

**UNITED STATES DISTRICT COURT  
FOR THE DISTRICT OF MASSACHUSETTS**

COMMONWEALTH OF MASSACHUSETTS,  
et al.,

Plaintiffs,

v.

MEHMET OZ, M.D., et al.,

Defendants.

Case No. 1:26-cv-12962-RGS

**BRIEF OF *AMICI CURIAE* NATIONAL HEALTH LAW PROGRAM, CENTER FOR PUBLIC  
REPRESENTATION, AND 69 ADDITIONAL ORGANIZATIONS  
IN SUPPORT OF PLAINTIFF STATES' MOTION  
FOR PARTIAL SUMMARY JUDGMENT**

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| T. Trimble & Scott H. Donaldson, <i>Ivacaftor Withdrawal Syndrome in Cystic Fibrosis Patients with the G551D Mutation</i> , 17 J. Cystic Fibrosis e13 (2018),<br><a href="https://pubmed.ncbi.nlm.nih.gov/29079142/">https://pubmed.ncbi.nlm.nih.gov/29079142/</a> .....                                                                                 | 12 |
| Darshali A. Vyas et al., <i>Functional Status of Adults at Risk of Medicaid Disenrollment Under National Work Requirements</i> , 179 Annals Internal Med. 666 (2026), <a href="https://pubmed.ncbi.nlm.nih.gov/41911556/">https://pubmed.ncbi.nlm.nih.gov/41911556/</a> .....                                                                            | 5  |
| K. Robin Yabroff et al., <i>Health Insurance Coverage Disruptions and Cancer Care and Outcomes: Systematic Review of Published Research</i> , 112 J. Nat'l Cancer Center Inst. 671 (2020), <a href="http://pmc.ncbi.nlm.nih.gov/articles/PMC7357319/">http://pmc.ncbi.nlm.nih.gov/articles/PMC7357319/</a> .....                                         | 7  |
| Jingxuan Zhao et al., <i>Medicaid Expansion and Stage at Diagnosis, Timely Initiation and Receipt of Guideline-Concordant Treatment, and Survival Among People with Non-Small Cell Lung Cancer</i> , 44 J. Clinical Oncology 1296 (2026),<br><a href="http://doi.org/10.1200/JCO-25-01892">http://doi.org/10.1200/JCO-25-01892</a> .....                 | 7  |

## INTEREST OF THE *AMICI CURIAE*

The 71 organizations listed in Appendix A are filing this *amicus curiae* brief. Although each *amicus* has its own interests, all of them are dedicated to ensuring that limited-income people—a substantial percentage of whom have diseases and disabilities—are able to obtain and maintain health coverage. As such, *amici* have an interest in the U.S. Department of Health and Human Services Interim Final Rule being challenged in this case. *See* Medicaid Program; Community Engagement Requirement for Certain Individuals, [91 Fed. Reg. 33,348](#) (June 3, 2026) (“the IFR”). As a result of the IFR, medically frail individuals across the country will lose Medicaid coverage to a far greater degree than was anticipated by Congress; the rule is projected to cause a roughly 30% increase in coverage losses.

In this brief, *amici* will discuss some of the design features Congress has incorporated into the Medicaid Act to ensure that low-income, medically frail people have access to early, continuous, and comprehensive health coverage. *Amici* will explain why the IFR will cause additional coverage loss among medically frail people. Finally, *amici* will describe some of the medically frail population groups affected by the IFR and provide the Court with snapshots of medically frail people who will be harmed by the IFR.

## ARGUMENT

### **I. Congress Structured Medicaid to Ensure Early, Broad, and Continuous Coverage of People Who Are Medically Frail.**

One reason Medicaid was enacted in 1965 was to provide medical assistance to low-income people with chronic and disabling health conditions. *See* [42 U.S.C. § 1396-1](#). To this end, the Act requires participating states to extend Medicaid coverage to all individuals who fall within a mandatory population group listed in the Act, *id.* § 1396a(a)(10), and establishes a scope of benefits tailored to meet the immediate and long-term service and support needs of eligible people,

*id.* § 1396d(a). Unlike other insurance, Medicaid enrollment is not limited to open enrollment periods. Individuals can enroll at any time, for example when they realize they have a disease, disability, or chronic condition. The Act extends retroactive coverage to beneficiaries, thus enabling people to avoid accumulating medical debt when an unexpected health crisis, such as a stroke, occurs prior to their enrollment. *Id.* § 1396a(a)(34). Further, presumptive Medicaid eligibility can allow immediate, on-the-spot enrollment at hospitals and clinics, *id.* § 1396a(a)(47), and for older adults and people with disabilities who need home and community-based services, *id.* § 1396n(i)(1)(j). The Medicaid Act requires medical assistance to be provided with “reasonable promptness,” *id.* § 1396a(a)(8), and “in a manner consistent with simplicity of administration and the best interests of the recipients,” *id.* § 1396a(a)(19).

