October 25, 2019

Nate Checketts
Deputy Director
Utah Department of Health
PO Box 143106
Salt Lake City, UT 84114
Submitted via email to Medicaid1115waiver@utah.gov

Re: Utah Section 1115 Demonstration Waiver Application

Dear Director Checketts:

On behalf of the 1-in-10 Utah residents with one of the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) appreciates the opportunity to submit comments on Utah's 1115 Demonstration Waiver Application.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families, and NORD is committed to ensuring that Medicaid provides adequate, affordable and accessible healthcare coverage. In November 2018, Utah voters clearly decided to improve access to healthcare by expanding Medicaid coverage to individuals with incomes below 138 percent of the federal poverty level ($28,577 for a family of three), extending coverage to an estimated 150,000 low-income individuals in the state. Unlike the two previous waivers released by the state this year, this version of Utah's waiver application would finally fully expand coverage to this population. NORD strongly supports this expansion.

Unfortunately, this application also includes a number of policies that add new financial and administrative barriers to Utah's Medicaid program and will reduce the number of individuals able to access comprehensive, affordable health insurance coverage. NORD therefore offers the following comments on Utah's waiver.

Premiums

Under Utah's new application, individuals in the adult expansion population with incomes above 100 percent of the federal poverty level ($1,778 per month for a family of three) would have to pay premiums ranging from $20 to $30 per month and could lose their coverage if they are unable to pay them. This policy would likely both increase the number of enrollees who lose

Medicaid coverage – the application itself estimates that 1,200 people would lose coverage as a result of this policy – and also discourage eligible people from enrolling in the program. Research has shown that even relatively low levels of cost-sharing for low-income populations limit the use of necessary healthcare services.[1] For example, when Oregon implemented a premium in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage.[2] NORD believes that these premiums will create significant financial barriers for rare patients that jeopardize their access to needed care and therefore opposes this policy.

ED Copay

Utah's waiver would allow the state to charge a $25 copayment for non-emergent use of the emergency department (ED) for individuals in the adult expansion population with incomes above 100 percent of the federal poverty level. This policy could deter rare patients and families from seeking necessary care during emergency situations that could be life or death.

People should not be financially penalized for seeking lifesaving care for their rare disease or any other critical health problem that requires immediate care. When people do experience severe symptoms, they should not try to self-diagnose their condition or worry that they cannot afford to seek care. Instead, they must have access to quick diagnosis and treatment in the ED.

Evidence suggests this type of cost sharing may not result in the intended cost savings.[3] Research demonstrates that low-income individuals served by Medicaid are more price sensitive compared to others, more likely to go without needed care, and more likely to experience long-term adverse outcomes. A study of enrollees in Oregon's Medicaid program demonstrated that implementation of a copay on emergency services resulted in decreased utilization of such services but did not result in cost savings because of subsequent use of more intensive and expensive services.[4] This provides further evidence that copays may lead to inappropriate delays in needed care. NORD opposes this punitive proposal for a $25 copayment for non-emergent use of the ED.

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[1] Samantha Artiga, Petry Ubri, and Julia Zur, "The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings," Kaiser Family Foundation, June 2017. Available at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/.

[2] Id.

[3] See for example: Chernew M, Gibson TB, Yu-Isenberg K, Sokol MC, Rosen AB, Fendrick AM. Effects of increased patient cost sharing on socioeconomic disparities in health care. J Gen Intern Med. 2008. Aug; 23(8):1131-6. Ku, L and Wachino, V. "The Effect of Increased Cost-Sharing in Medicaid: A Summary of Research Findings." Center on Budget and Policy Priorities (July 2005), available at http://www.cbpp.org/5-31-05health2.htm.

[4] Wallace NT, McConnell KJ, et al. How Effective Are Copayments in Reducing Expenditures for Low-Income Adult Medicaid Beneficiaries? Experience from the Oregon Health Plan. Health Serv Res. 2008 April; 43(2): 515–530.

Program Lockout

Utah's waiver would also add a new six-month lock-out for individuals in the adult expansion and targeted adult populations that the state determines have committed an intentional program violation (IPV). This provision is unnecessary, as the state already has the ability to take individuals to court for possible fraud and protect the fiscal sustainability of the program. NORD opposes this proposal.

This policy would increase the administrative burden on both patients and the state Medicaid program and, as the state itself acknowledges, result in coverage losses. For example, under this new policy, an IPV would include failing to report a required change within ten days. NORD fears that patients could be confused over what they have to report or get caught up in red tape trying to provide the required information, resulting in the patients losing coverage over bureaucracy. Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

This policy could also have huge financial implications for patients. It is also not clear what overpayments a patient could be responsible for if the state determines an IPV occurred. For example, could a patient be forced to repay a per-member-per-month fee to a managed care plan, even if they used no healthcare services during the period in question? The application does clearly state that patients could be charged for overpayments related to coverage they received while appealing an IPV determination. This could discourage patients from appealing decisions even when they know they have not committed an IPV, leading to unnecessary coverage losses and additional financial burdens on the already low-income patients served by the Medicaid program.

Presumptive Eligibility

Utah's waiver would prevent hospitals from making presumptive eligibility determinations for individuals in the adult expansion population and continue to prevent hospitals for making these determinations for the targeted adult population. Presumptive eligibility allows hospitals to provide temporary Medicaid coverage to individuals likely to qualify for Medicaid. This is an important entry point for individuals who qualify for Medicaid but are not yet enrolled to receive access to coverage promptly and helps to protect patients from large medical bills. NORD opposes this request.

