



























THE COALITION FOR HEMOPHILIA

















INTERNATIONAL FOUNDATION FOR AUTOIMMUNE

August 8, 2025

The Honorable Robert F. Kennedy Secretary U.S. Department of Health and Human Services 200 Independence Ave, SW Washington, DC 20201

Re: Utah Section 1115 Demonstration Amendment

Dear Secretary Kennedy:

Thank you for the opportunity to submit comments on Utah's 1115 Demonstration Amendment.

The undersigned organizations represent millions of individuals facing serious, acute and chronic health conditions. We have a unique perspective on what individuals and families need to prevent disease, cure illness and manage chronic health conditions. The diversity of our organizations and the populations we serve enable us to draw upon a wealth of knowledge and expertise that is an invaluable resource regarding any decisions affecting the Medicaid program and the people that it serves. We urge the Centers for Medicare and Medicaid Services (CMS) to make the best use of the recommendations, knowledge and experience our organizations offer here.

Our organizations are committed to ensuring that Utah's Medicaid program provides quality and affordable healthcare coverage. Our organizations are strongly opposed to Utah's proposal to implement work reporting requirements for Medicaid beneficiaries. These requirements will lead thousands of people to lose coverage and jeopardize the health of people with serious and chronic conditions in Utah. Our organizations urge CMS to reject this request and offer the following comments on the Utah 1115 Demonstration Amendment:

Work reporting requirements will result in significant coverage losses. Under Utah's proposal, adults under 60 must demonstrate that they meet the work reporting requirements or are exempt. If the state believes that individuals have not met these requirements, it will suspend coverage for three months, after which they will lose eligibility until their certification period ends. When Arkansas implemented a similar policy requiring Medicaid enrollees to report their hours worked or their exemption, the state terminated coverage for over 18,000 individuals before a federal court halted the policy. Similarly, Georgia's Pathways to Coverage Program, which includes work reporting requirements, enrolled less than 5,000 individuals in its first year, instead of the projected 31,000-100,000 beneficiaries originally estimated to be eligible. The state projects that 3,948 individuals could lose coverage due to these requirements. For patients with serious or chronic conditions, a gap in healthcare coverage can disrupt access to regular care and medications needed to manage their condition, leading to exacerbations that require emergency department visits at a higher cost to both the patient and the state.

Our organizations are deeply concerned that the proposal may negatively impact eligibility for individuals with, at risk of, or in the process of being diagnosed with, serious and chronic health conditions that prevent them from working. While the demonstration has an exemption for individuals who are 'physically or mentally unable to meet the requirements,' the state does not clearly define what that means, which could leave many patients with chronic conditions unable to get the exemption. Regardless, any reporting process for exempt enrollees and those with good cause exceptions will create opportunities for administrative error that could jeopardize people's coverage. This is exactly what happened in Arkansas – as one study found, "more than 95% of persons who were targeted by the policy already met the requirement or should have been exempt. Many Medicaid beneficiaries were unaware of the policy or were confused about how to report their status to the state, which suggests that bureaucratic obstacles played a large role in coverage losses under the policy." No criteria can circumvent these problems and the serious risk to the health of people we represent.

For individuals who are not working at least 80 hours per month or meeting one of the other listed exemptions, the demonstration would require community engagement in the form of registering for work, completing an evaluation, finishing job training modules and applying to 48 potential employers within three months. This requirement is an unrealistic expectation for enrollees, who may struggle to complete it due to other factors, such as limited transportation, caregiving responsibilities, or as a result of a medical condition.

In addition, though the proposal intends to rely on Department of Workforce Services systems for data verification, the proposed process for tracking job applications, monitoring exemption status, and handling appeals is not clearly outlined in the demonstration. Additional processes to determine patient eligibility and participation in program requirements inherently create opportunities for administrative errors that jeopardize access to care. There will undoubtedly be individuals whose data is incomplete, outdated, or not accurately captured by the systems in use. For example, during the unwinding of the Medicaid continuous coverage requirements, only 21% of enrollees in Utah were automatically reenrolled, demonstrating the significant gaps in existing data and the increased administrative burden many people will face. Furthermore, the waiver is unclear on how individuals will be able to demonstrate compliance or address inaccuracies if data sources fail to verify their eligibility. Navigating an appeals process can be time-consuming and burdensome. Patients may not have the time or

resources to complete a lengthy eligibility appeal, leading to loss of coverage. Our organizations are opposed to the administrative burden that this proposal will place on patients and the program.