In the One Big Beautiful Bill Act, also called H.R.1, Congress established a mandatory work requirement for people who qualify for Medicaid through the Affordable Care Act’s Medicaid expansion (*i.e.*, individuals aged 19-64 who are not eligible for Medicare and not otherwise eligible for Medicaid). While sometimes referred to “able-bodied adults,” that label is misleading:

- Nearly half (44%) of expansion adults have at least one chronic condition, including 33% with a chronic physical condition and 24% with a behavioral health condition. Jessica Mathers et al., KFF, *5 Key Facts About Medicaid Expansion* (2025), <https://www.kff.org/medicaid/5-key-facts-about-medicaid-expansion/>.
- Of Medicaid enrollees with at least one chronic condition, 53% are enrolled through Medicaid expansion. *Id.*; see Melissa McInerney et al., *Association of Medicaid Expansion With Medicaid Enrollment and Health Care Use Among Older Adults With Low Income and Chronic Condition Limitations*, 3 JAMA Health Forum e221373 (2022), <https://pmc.ncbi.nlm.nih.gov/articles/PMC9166222/> (concluding that enrollment increases from Medicaid expansion were concentrated among older adults with a chronic condition limitation).

When enacting mandatory work requirements, Congress was careful to explicitly exclude people “who [are] medically frail or otherwise ha[ve] special medical needs.” 42 U.S.C. § 1396a(xx)(9)(A)(ii)(V). The statute specifies five categories of people who must be included as medically frail and, thus, excluded from work requirements. These are individuals: (1) who are “blind or disabled (as defined in section 1614)”; (2) “with a substance use disorder”; (3) “with a disabling mental disorder”; (4) “with a physical, intellectual, or developmental disability that significantly impairs their ability to perform 1 or more activities of daily living”; or (5) “with a serious or complex medical condition.” *Id.*

These categorical exclusions serve one purpose: to ensure that medically frail people maintain necessary health care coverage and avoid harmful interruptions or delays in care. Members of Congress made this intent clear. For example, Representative Brett Guthrie, Chairman of the House Energy and Commerce Committee, stated that individuals are “exempt if you’re medically frail, which includes anyone who’s blind, disabled, battling a chronic substance-use disorder or living with a serious and complex medical condition like cancer,” and “our bill couldn’t be clearer” that it “includes a long list of exempted individuals.” Ctr. for Health Law & Pol’y Innovation, Harvard L. Sch., *A Shift Between Congressional Intent and Implementation: Work Requirements* (2026), [https://chlp.org/wp-content/uploads/2026/06/HCIM\\_Congressional-Quotes\\_FINAL\\_6.17.26-1.pdf](https://chlp.org/wp-content/uploads/2026/06/HCIM_Congressional-Quotes_FINAL_6.17.26-1.pdf). Senator Mike Crapo, Chairman of the Senate Finance Committee, stated that the statute “does not take Medicaid away from . . . the medically frail,” and Senator Dan Sullivan stated that exemptions for “individuals who are medically frail or are dealing with a substance use disorder” are unqualified protections. *Id.*

Disregarding the statute’s categorical exclusions and congressional intent, the IFR adds harmful conditions on medically frail people. It introduces a new requirement that medically frail

individuals establish that their condition “significantly impairs” their ability to meet the work requirement. 42 C.F.R. § 435.554(c)(5)(i). It also adds procedural hurdles. While existing Medicaid regulations permit states to allow beneficiaries to self-attest to most information needed to establish Medicaid eligibility, *see id.* § 435.945(a), the IFR limits the use of self-attestation to establish medically frail status. *Id.* § 435.557(f)(1)(ii)-(iii); *see id.* § 435.557(a).

## **II. The IFR’s Restrictions on the Medically Frail Exclusion Will Result in Substantial Additional Coverage Loss.**

Congress’s exclusion of medically frail people from work requirements recognizes that persistent health conditions are best controlled when people have access to necessary care. However, the IFR will harm many medically frail people who do not meet the “significantly impairs” standard but will not be able to work enough to meet the 80-hour minimum work requirement because of social and economic conditions outside of their control. *See, e.g.,* Akeiisa Coleman & Sara Federman, Commonwealth Fund, *Work Requirements for Medicaid Enrollees* (2025), <https://www.commonwealthfund.org/publications/explainer/2025/sep/work-requirements-medicaid-enrollees> (listing barriers such as limited transportation and internet access and available work only in low-pay jobs with variable hours); CDC, *Disability Barriers to Inclusion* (Apr. 3, 2025), <https://www.cdc.gov/disability-inclusion/barriers/index.html> (listing the many barriers that can prevent people with a disability from functioning within society).

Many others who do, in fact, meet the “significantly impairs” standard will nevertheless lose coverage because they will fall victim to documentation requirements and other administrative barriers. *See, e.g.,* 91 Fed. Reg. at 33,395, 33,405-33,407, 33,434-33,435, 33,446, 33,455 (noting requirements for gathering documentation). In a 2026 survey of cancer patients and survivors, three-fourths of respondents said it would be difficult for someone undergoing cancer treatment to submit paperwork establishing that their cancer prevented them from working; 81% said patients

are already overwhelmed with tasks essential to their survival, and 75% said cancer and the side effects of treatment make paperwork very difficult to complete. Am. Cancer Soc’y Cancer Action Network, *Survey: Majority of Cancer Patients Would Not Have Been Able to Meet Work Requirements* (2026), <https://www.fightcancer.org/policy-resources/survey-majority-cancer-patients-would-not-have-been-able-meet-work-requirements>.