Managed Care

Utah's application also requests authority to implement managed care contracts and rates prior to CMS approval and set it owns "approach to network adequacy, access to care, and availability of services," which is not fully explained. NORD is extremely concerned that these changes would limit oversight over patient care provided through managed care organizations (MCOs) in Utah, where more than 80 percent of beneficiaries are enrolled in comprehensive managed care organizations. Federal standards related to rate review, network adequacy and other areas are important to ensure that patients can actually see the appropriate providers and receive the care

they need. These complex issues require significant oversight and more specificity to ensure that taxpayer funds are being spent appropriately and that patients are receiving the care they need. NORD believes that such a vague request with such profound implications should not be approved.

Additional Changes Through State Administrative Rulemaking

Utah's application includes a request to make additional changes to its Medicaid program through the state's administrative rulemaking process. Many of the proposed changes would impact patients' access to coverage – such as the changes to retroactive eligibility – or the comprehensiveness of patients' coverage – such as changing the benefit package for expansion enrollees. It is critical that any changes of this nature go through the full notice and comment process at both the state and federal level to ensure that all stakeholders, including beneficiaries, have the opportunity to provide feedback. If the state would like to make these changes at this time, it should explicitly ask CMS to waive these provisions in its current application and include a more complete analysis of their impact on beneficiaries.

Provisions Continued from Previous Waivers

Utah's application also includes requests to extend certain features already approved by CMS in the state's previous waiver on March 29, 2019. NORD continues to have serious concerns about the impact of these policies on the patients we represent.

Work Requirements

Under the application, individuals in the adult expansion population would be required to complete job search and training requirements unless they either demonstrate that they work at least 30 hours per week or meet other exemptions. One major consequence of this proposal will be to increase the administrative burden on individuals in the Medicaid program. Increasing administrative requirements 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.[5] In another case, after Washington state changed its renewal process from every twelve months to every six months and

[5] 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. Accessed 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

instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.[6]

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, their coverage could be terminated.

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. Regardless, it appears that even exempt enrollees will have to provide documentation of their medical condition validated by a medical professional or other data source, 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.[7] 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 will cost tens of millions of dollars.[8] 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.[9] A study published in JAMA Internal Medicine, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[10] The study found only about a quarter were unemployed (27.6 percent). Of this 27.6

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[6] Tricia Brooks, "Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP," Georgetown University Health Policy Institute Center for Children and Families, January 2009.

[7] Jessica Greene, "Medicaid Recipients' Early Experience With the Arkansas Medicaid Work Requirement," Health Affairs, Sept. 5, 2018. Accessed at: https://www.healthaffairs.org/do/10.1377/hblog20180904.979085/full/.

[8] 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.

[9] 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/.

[10] 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

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, recent research shows that the work reporting requirement in Arkansas did not lead to increased employment among the Medicaid population. A study in The New England Journal of Medicine found that the implementation of Arkansas's work requirement was associated with a significant loss of Medicaid coverage and no corresponding increase in employment, which indicates that individuals did not find other jobs that increased their income and provided other healthcare coverage. The study also estimates that 95 percent of Arkansans subject to the requirements already worked enough hours to meet the requirements or qualified for an exemption, which further confirms that most Medicaid beneficiaries are working if they are able to do so.

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. Suspending individuals' Medicaid coverage for non-compliance with these requirements will hurt rather than help people search for and obtain employment. NORD opposes this policy.

Enrollment Limits

In a letter to Governor Hebert on August 16, 2019, CMS stated that it would not approve an enrollment limit for the adult expansion population in conjunction with the 90 percent enhanced matching rate for this population.[11] However, Utah's current application still proposes to continue the previously approved enrollment limits for the adult expansion and targeted adult populations. NORD opposes these enrollment limits.

Enrollment limits will inevitably harm patients. This policy will reduce access to preventive services, regular visits with healthcare providers, daily medications that patients need to manage their chronic conditions and life-saving treatments for other serious illnesses. Under this policy, patients could be diagnosed with a life-threatening disease that requires immediate treatment but be denied coverage, forcing them to choose between delaying care and massive medical bills. This denial of coverage is not consistent with the statutory objectives and purpose of the Medicaid program.

[11] https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ut/per-capita-cap/ut-per-capita-cap-correspondence-ltr-20190816.pdf

EPSDT

Finally, Utah's application proposes to continue to waive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) for aged 19 and 20 in the adult expansion and targeted adult populations. EPSDT requirements provide access to critical services and treatments for kids and young adults living in poverty. As these young adults transition to higher education or jobs, it is important that they receive the same medical care for any illness or chronic disease they might have. Disruption in medical treatment could have negative consequences for their long-term health and economic security. Unnecessarily changing treatment will hinder patients' success. NORD opposes this provision.

NORD supports the full expansion of Utah's Medicaid program, but continues to be deeply concerned that some of the policy proposals in this waiver application will add additional financial and administrative barriers that will jeopardize patients' coverage. Thank you for the opportunity to provide comments. For further questions, please do not hesitate to contact me at ddelcarlo@rarediseases.org.

Sincerely,

/s/

Danielle Del Carlo
Director of State Policy