection-associated chronic conditions

Dear Deputy Commissioner Ricci,

On behalf of #MEAction and the tens of millions of Americans living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long COVID, and other infection-associated chronic conditions, we urge you to adopt the following recommendations for Medicaid work requirements in order to minimize harm and preserve access to essential services for the chronically ill.[1]

As you know, under the One Big Beautiful Bill Act (OBBBA), by January 2027, states must start requiring adults 19-64 who are members of the Medicaid expansion group to comply with new federal work—or "community engagement"—requirements that entail documenting 80 hours per month in activities including work, volunteering, or school and **implementing exemptions** from these requirements for individuals who are **medically frail or have special medical needs**, which specifically includes a provision for those with a **serious or complex medical condition**.[2]

People with ME/CFS, Long COVID, and related conditions risk losing essential healthcare and worsening health if their conditions aren't properly recognized as serious or complex medical conditions. We recognize you face a challenging mission to implement new systems for reporting work requirements and exemptions in a very limited timeline. To minimize missed exemptions and procedural churn as efficiently as possible we recommend the following:

1. Recognize infection-associated chronic conditions as medically frail

Medical frailty should encompass the full range of conditions and functional impairments affecting people with disabilities and chronic illnesses. The medically frail exemption must extend beyond strict Social Security disability criteria to include serious or complex medical conditions including ME/CFS, Long COVID, and other infection-associated chronic conditions.

Work requirements will exacerbate illness in people with ME/CFS and Long COVID, with the potential to lead to permanent decreases in functional capacity.[3] While there are no

FDA-approved treatments for these conditions, healthcare providers recommend that patients prevent overexertion through careful pacing to prevent worsening of their disease.[4] Loss of health coverage and access to medical care makes it hard for these individuals to manage their health conditions as well, which may also exacerbate their illnesses.

People with ME/CFS have a lower quality of life on average than multiple sclerosis, chronic kidney failure, or congestive heart failure.[5] 25% of the ME/CFS population are housebound or bedbound, and inability to work is common, with only 13% able to work full-time.[6] Over 1 in 4 adults with Long COVID report "significant activity limitations."[7] Surveys of Long COVID consistently show decreases in work capacity, including needing to reduce hours, miss work due to health, or leave the labor force for health or disability reasons.[8] Fluctuation, diversity and uncertainty of Long COVID symptoms create significant barriers for people to return to work.[9] Economists estimate that between 1.6 and 4 million previously- employed persons have left the workforce in the US due to Long COVID.[10]

2. Accept self-declarations of medical frailty whenever possible to reduce barriers

The simplest and most accurate way to identify people with ME/CFS, Long COVID, other infection-associated chronic conditions for medical frailty exemptions is to allow people applying for or enrolled in Medicaid to self-identify that they have a serious or complex medical condition that meets exemption criteria. States should accept this declaration as sufficient verification as permitted under federal law and consistent with current practices for other eligibility categories in many states.

Allowing self-declaration is important because people with serious health conditions like ME/CFS and Long COVID may not have information on these health conditions in their claims data or they may struggle to access medical or other formal records, especially if they are newly applying for Medicaid and do not have access to medical care after losing employment due to serious illness. For example, it is estimated that up to 91% of ME/CFS cases may go undiagnosed and the time to diagnosis in 29% of cases is at least 5 years.[11] Using the simplest possible verification methods for medical frailty, such as screening forms and self-declarations, will reduce administrative burdens on both applicants and agency employees, speeding processing, and preventing unnecessary coverage disruptions.

An estimated 84-91% of people with ME/CFS have not yet been diagnosed. Often there is a lengthy duration of time between symptom onset and diagnosis. It is estimated that in 29% of diagnosed ME/CFS patients the time to diagnosis was at least 5 years.