Individuals with cancer are not alone. Research suggests a “sizable number of [expansion enrolled] adults may struggle with navigating the reporting and verification requirements necessary to maintain coverage.” Darshali A. Vyas et al., *Functional Status of Adults at Risk of Medicaid Disenrollment Under National Work Requirements*, 179 *Annals Internal Med.* 666 (2026), <https://pubmed.ncbi.nlm.nih.gov/41911556/>; see, e.g., Benjamin D. Sommers et al., *Medicaid Work Requirements — Results from the First Year in Arkansas*, 381 *New Eng. J. Med.* 1073 (2019), <https://www.nejm.org/doi/full/10.1056/NEJMSr1901772> (associating confusion and administrative burdens with thousands of Arkansans losing Medicaid coverage even though the vast majority of them appeared to meet the work requirements or qualify for an exemption).

In New Hampshire, beneficiaries who were required to submit provider verification of a disability-related exemption from Medicaid work requirements struggled to find a provider willing or able to sign. Letter from Elizabeth Richter, Acting Adm’r, CMS, to Lori Shibinette, Comm’r, N.H. Dep’t of Health & Hum. Servs. 6 (Mar. 17, 2021), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/nh-granite-advantage-health-care-program-ca2.pdf>. Notably, because Medicaid beneficiaries can see only providers who accept Medicaid—and, under managed care, an even smaller number of in-network providers—obtaining the necessary documentation is particularly challenging. See, e.g., Walter R. Hsiang et al., *Medicaid Patients Have Greater Difficulty Scheduling Health Care Appointments*

*Compared with Private Insurance Patients: A Meta-Analysis*, 56 Inquiry 1 (2019), <https://pmc.ncbi.nlm.nih.gov/articles/PMC6452575/> (finding Medicaid patients, and adults in particular, have reduced access to appointments compared to privately insured patients).

Not surprisingly, the IFR will cause massive coverage loss among medically frail people. Experts project a 10% overall reduction in nationwide Medicaid enrollment due to the IFR’s “significantly impairs” standard and limits on self-attestation—both of which increase the need for individuals to provide documentation to the State to establish eligibility. Patricia M. Boozang et al., Manatt Health, *CMS' Medicaid Work Requirements Rule: A 50-State Analysis of Additional Coverage Losses, FFY 2027–2034* (2026), <https://www.manatt.com/insights/white-papers/2026/cms-medicaid-work-requirements-rule-a-50-state-analysis-of-additional-coverage-losses-ffy-2027-2034>. This amounts to an average of 1.8 million additional people losing Medicaid coverage per year between 2027 and 2034. *Id.*

### **III. The Conditions That Render Individuals Medically Frail Vary Widely, and Continuous Health Care Coverage is Required to Manage Each of Them.**

Each of the conditions described below qualifies an individual as “medically frail” under the statute. They represent only a small share of the conditions affecting medically frail beneficiaries in the expansion population. Broad and continuous coverage can be a matter of life or death for individuals with these conditions.

**Cancer.** The Centers for Medicare & Medicaid Services (CMS) has recognized cancer as a serious, chronic medical condition since at least 2013. *See* Medicaid and Children's Health Insurance Programs, [78 Fed. Reg. 42,160](#), 42,233 (July 15, 2013); Medicare and Medicaid Programs, [88 Fed. Reg. 78,818](#), 78,938 (Nov. 16, 2023). Medicaid covers one in five non-elderly adults newly diagnosed with cancer and approximately two million people with a history of the disease. Am. Soc’y for Clinical Oncology, *ASCO Urges CMS to Protect Patients with Cancer from*

*Medicaid Work Requirements* (July 30, 2026), <https://www.asco.org/news-initiatives/policy-news-analysis/ASCO-urges-CMS-protect-cancer-patients-Medicaid-work-requirements>. Without coverage, individuals face poor access to care and reduced rates of survival. K. Robin Yabroff et al., *Health Insurance Coverage Disruptions and Cancer Care and Outcomes: Systematic Review of Published Research*, 112 J. Nat'l Cancer Inst. 671 (2020), <https://pmc.ncbi.nlm.nih.gov/articles/PMC7357319/>. Conversely, coverage through the Medicaid expansion is associated with improvements in timeliness of guideline-concordant treatment and survival. See, e.g., Jingxuan Zhao et al., *Medicaid Expansion and Stage at Diagnosis, Timely Initiation and Receipt of Guideline-Concordant Treatment, and Survival Among People with Non-Small Cell Lung Cancer*, 44 J. Clinical Oncology 1296 (2026), <https://doi.org/10.1200/JCO-25-01892>.

**Sickle Cell Disease (SCD).** CMS has recognized SCD as a serious and complex medical condition. See, e.g., CMS, Dear State Medicaid Dir. Letter, SMD # 22-004 (2022), <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22004.pdf>. Roughly half of the 100,000 Americans with SCD rely on Medicaid. CMS, *Action Plan, CMS Sickle Cell Disease* (2023), <https://www.cms.gov/files/document/sickle-cell-disease-action-plan.pdf>. SCD is incurable and life-shortening. *Id.* Individuals with SCD need a range of preventive and treatment services to manage the condition and prevent complications. CDC, *Sickle Cell Disease, Prevention and Treatment of SCD Complications* (Aug. 7, 2026), <https://www.cdc.gov/sickle-cell/about/prevention-and-treatment.html>.

