



June 10 2021

Utah Department of Health
Medicaid and Health Financing
PO Box 143106
Salt Lake City, UT 84114-3106
Attn: Michelle Smith

Re: Utah Section 1115 Demonstration Renewal

Dear Ms. Smith:

The National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on the draft proposal for the Utah's Medicaid Section 1115 Demonstration Renewal under Section 1115 of the Social Security Act. NORD is a unique federation of voluntary health organizations dedicated to helping the 25-30 million Americans living with a rare disease. We believe that all patients should have access to quality, accessible, and affordable health coverage that is best suited to their medical needs.

Medicaid coverage serves as a lifeline to many rare disease patients and their families, who often find their lives upended by the debilitating nature of their diseases. While we support the state's proposal to extend Medicaid coverage to qualified justice-involved individuals in the 30-day period prior to release, we are concerned that several of the proposals within this waiver request would limit access to care for Utahns with rare disorders. We urge the state to revise this proposal to eliminate the proposed work requirements and to extend the full benefit Medicaid package to adults with dependent children before the waiver is submitted to the Centers for Medicare and Medicaid Services (CMS).

Work Requirements

Under the application, after the COVID-19 public health emergency has ended, non-exempt individuals between the ages of 19 and 60 would have to comply with a work requirement to remain eligible for coverage. This proposal would significantly increase the administrative burden on individuals in the Medicaid program and will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, Arkansas implemented a similar policy requiring Medicaid enrollees to report their hours worked or their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals and locked them out of



coverage until January 2019.¹ In New Hampshire, nearly 17,000 individuals would have lost coverage if the state had not suspended implementation of its work requirement.²

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases. If the state finds that individuals have failed to comply with the new requirements, after three months they will be disenrolled from coverage. For rare disease patients who require daily, weekly or monthly medications and/or health care provider engagement, this sudden disenrollment in Medicaid coverage could result in their being unable to meet with their provider or get prescriptions filled, leading to disease progression, hospitalization or death.

NORD is also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from working. While some rare disease patients are able to maintain regular employment, the ability of other rare disease patients to work continuously fluctuates as a result of their disorder, which could jeopardize their Medicaid coverage under this proposal. Regardless, even exempt enrollees may have to report their exemption, creating opportunities for administrative error that could jeopardize their coverage. In Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption.ⁱⁱ No exemption criteria can circumvent this problem and the serious risk to the health of the people we represent.

Administering these requirements will also be expensive for the state of Utah. States such as Kentucky, Tennessee and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities would cost tens of millions of dollars.³ This would divert federal resources from Medicaid's core goal – providing health coverage to those without access to care – and compromise the fiscal health of Utah's Medicaid program.

Ultimately, these requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.⁴ A study published in *JAMA Internal Medicine* looked at the employment status and characteristics of Michigan's Medicaid enrollees.⁵ The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work. Additionally, studies in *The New England Journal of Medicine* and

¹ Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at November State Data for Medicaid Work Requirements in Arkansas," Kaiser Family Foundation, 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://d31hzlhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fbd6c891d9bacb6/011519_AWReport.pdf

² New Hampshire Department Health and Human Services, DHHS Community Engagement Report, June 2019. Available at: <https://www.dhhs.nh.gov/medicaid/granite/documents/ga-ce-report-062019.pdf>.

³ Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018. Available at <https://www.rollcall.com/news/politics/medicaid-kentucky>.

⁴ Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017. Available at: <http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>.

⁵ Renuka Tipirneni, Susan D. Goold, John Z. Ayanian. Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan. *JAMA Intern Med*. Published online December 11, 2017. doi:10.1001/jamainternmed.2017.7055



Health Affairs have found that Arkansas's work requirement was associated with a significant loss of Medicaid coverage, but no corresponding increase in employment.^{6,7}

Continuous Medicaid coverage can actually help people find and sustain employment. In another report looking at the impact of Medicaid expansion in Ohio, the majority of enrollees reported that that being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively). That report also found that many enrollees were able to get treatment for previously untreated health conditions, which made finding work easier. Terminating individuals' Medicaid coverage for non-compliance with these requirements will hurt rather than help people search for and obtain employment.

The U.S. Court of Appeals for the District of Columbia has reaffirmed that the purpose of the Medicaid program is to provide healthcare coverage and that Arkansas' restrictive waiver, including the work requirement policy, did not meet that objective.⁸ Additionally, in light of coverage losses and the ongoing impact of the COVID-19 pandemic, CMS has withdrawn work and community engagement guidance as well as approvals of work and community engagement requirements in Arkansas and several other states. Continuing to pursue this policy is not a good use of Utah's time and resources.

