September 13, 2019

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Utah Section 1115 Demonstration Application

Dear Secretary Azar:

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

The undersigned organizations represent millions of individuals facing serious, acute and chronic health conditions across the country. Our organizations have a unique perspective on what individuals need to prevent disease, cure illness and manage chronic health conditions. The diversity of our groups and the patients and consumers we represent enables us to draw upon a wealth of knowledge and expertise and serve as an invaluable resource regarding any decisions affecting the Medicaid program and the people that it serves. We urge the Department of Health and Human Services (HHS) to make the best use of the recommendations, knowledge and experience our organizations offer here.

The purpose of the Medicaid program is to provide healthcare coverage for low-income individuals and families, and our organizations are committed to ensuring that Medicaid provides adequate, affordable and accessible healthcare coverage. Unfortunately, several 1115 waiver proposals submitted to and approved by the Centers for Medicare and Medicaid Services (CMS) in recent months have threatened patients' access to quality and affordable healthcare coverage.[1] 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). This decision should have expanded coverage to 150,000 low-income individuals in the state. Instead – through both a waiver approved by CMS on March 29, 2019 and the state's current waiver application – Utah moved forward with an alternative plan that will reduce the number of individuals able to access comprehensive,

affordable health coverage and add new barriers to Utah's Medicaid program. Our organizations oppose that contraction and urge CMS to reject Utah's waiver.

Per Capita Cap

Many of our organizations have already written to this Administration about our strong opposition to policies that would encourage, invite or allow states to apply for block grants or per capita caps for their Medicaid programs.[2] Our organizations similarly oppose Utah's proposal to change the financing structure for its Medicaid program to a per capita cap model. Per capita caps are designed to reduce federal funding for Medicaid, forcing states to either make up the difference with their own funds or cut their programs by reducing the number of people they serve and the benefits they provide. These cuts are unacceptable for individuals with serious and chronic health conditions.

Utah's application does not speak to the specific changes it would make to achieve a growth rate below the state's new per capita cap. Our organizations fear that the state will cut coverage for certain treatments completely or impose additional barriers to important services, making it more difficult for patients to access the care that they need. Our communities have already had experiences, some dire, in which Medicaid programs have denied patients needed therapies because of budget constraints. Additionally, Utah may choose to cut payments to providers to help keep spending under the new per capita cap. These cuts could make it harder for patients with serious and chronic health conditions – who rely on prompt access to primary care providers as well as specialists – to get appointments with providers who can help them find the best treatments and manage their conditions.

Utah's application requests that CMS allow the state to make changes to its per capita cap in a few special circumstances. This is a clear acknowledgement that a per capita cap financing structure does not protect either the state or patients from financial risk as the result of an economic downturn or other unexpected event. The exceptions in the application are not clearly defined and are not sufficient to protect the state if healthcare costs grow above the per capita cap. For example, there are many ground-breaking treatments in development for patients with serious and chronic illnesses. If an expensive but highly effective treatment became available, Utah's spending could rise above the cap, putting the state's budget at risk and creating an incentive for the state to impose additional barriers for that treatment.

Finally, if Utah is truly concerned about the fiscal sustainability of its Medicaid program, the state could submit a state plan amendment to fully expand Medicaid to 138 percent of the federal poverty level and receive a 90 percent match from the federal government for all expenses for the adult expansion population without any per capita cap, as Utah voters approved in November. This policy would both benefit the state financially and extend access to care to more low-income individuals in need of coverage, a core objective of the Medicaid program.

Program Lockout

Utah's waiver would also add a new six-month lock-out for individuals in the adult expansion population 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. Our organizations oppose 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. Our organizations fear 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.

Continuous Eligibility

Utah's waiver would allow for up to 12 months of continuous eligibility for the adult expansion population. Research has shown that continuous eligibility helps to reduce churn and temporary gaps in Medicaid coverage, which can be particularly problematic for individuals trying to manage serious and chronic health conditions.[3] However, our organizations are concerned that the benefits of continuous eligibility will be reduced by the IPV policy and other provisions in this waiver, and we do not see a justification for allowing the state to limit continuous eligibility by administrative rule.

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. Presumptive eligibility also helps to protect patients from large medical bills as well as hospitals from the costs of uncompensated care. Our organizations oppose this request.

Previously Approved Provisions

Utah's application also requests to extend certain features already approved by CMS in the state's previous waiver. Our organizations continue 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.[4] In another case, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.[5]

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 the following month. People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

Our organizations are 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.[6] 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.[7] 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.[8] A study published in *JAMA Internal Medicine*, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[9] 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, a study in *The New England Journal of Medicine* found that Arkansas's work requirement was associated with a significant loss of Medicaid coverage, but no corresponding increase in employment, which negates the state's argument that Medicaid enrollment is down because individuals are finding jobs and gaining other coverage.[10] 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 being enrolled in Medicaid made it easier to work or look for work (83.5 percent and 60 percent, respectively).[11] 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. Our organizations oppose this work reporting requirement policy.

Enrollment Limits

CMS has already granted Utah the authority to cap enrollment through the state's previous waiver, authority which the state is requesting to continue in this application. While we understand that CMS has denied Utah's request to cap enrollment for the adult expansion population when receiving an

enhanced matching rate, our organizations would still like to note our strong opposition to enrollment limits in the Medicaid program.

Enrollment limits will inevitably harm patients. This policy will reduce access to preventive services, regular visits with health care providers, daily medications that patients need to manage their chronic conditions and life-saving treatments for other serious illnesses. Under this policy, a patient 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. While Utah claims that it does not expect this policy to impact enrollment, the additional financial pressures on the state because of the per capita cap policy could easily lead the state to shut large number of individuals out of coverage. This denial of coverage is not consistent with the statutory objectives and purpose of the Medicaid program.

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. Our organizations oppose this provision.

Our organizations are deeply concerned about the policy proposals in this waiver application. Healthcare should be affordable, accessible and adequate for patients in the Medicaid program, and Utah's application does not meet that standard. Thank you for the opportunity to provide comments.

Sincerely,

American Heart Association
American Liver Foundation
American Lung Association
Chronic Disease Coalition
Epilepsy Foundation
Family Voices
Hemophilia Federation of America
Leukemia & Lymphoma Society
Lutheran Services in America
Mended Little Hearts
National Alliance on Mental Illness
National Hemophilia Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
National Psoriasis Foundation
Susan G. Komen
United Way Worldwide

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[2] Letter to Administrator Verma Re: Block Grant Policies, July 18, 2019. Available at: https://www.lung.org/assets/documents/advocacy-archive/health-partner-letter-to-cms-1.pdf.
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