One of the most common complications is pain. SCD causes unpredictable vaso-occlusive pain crises that can require emergency care and hospital admissions. CDC, *Sickle Cell Disease, Complications of SCD: Pain* (Aug. 7, 2026), <https://www.cdc.gov/sickle->

[cell/complications/pain.html](#); NIH, Nat'l Heart, Lung, & Blood Inst., *Living with Sickle Cell Disease* (Aug. 22, 2024), <https://www.nhlbi.nih.gov/health/sickle-cell-disease/living-with>. Medication is necessary to reduce pain crises and anemia, in turn reducing the need for blood transfusions and hospitalizations. NIH, Nat'l Heart, Lung, & Blood Inst., *Sickle Cell Disease, Treatment*, (Sept. 30, 2024), <https://www.nhlbi.nih.gov/health/sickle-cell-disease/treatment> (also noting that some individuals with SCD benefit from a blood and bone marrow transplant or gene therapies). Research suggests that when access to consistent care is disrupted for people with SCD, care shifts to the emergency department. *See, e.g.,* B.G. Hemker et al., *When Children with Sickle-Cell Disease Become Adults: Lack of Outpatient Care Leads to Increased Use of the Emergency Department*, 86 Am. J. Hematology 863 (2011), <https://pubmed.ncbi.nlm.nih.gov/21815184/>.

**Diabetes.** Medicaid covers 12.5% of adults with diabetes. Am. Diabetes Ass'n, *Impact of Recent Medicaid and Affordable Care Act Policy Changes on Health Insurance Coverage and Cost-Sharing for Americans with Diabetes* 1 (2026), <https://diabetes.org/sites/default/files/2026-07/Affordable%20Care%20White%20Paper%20FINAL.pdf>. Individuals with type I diabetes, as well as some individuals with type II diabetes, need insulin to stay alive. NIH, Nat'l Inst. of Diabetes & Digestive & Kidney Diseases, *Insulin, Medicines, & Other Diabetes Treatments*, (Mar. 2022), <https://www.niddk.nih.gov/health-information/diabetes/overview/insulin-medicines-treatments> (noting other medications and treatments that are also used to manage diabetes in some patients).

When diabetes patients lose their health coverage and, thus, their access to insulin, they end up sick and in the hospital. Ashish Jha et al., *Greater Adherence to Diabetes Drugs Is Linked to Less Hospital Use and Could Save Nearly \$5 Billion Annually*, 31 Health Affs. 1836 (2012), <https://pubmed.ncbi.nlm.nih.gov/22869663/>. One study found that insulin rationing—which

occurs when individuals are unable to afford prescribed amounts of insulin—was the primary cause of diabetic ketoacidosis, an acute and life-threatening complication of diabetes. *See* V.C. Musey et al., *Diabetes in Urban African Americans: Cessation of Insulin Therapy Is the Major Precipitating Cause of Diabetic Ketoacidosis*, 18 *Diabetes Care* 483, 485–86 (1995), <https://pubmed.ncbi.nlm.nih.gov/7497857/>. Inadequately treated diabetes can cause other severe complications, including blindness and neuropathy. *See* Am. Diabetes Ass'n, *12. Retinopathy, Neuropathy, and Foot Care: Standards of Care in Diabetes—2026*, 49 *Diabetes Care* S252, S262 (2026), <https://doi.org/10.2337/dc26-S012>. Even though diabetes is a serious or complex condition, CMS has said it does not expect it to meet the “significantly impairs” standard. *Cf.* 91 Fed. Reg. at 33,376 (listing type I and type II diabetes as conditions that CMS does not expect to meet the “significantly impairs” standard).

**HIV.** CMS has recognized HIV as a serious, chronic medical condition for well over a decade. *See* 78 Fed. Reg. at 42,233. Medicaid covers 46% of adults with diagnosed HIV. Lindsey Dawson & Jennifer Tolbert, KFF, *Medical Frailty and Medicaid Work Requirements: Challenges for People with HIV* (2026), <https://www.kff.org/medicaid/medical-frailty-and-medicaid-work-requirements-challenges-for-people-with-hiv/>. In expansion states, 60% of adults under 65 with HIV are covered through Medicaid expansion. *Id.*

HIV is incurable and requires lifelong, uninterrupted antiretroviral therapy (ART). NIH, *HIV Treatment: The Basics* (Jan. 14, 2025), <https://hivinfo.nih.gov/understanding-hiv/fact-sheets/hiv-treatment-basics>. When ART is interrupted, blood levels of the virus rise quickly. This gives the virus a chance to mutate and become drug-resistant, making treatment more difficult. NIH, *HIV Treatment, Drug Resistance* (July 10, 2026), <https://hivinfo.nih.gov/understanding-hiv/fact-sheets/drug-resistance>. Coverage lapses also lead to larger public health concerns. When

an individual has sustained viral suppression due to ART, it prevents sexual transmission. NIH, *HIV Treatment: The Basics*, *supra*.

**Kidney Disease.** While most people with End Stage Renal Disease (ESRD) qualify for Medicare, *see* [42 U.S.C. § 1395rr](#), and thus, are not eligible for enrollment through the Medicaid expansion, approximately 9% of individuals with ESRD rely on Medicaid fully for their coverage. Kevin F. Erickson et al., *Safety-Net Care for Maintenance Dialysis in the United States*, 31 J. Am. Soc'y Nephrology 424 (2020), <https://doi.org/10.1681/ASN.2019040417>. Many more have not progressed to ESRD and therefore do not qualify for Medicare coverage, making Medicaid a vital coverage source.