The administrative burdens of complicated exemption eligibility processes are particularly hard for people with ME/CFS and Long COVID. Their significant physical and cognitive impairments make it difficult for them to respond to requests for information especially when low-cost, accessible assistance is not available.[12]

People with ME/CFS, Long COVID, and related conditions need the opportunity to self-report having a serious or complex medical condition because they may struggle to access

exemptions based on strict disability criteria, especially in a timely manner necessary to maintain their access to medical care.[13] Many of them are part of the 24 percent of all Medicaid enrollees who report having a disability but did not qualify through a Medicaid disability pathway.[14]

3. Include new diagnostic codes in *ex parte* verification processes for exemptions

While self-declaration on Medicaid applications, renewals, and other forms is the most widely accessible way to identify medically frail individuals with infection-associated chronic conditions, this can and should be supplemented with ex parte processes that check for newly available diagnostic codes for **Long COVID (U09.9)** and **ME/CFS (G93.32)**. These ICD-10-CM codes were recently implemented in 2021 and 2022, so their presence in current Medicaid claims data may be limited but is expected to grow (previously ME/CFS was coded as R53.82).

These codes should be included in any state review of claims data for select diagnosis codes to identify individuals considered medically frail in order to reduce paperwork for future renewals.

ME/CFS and Long COVID are complex chronic conditions where multimorbidity is common and associated with more condition severity and a lower quality of life. Other infection-associated chronic conditions frequently diagnosed in people with ME/CFS and Long COVID are autonomic disorders such as **postural orthostatic tachycardia syndrome (G90.A)**, **hypermobile Ehlers-Danlos syndromes (Q79.62)** and **mast cell activation syndrome (D89.4)**.[15]

4. Additional recommendations to reduce procedural terminations

- **Redetermine medical frailty only when an enrollee's health condition improves,**

  To minimize administrative burden and keep eligible people enrolled.

- **Exemptions from work requirements should not require exclusion from work.**

  Individuals who are episodically disabled by chronic illness should not be required to show that they cannot work to qualify as medically frail so as not to disincentive community engagement when it is possible.

- **Fully recognize family caregivers of people with disabilities and chronic illness.**

  Define the caregiver exemption from work requirements using the RAISE Family Caregivers Act definition of caregiver, which includes adults who provide a broad range of assistance to a person with a disability or health condition, whether or not they live in the same household or have legal custody. Avoid adding restrictions such as minimum caregiving hours or requirements that the person receiving care be a dependent or have a specific diagnosis.

- **Explain to applicants and enrollees why health-related questions are asked and how privacy will be protected.**

- **Ensure adequate Medicaid program staff are available to meet the state's duty to assist with application and renewal processes**

  Additional staff may be needed to help people with disabilities apply for exemptions, and/or apply for reasonable modifications to the requirements.

- **Provide additional training for Medicaid program staff on how to recognize and work with people who have hidden disabilities (such as chronic illnesses, mental health disabilities, or intellectual disabilities).**

Conclusion

We appreciate your attention to these concerns and your commitment to safeguarding Medicaid access for people with ME/CFS and Long COVID. We welcome the opportunity to meet with you and your team to discuss these recommendations and to provide input as you develop policies, test systems, and plan outreach related to work requirements and exemptions.

Sincerely,

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References

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2. CMCS, CIB (Dec. 2025); OBBBA H.R.1, 119th Congress
3. CDC, *Managing PEM in ME/CFS*; Durstenfeld et al., *Br J Sports Med* (2026)
4. Grach et al., *Mayo Clinic Proceedings* (2023)
5. Hvidberg et al., *PMC* (2015)
6. Kingdon et al., *PMC* (2018)
7. CDC, *Long COVID Household Pulse Survey* (2024)
8. Urban Institute (2022); Gottlieb et al., *JAMA Network Open* (2024); *J Am Board Fam Med* (2022); Brookings (2022)
9. Stelson et al., *Social Science & Medicine* (2023)
10. Brookings (2022); Minneapolis Fed (2022)
11. *National Academies* (2015)
12. Jaywant et al.], *JAMA Network Open* (2024); Robinson et al., *PMC* (2019)
13. See *Appendix 1* for examples of Long COVID and ME/CFS Medicaid procedural termination risk.
14. SHVS, *The Disability Gap in Medicaid*
15. Grach et al., *Mayo Clinic Proceedings* (2023); Grach et al., *Front. Neurology* (2024); Weinstock et al., *PMC* (2021); Pearson et al., *PMC* (preprint)

Appendix 1: Examples of Long COVID and ME/CFS Medicaid procedural termination risk

The below examples illustrate ways that individuals with Long COVID, ME/CFS, and related conditions are **at risk of Medicaid procedural terminations** unless **self-attestation of medical frailty** is provided as an option for exemption from Medicaid work requirements.