Benefit limits for adults with dependent children

The state requests continued authority to provide reduced benefits for enrolled adults with dependent children. These benefit limitations include waiving non-emergency transportation (NEMT). Due to the often significant economic and health care costs associated with having a rare disease, many patients may not own a car and may lack access to reliable public transportation, especially in the rural parts of Utah. Rare disease patients may also have to travel a significant distance to see a health care provider with expertise in their condition. According to a survey conducted by NORD in 2019, 39% of rare disease patients needed to travel 60 or more miles in order to see a provider.⁹ Maintaining NEMT ensures that rare disease patients will be able to make it to all their scheduled and routine medical appointments, allowing them to better maintain their health and avoid unnecessary complications and hospitalizations.¹⁰

NORD strongly urges the state to revise its proposal and extend the full benefit package to adults with dependent children.

⁶ 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,

https://cdf.nejm.org/register/reg_multistep.aspx?promo=ONFGMM02&cpc=FMAAALLV0818B

⁷ Sommers, B., Chen, L., R. Blendon, E. Orav, and A. Epstein. 2020. Medicaid work Requirements in Arkansas: Two-Year Impacts on Coverage, Employment, and Affordability of Care, *Health Affairs* 39(9): 1522-1530. Accessed at:

<https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.00538>

⁸ US Court of Appeals for the District of Columbia Circuit, *Gresham v. Azar*, Feb. 14, 2020. Available at:

<https://healthlaw.org/wp-content/uploads/2020/02/Gresham-v.-Azar-DC-Circuit-Ruling-Feb-14.pdf>.

⁹ Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." National Organization for Rare Disorders, 2020. Available at: https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088-Barriers-30-Yr-Survey-Report_FNL-2.pdf

¹⁰ Michael Adelberg and Marsha Simon, "Non-Emergency Medical Transportation: Will Reshaping Medicaid Sacrifice an Important Benefit?" *Health Affairs Blog*, September 20, 2017. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20170920.062063/full/>



Coverage for justice-involved populations

Finally, the application includes a request to provide Medicaid coverage to qualified justice involved individuals in the 30-day period prior to release. Qualified individuals would include those with a chronic physical or behavioral health condition, a state-defined mental illness, or an opioid use disorder. The state estimates that 3,200 individuals would be enrolled through this proposal. This proposal will help high-risk justice involved populations put critical supports needed to treat physical and behavioral health conditions in place before being released from incarceration. Improved access to care can improve health and other outcomes for justice involved populations. For example, studies in Florida and Washington reported that people with severe mental illness and Medicaid coverage at the time of their release were more likely to access community mental health services and had fewer detentions and stayed out of jail longer than those without coverage.¹¹

NORD supports this proposal to improve continuity of care for individuals with the serious and chronic health conditions and urges the state to expand eligibility to all individuals who qualify for Medicaid coverage 30 days prior to release, regardless of whether they have a diagnosis for one of the health conditions listed above. Other individuals may have undiagnosed rare health conditions and/or still benefit from being connected to a regular source of health coverage than can provide preventive health services, primary care, and other services needed to stay healthy.

Conclusion

The core objective of the Medicaid program is to furnish health care to low-income populations, and while we support extending Medicaid coverage to eligible justice involved individuals within 30 days of release, many provisions of this waiver renewal application do not further Medicaid's core goal and indeed may create significant barriers to care for the patients that we represent. We strongly urge the state to remove the work requirement provision and to provide the full benefit package to all Medicaid enrollees.

Thank you again for the opportunity to submit comments. For questions regarding NORD or the above comments please contact Corinne Alberts at calberts@raredisease.org.

Sincerely,

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders

¹¹ Joseph Morrissey et al. Medicaid Enrollment and Mental Health Service Use Following Release of Jail Detainees with Severe Mental Illness. *Psychiatric Services* 57, no. 6 (June 2006): 809-815. DOI: 10.1176/ps.2006.57.6.809, and Joseph Morrissey et al. The Role of Medicaid Enrollment and Outpatient Service Use in Jail Recidivism Among Persons with Severe Mental Illness. *Psychiatric Services* 58, no. 6 (June 2007): 794-801. DOI: 10.1176/ps.2007.58.6.794.