Chronic kidney disease (CKD) is common and concentrated in working-age adults; an estimated 37 million adults have CKD. CDC, *Chronic Kidney Disease in the United States* (Mar. 31, 2026), <https://www.cdc.gov/kidney-disease/php/data-research>. As with the other chronic conditions, health coverage prevents progression. Continuous access to primary care, blood pressure management, and kidney-protective medication is essential. Alon Peltz & Jay G. Berry, *Medicaid Expansion Helps Young Adults with Kidney Failure*, 180 JAMA Pediatrics 824 (2026), <https://doi.org/10.1001/jamapediatrics.2026.1723>. Medicaid expansion was associated with a reduced incidence of kidney failure among nonelderly adults. Rebecca Thorsness et al., *Medicaid Expansion and Incidence of Kidney Failure Among Nonelderly Adults*, 32 J. Am. Soc'y Nephrology 1425 (2021), <https://doi.org/10.1681/ASN.2020101511>. Among young adults initiating dialysis, expansion was associated with a decline in one-year mortality from 3.6% to 2.1%, along with higher rates of pre-dialysis nephrology care, which is the care delivered before kidney failure. Shailender Swaminathan et al., *Medicaid Expansion and 1-Year Mortality Among Young Adults*

*Initiating Dialysis*, 180 JAMA Pediatrics 851 (2026), <https://doi.org/10.1001/jamapediatrics.2026.1530>.

**Seizure Disorders.** Epilepsy is among the most common, serious neurological conditions in the country. Medicaid covers more than 40% of adults with active epilepsy. Niu Tian et al., *Barriers to and Disparities in Access to Health Care Among Adults Aged  $\geq 18$  Years with Epilepsy — United States, 2015 and 2017*, 71 Morbidity & Mortality Weekly Rep. 697 (2022), <https://www.cdc.gov/mmwr/volumes/71/wr/mm7121a1.htm>. Uncontrolled seizure disorders lead to death. Using Medicaid claims data, research shows that “[p]eriods of non-adherence [with antiepileptic drugs] were associated with a more than three times increase in mortality compared with adherence.” Torbjörn Tomson et al., *Sudden Unexpected Death in Epilepsy*, 7 Lancet Neurology 1021 (2008), <https://pubmed.ncbi.nlm.nih.gov/18805738/>; see also David J. Thurman et al., *Sudden Unexpected Death in Epilepsy: Assessing the Public Health Burden*, 55 Epilepsia 1479 (2014), <https://pubmed.ncbi.nlm.nih.gov/24903551/>; CDC, *Treatment of Epilepsy* (May 15, 2024), <https://www.cdc.gov/epilepsy/treatment/index.html> (noting sudden cessation of medication can cause life-threatening seizures).

**Cystic Fibrosis (CF).** One-third of adults with CF rely on Medicaid. Cystic Fibrosis Found., *2024 Patient Registry Annual Data Report* (2025), <https://www.cff.org/media/38406/download>. CF is a progressive genetic disease affecting the lungs, pancreas, and other organs, in which the body produces mucus that obstructs these organs and gives rise to life-threatening infections. NIH, Nat’l Heart, Lung, & Blood Inst., *Cystic Fibrosis, Living With* (Nov. 15, 2024), <https://www.nhlbi.nih.gov/health/cystic-fibrosis/living-with>. It is incurable, progressive, and requires targeted, specialized treatment and medications delivered without interruption. NIH, Nat’l Heart, Lung, & Blood Inst., *Cystic Fibrosis, Treatment* (Nov. 15,

2024), <https://www.nhlbi.nih.gov/health/cystic-fibrosis/treatment>. Even a short gap in coverage places a person with CF in danger of declining health, increasing their risk of pulmonary exacerbations, irreversible lung damage, and hospitalization. Cystic Fibrosis Found., *Protecting Access to Medicaid*, <https://www.cff.org/about-us/protecting-access-medicaid> (last visited Sept. 6, 2026); see also Aaron T. Trimble & Scott H. Donaldson, *Ivacaftor Withdrawal Syndrome in Cystic Fibrosis Patients with the G551D Mutation*, 17 J. Cystic Fibrosis e13 (2018), <https://pubmed.ncbi.nlm.nih.gov/29079142/> (noting CF is a progressive disease, and patients who delay or forgo treatment face an increased risk of lung exacerbations, irreversible organ damage, and costly hospitalizations.).

**Muscular Dystrophy.** Nearly 40% of the neuromuscular disease community relies on Medicaid for home care, specialty care, therapies, and life-sustaining equipment that make daily life and community participation possible. Muscular Dystrophy Assoc., *Proposed Medicaid and Health Coverage Cuts Raise Substantial Concern for the Neuromuscular Community* (May 14, 2025), <https://www.mda.org/press-releases/proposed-medicaid-and-health-coverage-cuts-raise-substantial-concern-for-the-neuromuscular-community>. Muscular dystrophy is a group of genetic diseases that cause muscles to become progressively weaker over time, with varied severity, symptoms, and progression. CDC, *About Muscular Dystrophy* (Jan. 7, 2025), <https://www.cdc.gov/muscular-dystrophy/about/index.html/>. Muscular dystrophy can appear in childhood, or it may not appear until well into adulthood. NIH, Nat'l Inst. of Neurological Disorders & Stroke, *Muscular Dystrophy* (Mar. 13, 2026), <https://www.ninds.nih.gov/health-information/disorders/muscular-dystrophy>.