When Medicaid work requirements begin, these individuals will **lose their Medicaid status** because they:

1. Can't satisfy the 80 hours/month requirement due to their symptom impairment,
2. Don't yet have a disability determination or fail to get an accurate functional assessment,
3. Don't have Medicaid claims data that will automatically identify them as medically frail either because they only have generic symptom-based diagnostic codes, or are newly enrolled in Medicaid after losing their job due to illness, and
4. Are too physically and cognitively impaired to navigate more complex eligibility exemption processes without accessible assistance.

Maria - **newly sick with fatigue and shortness of breath after COVID**

Maria got COVID-19 last year. She had to reduce her grocery store clerk hours from full time to 15 hours per week due to severe fatigue and shortness of breath. She lost her health insurance from work when she reduced hours and enrolled with Medicaid. She sees her primary care doctor who prescribes medications covered by Medicaid that help a little bit with her symptoms so she can maintain part-time work.

When Maria loses her Medicaid because she can't meet the work requirements, she will lose access to her doctor and medications that are the only reason she's able to sustain her part-time work and will lose her grocery clerk job entirely.

Minerva - chronic conditions worsened by Long COVID

Minerva has chronic pain and some chronic conditions, including lupus. She was working full time before getting COVID-19, but has been on unpaid medical leave for months since COVID-19 flared her lupus and triggered a new chronic condition (Long COVID) that causes fatigue. While on medical leave, she did not have income and enrolled in Medicaid to cover a different medication needed to manage her symptoms, which helped her feel well enough to start a gradual return to work for 10 hours per week. Minerva did not have a disability application prior to medical leave because she was working full time, and hopes to be able to return to full time work at some point in the future.

Albert - undiagnosed ME/CFS and soon to be uninsured

Albert has been unwell since getting a virus several years ago. He has been going to doctors, but none of them know what's causing his fatigue, ongoing flu-like symptoms, and chronic sore throat.[1] He has been unable to work for several years since getting sick, and has been denied Social Security disability even after appeal and judge review due to lack of sufficient medical documentation showing his functional impairment.. He enrolled on Medicaid because he has no income. Albert is still waiting to get into a neurologist his primary care referred him to, and hopes maybe the specialist will help figure out what's wrong, but there is a one-year waitlist.

Albert will lose his Medicaid coverage before he can see the neurologist, which his primary care doctor depended on to help diagnose him. Albert will continue to be unwell with fatigue, chronic flu-like symptoms, and chronic sore throat that cause daily activity limitations and leave him primarily homebound without health insurance, as he is unable to work at all and was denied Social Security disability benefits.

Deborah - disabled but denied access Medicaid HCBS waiver

Deborah got sick with COVID-19 and ended up dropping out of her junior year of college. She moved back in with her mother because she cannot care for herself. Her mother is confused and upset when doctors can't explain what is wrong with Deborah and questions whether she is really sick. Initially, Deborah qualified for Medicaid on the basis of having no income. Later she tried to apply for a Medicaid Home and Community Based Services waiver, but her anxiety and brain fog prevented her from accurately answering the questions about her functional capacity during the home assessment, so she was denied. She also applied for Social Security Disability but was denied. She felt shame to again not be believed and did not have the cognitive ability to appeal either decision, so Deborah will lose Medicaid when work requirements are implemented as she doesn't have a disability determination and won't fit medical exemptions for work requirements.

[1] Albert likely has undiagnosed ME/CFS but if he was diagnosed with "chronic fatigue syndrome" prior to 2022 the ME/CFS diagnostic code (G93.32) would still not be listed in his claims data. The billing code used would have been R53.82 for "Chronic fatigue, unspecified."