Our organizations are concerned by the cost to implement this waiver. There will likely be large administrative costs to the state given the complexity of tracking work activities, building a data-sharing infrastructure across programs, and having a system in place to identify and track exemptions. For example, a GAO study of work reporting requirements estimated that the administrative costs could be up to \$272 million.⁵ In Georgia, the state spent over \$86 million within a year of implementing the Georgia Pathways to Coverage Program, despite the low enrollment, and it is estimated that three quarters of this was for administrative and consulting costs.⁶ Furthermore, the aforementioned changes in coverage status are likely to lead to increased churn, placing greater administrative burden on Utah's Medicaid program. The administrative cost of churn is estimated to be between \$400 and \$600 per person.⁷ Utah's Medicaid program is likely unprepared for the additional cost and administrative burden that the work reporting requirements will generate.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals find work. Most people on Medicaid who can work already do so. According to KFF, 92% of adults with Medicaid coverage under age 65 who do not receive Social Security disability benefits are either workers, caregivers, students, or unable to work due to illness. And continuous Medicaid coverage can actually help people find and sustain employment. In a report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that being enrolled in Medicaid made it easier to work or look for work (83.5% and 60%, respectively). That report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Additionally, a study in *The New England Journal of Medicine* found that Arkansas's work reporting requirement was associated with a significant loss of Medicaid coverage, but no corresponding increase in employment. Terminating individuals' Medicaid coverage for noncompliance with these requirements will hurt rather than help Utahns search for and obtain employment.

Finally, Utah's proposal does not align with the work reporting requirements specified by Public Law 119-21, and the Secretary does not have the authority to waive these specifications. States may only use Section 1115 demonstrations to enact work reporting requirements earlier than 2027 if those demonstrations comply with the provisions of the law. If the state wants to implement work reporting requirements before the statutory effective date of January 1, 2027, the Secretary should require that the state revise its amendment to comply with P.L. 119-21 and seek comment on the revised application at the state level (consistent with 42 C.F.R. 431.408) prior to resubmitting to CMS. However, even if Utah does go through this process, the issues outlined above related to coverage losses, confusion for enrollees, administrative burden to patients and the state, and implementation costs will only be exacerbated if Utah rushes implementation and has to change key details of its work reporting requirements program as CMS releases guidance on implementation of P.L. 119-21.

Our organizations remain strongly opposed to work reporting requirements and urge CMS to reject this proposal.

Sincerely,

AiArthritis

American Cancer Society Cancer Action Network

American Diabetes Association

American Heart Association

American Kidney Fund

American Lung Association

Cancer Nation (formerly National Coalition for Cancer Survivorship)

Coalition for Hemophilia B

Epilepsy Foundation of America

Hemophilia Federation of America

Hypertrophic Cardiomyopathy Association

Leukemia & Lymphoma Society

Lupus Foundation of America

March of Dimes

National Bleeding Disorders Foundation

National Multiple Sclerosis Society

National Patient Advocate Foundation

National Psoriasis Foundation

Susan G. Komen

The AIDS Institute

WomenHeart

ZERO Prostate Cancer

¹ Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at November State Data for Medicaid Work Requirements in Arkansas," KFF, December 18, 2018. Available at: https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: http://d31hzlbk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bach6/

http://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

² Chan, Leah. "One-Year Anniversary of Georgia's Pathways to Coverage Program Highlights Need for Reform," Georgia Budget and Policy Institute. July 2, 2024. Available at: https://gbpi.org/one-year-anniversary-of-georgias-pathways-to-coverage-program-highlights-need-for-reform/

³ Benjamin D. Sommers, MD, et al. "Medicaid Work Requirements—Results from the First Year in Arkansas," New England Journal of Medicine. Published online June 18, 2019. Available at: https://www.nejm.org/doi/full/10.1056/NEJMsr1901772

⁴ "What is happening with Medicaid renewals in each state?" Georgetown University McCourt School of Public Policy, Center for Children and Families. Accessed 8 January 2025. Available at: https://ccf.georgetown.edu/2023/07/14/whats-happening-with-medicaid-renewals/

⁵ Medicaid Demonstrations: Actions Needed to Address Weaknesses in Oversight of Costs to Administer Work Requirements. U.S. Government Accountability Office. October 1, 2019. Available at: https://www.gao.gov/products/gao-20-149

⁶ Coker, Margaret. "Georgia Touts its Medicaid Experiment as a Success. The Numbers Tell a Different Story. ProPublica. February 19, 2025. Available at: https://www.propublica.org/article/georgia-medicaid-work-requirement-pathways-to-coverage-hurdles

⁷ Swartz, Katherine et al. Reducing Medicaid Churning: Extending Eligibility For Twelve Months or To End of Calendar Year Is Most Effective. Health Affairs July 2015 34:7, 1180-1187 Available at: https://www.healthaffairs.org/doi/10.1377/hlthaff.2014.1204

⁸ KFF. Understanding the Intersection of Medicaid & Work: A Look at What the Data Say. April 24, 2023. Available at: https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-work-a-look-at-what-the-data-say/.

⁹ Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Available at: <a href="https://medicaid.ohio.gov/wps/wcm/connect/gov/2468a404-5b09-4b85-85cd-4473a1ec8758/Group-VIII-Final-Propert add?MOD-AUREPES & CONVERT TO-URIS CACHED-PROTEWORKS BACE 718, KOMOLSOLH 7E40ORNULL 3SOLES 6.

¹⁰ Benjamin D. Sommers, MD, et al. "Medicaid Work Requirements—Results from the First Year in Arkansas," New England Journal of Medicine. Published online June 18, 2019. Available at: https://www.nejm.org/doi/full/10.1056/NEJMsr1901772