Individuals with muscular dystrophy require a range of ongoing preventive and treatment services overseen by multiple specialists to slow progression and prevent complications. See, NIH,

Eunice Kennedy Shriver Nat'l Inst. of Child Health & Human Dev., *What Are the Treatments for Muscular Dystrophy (MD)?* (Nov. 9, 2020), <https://www.nichd.nih.gov/health/topics/musculardys/conditioninfo/treatment> (listing several classes of medications; physical, respiratory, speech, and occupational therapy; surgery, and other treatments). Research suggests that when access to consistent specialty care is disrupted, care shifts to the emergency department. See R.S. Scalco et al., *Improving Specialised Care for Neuromuscular Patients Reduces the Frequency of Preventable Emergency Hospital Admissions*, 30 Neuromuscular Disorders 173 (2020), [https://discovery.ucl.ac.uk/id/eprint/10089281/7/Quinlivan\\_1-s2.0-S0960896619312209-main.pdf](https://discovery.ucl.ac.uk/id/eprint/10089281/7/Quinlivan_1-s2.0-S0960896619312209-main.pdf) (preventable admissions fell from 63% to 33% as more patients were followed by specialized neuromuscular centers).

**Intellectual and Developmental Disabilities (I/DDs).** I/DDs include intellectual disabilities, autism, developmental delays, and learning disabilities. Priya Chidambaram et al., KFF, *5 Key Facts About Medicaid Coverage for People with Intellectual and Developmental Disabilities (I/DD)* (2025), <https://www.kff.org/medicaid/5-key-facts-about-medicaid-coverage-for-people-with-intellectual-and-developmental-disabilities-idd/>. I/DDs often manifest in childhood and continue through life. *Id.*

Roughly 3.4 million Medicaid enrollees under age 65 had an I/DD in 2021, and approximately 24% of nonelderly adult enrollees with an I/DD qualified through Medicaid expansion rather than a disability eligibility pathway. *Id.* Enrollees aged 19-64 with an I/DD are: more likely than those without an I/DD to have a chronic condition (67% vs. 42%); twice as likely to be diagnosed with a behavioral health condition (46% vs. 23%); and twelve times as likely to be diagnosed with a physical health condition (24% vs 2%). *Id.* Individuals with an I/DD need

continuous access to Medicaid for necessary health care. Among other things, Medicaid is the primary payer of long-term services and supports that enable individuals with an I/DD to engage in “activities of daily living (such as eating, bathing, and dressing) and instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping).” *Id.*

While an individual with an I/DD can develop or retain skills through habilitative and rehabilitative treatment, their disability is lifelong. Qian Li et al., *Prevalence and Trends of Developmental Disabilities Among US Children and Adolescents Aged 3 to 17 Years, 2018–2021*, 13 Sci. Reps. 17254 (2023), <https://doi.org/10.1038/s41598-023-44472-1>. As such, the need for health coverage is also lifelong.

**Disabling Mental Illnesses.** Nearly 1 in 3 adult Medicaid beneficiaries have a mental health or substance use disorder, and 24% of expansion enrollees have a diagnosed behavioral health condition. Heather Saunders et al., KFF, *Implications of Medicaid Work and Reporting Requirements for Adults with Mental Health or Substance Use Disorders* (2025), <https://www.kff.org/medicaid/implications-of-medicaid-work-and-reporting-requirements-for-adults-with-mental-health-or-substance-use-disorders/>. Medicaid is the single largest payer of behavioral health services, including substance use disorder treatment. See Medicaid and CHIP Payment & Access Comm’n, *Behavioral Health in the Medicaid Program—People, Use, and Expenditures* (2015), <https://www.macpac.gov/publication/behavioral-health-in-the-medicaid-program%E2%80%95people-use-and-expenditures/>.

Expansion is the primary coverage pathway for people with behavioral health needs: 51% of Medicaid-covered adults with any mental health disorder, 45% of those with serious mental illness, 59% of those with a substance use disorder, and 61% of those with opioid use disorder qualify through expansion rather than a disability eligibility pathway. *Id.* Access to care through

Medicaid coverage reduces severe psychological distress. See Stacey McMorro et al., *Medicaid Expansion Increased Coverage, Improved Affordability, and Reduced Psychological Distress for Low-Income Parents*, 36 Health Affs. 808 (2017), <https://pubmed.ncbi.nlm.nih.gov/28461346/>. Loss of coverage for this group means loss of care. Becoming uninsured after disenrollment from Medicaid has been associated with a 52% average reduction in the likelihood of receiving any outpatient services, a 35% reduction in receiving mental health related outpatient services, and a 52% reduction in receiving acute care. Xu Ji et al., *Effect of Medicaid Disenrollment on Health Care Utilization Among Adults with Mental Health Disorders*, 57 Med. Care 574 (2019), <https://doi.org/10.1097/MLR.0000000000001153>.

**Substance Use Disorders (SUDs).** SUDs are chronic, relapsing medical conditions that are treatable and manageable, but not curable in the traditional sense. Under the Diagnostic and Statistical Manual of Mental Disorders (DSM-V-TR), an individual continues to have an SUD if their condition is in remission; a SUD is in remission if the individual previously met the diagnostic criteria for the condition but has not met any of the criteria (other than craving or a strong desire to use the substance) for at least three months. Am. Psychiatric Ass’n, *Diagnostic and Statistical Manual of Mental Disorders* 547, 553-54, 575-76, 587-88, 601-02, 608-10, 620-21, 632-34, 645-46, 652-53 (5th ed., text rev.) (2022) (distinguishing between early remission—three months to twelve months—and sustained remission—twelve months or longer).

Approximately 21% of non-elderly adults covered by Medicaid have a diagnosed mild, moderate, or severe SUD. Heather Saunders & Robin Rudowitz, KFF, *Demographics and Health Insurance Coverage of Nonelderly Adults With Mental Illness and Substance Use Disorders in 2020* (2022), <https://www.kff.org/medicaid/issue-brief/demographics-and-health-insurance-coverage-of-nonelderly-adults-with-mental-illness-and-substance-use-disorders-in-2020/>.

Individuals with an SUD, including those with an SUD in remission, face serious harm if Medicaid coverage is terminated. This is because SUDs “change and evolve over time, and interventions need to include provisions to assess patients on a regular basis and to change or adapt treatment when warranted.” James R. McKay, *Impact of Continuing Care on Recovery from Substance Use Disorder* 41 Alcohol Rsch. 1 (2021), <https://pmc.ncbi.nlm.nih.gov/articles/PMC7813220/>. Among people who recognized a need for alcohol or drug treatment but did not receive it, 30.8% pointed to a lack of health coverage and the cost of care. SAMHSA, *Receipt of Services for Behavioral Health Problems: Results from the 2014 National Survey on Drug Use and Health* (2015), <https://www.samhsa.gov/data/sites/default/files/NSDUH-DR-FRR3-2014/NSDUH-DR-FRR3-2014/NSDUH-DR-FRR3-2014.htm>.

For opioid use disorder (OUD) in particular, maintenance therapy (ongoing treatment with an opioid agonist such as methadone or a partial agonist like buprenorphine) can be long-term or indefinite, and the DSM-5-TR treats a person receiving that therapy as continuing to have the disorder. SAMSHA, *Medications for Opioid Use Disorder: For Healthcare and Addiction Professionals, Policymakers, Patients, and Families* (Treatment Improvement Protocol Series No. 63, updated 2021), <https://www.ncbi.nlm.nih.gov/books/NBK574914/> (concluding that many people with OUD benefit from lifelong treatment with medication, and “ongoing outpatient medication treatment for OUD is linked to better retention and outcomes than treatment without medication”). Opioid agonist treatment is associated with roughly half the risk of all-cause mortality, a benefit that persists only while treatment continues. Thomas Santo, Jr. et al., *Association of Opioid Agonist Treatment with All-Cause Mortality and Specific Causes of Death Among People with Opioid Dependence*, 78 JAMA Psychiatry 979 (2021), <https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2780655>.

#### IV. The IFR Creates Yet One More Barrier to Health Care for Low-Income People Who Have Serious Health Conditions.

The IFR provisions that are being challenged in this case are going to hurt people, as illustrated by these individuals' stories:<sup>1</sup>

- **P.R.** is a person with an intellectual disability and serious health conditions, including anxiety, that limit their ability to work. P.R. relies on Medicaid for ongoing medical care and medications. P.R. has functional challenges that make it difficult to comply with reporting requirements and paperwork demands. Lacking regular income and transportation, P.R. has difficulty accessing the internet, affording postage stamps, and mailing documents. P.R. has gone without health care in the past and their health conditions worsened. P.R. is afraid the IFR will cause them to lose health care and, as a result, the ability to live. Comment ID CMS-2026-2047-38586.
- **D.R.** is enrolled in Medicaid in Ohio. It took doctors almost two years to finally diagnose him with a serious mental health condition. Had Medicaid not been in place through the diagnostic process, D.R. believes he would not be alive today. Without Medicaid, there would be no access to care and medications. D.R. is concerned that he will not only have to show that he has a serious illness but also that he is unable to work. Comment ID CMS-2026-2047-41380.
- Before becoming ill, **A.A.**, an Oregon resident, worked various professional jobs. With one exception, those jobs did not offer health insurance, and A.A. has relied on Medicaid. Since becoming ill, A.A. has juggled the full-time needs of managing serious, sometimes life

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<sup>1</sup> The stories are taken from comments submitted to CMS in response to the IFR. *See Medicaid Program: Community Engagement Requirement for Certain Individuals, Document Comments*, <https://www.regulations.gov/document/CMS-2026-2047-0002/comment> (last visited Sept. 6, 2026).

threatening health conditions requiring multiple specialists and drug trials. Nevertheless, A.A. takes pride in continued participation in the workforce. A.A.'s health, however, is unpredictable, and the conditions are chronic and expensive to treat. A.A. is currently working remotely in multiple positions but worries both about being able to work enough or that gathering all the required compliance documentation will tax a body already working at capacity. A.A. fears being pushed further into poverty. Comment ID CMS-2026-2047-38715.

- **M.L.** has severe myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a physical illness that causes significant fatigue, sleep issues, and difficulty with daily activities. People with ME/CFS face conditions such as post-exertional malaise and cognitive dysfunction. The symptoms make sustained work difficult and, in some cases, dangerous. The symptoms fluctuate, so what M.L. can accomplish in some months cannot be accomplished in others. M.L. relies on Medicaid for her medical needs and is concerned that the IFR neither reflects the realities of living with ME/CFS nor accounts for the difficulties those with the condition will experience establishing medical frailty and inability to work. Comment ID CMS-2026-2047-39227.
- **S.K-H.** is 62 years old. Medicaid is her lifeline for health care. S.K-H. has severe osteoarthritis in her hips, left knee, back, and shoulders. It is also developing in her hands. At times, she experiences significant pain and cannot work. She is concerned that she will also be unable to navigate the complex procedural hurdles because of her health. She points out that requiring medically frail people to prove inability to comply to keep their Medicaid will hurt people with health conditions who need both health insurance and an income. Comment ID CMS-2026-2047-0319.

- **L.S.** is a 56-year-old Medicaid enrollee who lives in Colorado. She has recently become widowed. L.S. is a breast cancer survivor. Due to the IFR's requirements for medically frail people, she is concerned that she will lose the medical care and prescription medications she needs to control her diabetes, high blood pressure, high cholesterol, osteopenia, and anxiety/depression and to obtain ongoing care and monitoring for recurrence of cancer. Comment ID CMS-2026-2047-0696.
- **H.M.** lives in Indiana. She is the parent of a 25-year-old son who is autistic. In January 2027, he will need to rely on Medicaid for his health care needs. Over the years, her son has worked jobs and enrolled in courses at a technical college. No matter how much effort he puts in, he has met tremendous barriers due to his condition-related behaviors. He has had to retake classes after receiving a failing grade and has been let go from jobs. H.M. is concerned that her son will be unable to comply with the work requirements and will not be excluded as medically frail due to the IFR's requirements. Comment ID CMS-2026-2047-10721.
- **C.K.** and her son live in Washington. Her son is a freelance audiovisual worker in the music industry. He is constantly trying to build his portfolio, but times are tough. In addition, he has epilepsy, and this affects his ability to engage in steady work; sometimes he is unable to work at all. C.K.'s son relies on Medicaid for life-saving health care. She is worried that the new IFR requirements for medically frail people will affect his access to life-saving health care. Comment ID CMS-2026-2047-24367.
- **L.J.**, an Oregon resident, has worked various jobs—as a caregiver for a special needs child, grocery delivery coordinator during the pandemic, volunteer elementary school arts teacher, assistant for religious services at a women's prison, church volunteer, and hospice

comfort care volunteer—and is a lifetime taxpayer. L.J. has been chronically ill since 2017 and is enrolled in Medicaid. L.J. wants to work but, due to illness, can volunteer 10 hours per week, maximum, and even these hours can be a challenge to achieve. L.J. is concerned that loss of Medicaid coverage will mean loss of access to necessary medical care. Comment ID CMS-2026-2047-39626.

### CONCLUSION

For the foregoing reasons, *amici* ask the Court to grant the States' Motion for Summary Judgment.

Dated: September 10, 2026

Respectfully submitted,

/s/ Jane Perkins

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**APPENDIX A - LIST OF AMICI CURIAE**

Access Ready Inc.

AiArthritis

American Association of People with Disabilities

American Cancer Society Cancer Action Network

American Civil Liberties Union Foundation

American Diabetes Association

American Heart Association

American Lung Association

American Network of Community Options and Resources (ANCOR)

American Society of Clinical Oncology

Arthritis Foundation

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Blood Cancer United

Center for Civil Justice

Center for Public Representation

Center For Elder Law & Justice

Colorado Center on Law and Policy

Colorado Legal Services

CommunicationFIRST

Community Legal Aid Society Inc. (Delaware)

Connecticut Health Policy Project

Cystic Fibrosis Foundation

Deaf Equality

Disability Belongs®

Disability Law Center of Utah

Disability Rights Connecticut

Disability Rights Education and Defense Fund (DREDF)

Disability Rights Iowa

Easterseals, Inc.

Epilepsy Foundation of America

Families USA

Georgetown University Center for Children and Families

Greater Hartford Legal Aid

Hawaii Disability Rights Center

Health Law Advocates, Inc.

Indiana Justice Project

Justice in Aging

Kentucky Protection & Advocacy

Legal Action Center

Legal Aid DC

The Legal Aid Society

Legal Council for Health Justice

Lupus Foundation of America

Massachusetts Law Reform Institute

Maternal and Child Health Access

Montana Legal Services Association

Muscular Dystrophy Association

NAACP

National Academy of Elder Law Attorneys (NAELA)

National Alliance on Mental Illness (NAMI)

National Bleeding Disorders Foundation  
National Disability Rights Network  
National Health Law Program  
National Kidney Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Patient Advocate Foundation  
Nebraska Appleseed Center for Law in the Public Interest  
New York Legal Assistance Group  
Northwest Health Law Advocates  
The Partnership for Inclusive Disaster Strategies  
Pennsylvania Health Access Network  
Pennsylvania Health Law Project  
Pisgah Legal Services  
Public Justice Center  
Susan G. Komen Breast Cancer Foundation  
TechTonic Justice  
UnidosUS  
William E. Morris Institute for Justice