August 18, 2018

Submitted via the Federal Medicaid.gov Portal

Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments for Kentucky HEALTH Application

To Whom It May Concern:

The HIV Health Care Access Working Group (HHCAWG) appreciates the opportunity to comment on Kentucky's Section 1115 Demonstration Application (the "Kentucky Application") under Section 1115 of the Social Security Act. HHCAWG is a coalition of over 100 national and community-based HIV service organizations representing HIV medical providers, public health professionals, advocates, and people living with HIV who are all committed to ensuring access to critical HIV- and Hepatitis C (HCV) related health care and support services.

The Medicaid program is a critical source of health coverage for life-saving care for people living with HIV. More than 40 percent of people living with HIV in care count on the Medicaid program for the healthcare and treatment that keeps them healthy and productive.[1] Ensuring uninterrupted access to effective HIV care and treatment is important to the health of people living with HIV and to public health.[2] When HIV is effectively managed, the risk of transmitting the virus drops to near zero.[3] Kentucky's proposal imposing work requirements and other restrictive policies on vulnerable populations threatens to reverse the progress in providing access to early prevention, care, and treatment and reducing health care costs.

---

[1] Kates, Jennifer and Lindsey Dawson. Insurance Coverage Changes for People with HIV Under the ACA. Kaiser Family Foundation. February 2017.
[2] Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. Available at http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL. pdf.
[3] Cohen, MS., et al. Antiretroviral Therapy for the Prevention of HIV-1 Transmission. N Engl J Med 2016; 375:830-839. September 1, 2016.

While HHCAWG understands and supports the value of work for those who are able to work we are, concerned about the work requirement policies put forth in the Kentucky Application. While the Application contemplates that people living with HIV will be formally exempt from these new requirements, HHCAWG is concerned that Kentucky's Application would substantially decrease meaningful access to care for many low-income individuals, including people who do not have HIV but are at risk of exposure and people living with HCV and other chronic health conditions. For the reasons discussed in detail below, we strongly oppose the Kentucky Application and urge the Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services (HHS) to reject it.

I. Kentucky's proposal goes directly against the core objectives of the Medicaid program and should not be approved under Section 1115

The Kentucky Application violates the basic conditions required for approval of a section 1115 waiver. Section 1115(a) of the Social Security Act, codified at 42 U.S.C. § 1315(a), allows a federal waiver to facilitate a State's "experimental, pilot, or demonstration project" that, "in the judgment of the Secretary, is likely to assist in promoting the objectives" of the Medicaid program. One of the primary objectives of Medicaid, as explained by § 1901 of the Social Security Act, is to enable each State to furnish "medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and costs are insufficient to meet the costs of medically necessary services."[4]

The policies contemplated in the Kentucky Application would achieve the exact opposite result intended by this objective. In particular, Kentucky's proposal to strip coverage from people who do not meet work requirements, pay premiums, or file increasingly burdensome paperwork on time will result in more individuals losing access to health coverage and medically necessary services. Kentucky's own estimates show that, at minimum, coverage will decrease by 95,000 over the course of the waiver. It is likely the case that this is a conservative estimate and the actual number of individuals losing coverage will be between 175,000 and 300,000.[5]

This devastating loss of coverage cannot be reconciled with the core purpose of Medicaid to furnish medical assistance. Approving policies that cause coverage losses, increase the number of uninsured individuals, and leaves vulnerable individuals without access to health services cannot be justified as a lawful and proper use of Section 1115's waiver authority. Medicaid is a lifeline for many individuals living with chronic health conditions, and losing Medicaid coverage would be particularly harmful for these individuals.

---

[4] 42 U.S.C. § 1396-1.

[5] Amicus Brief of Deans Chairs & Scholars, available at https://publichealth.gwu.edu/sites/default/files/downloads/HPM/Kentucky%20Medicaid%20Proposed%20Amici%20Curiae%20Brief.pdf.

If implemented, the Kentucky Application would take away health coverage for many who would otherwise be eligible. Far from addressing the health needs of vulnerable low-income populations, the Kentucky Application would decrease access to health coverage for these populations by creating new barriers to health care. As a result, individual and public health in the state will suffer. Given the multitude of ways in which these proposals will take health care away from individuals and worsen health outcomes, HHS should reject Kentucky's Application for failing to promote the objectives of the Medicaid program, thereby violating the requirements of section 1115.[6]

II. Work requirements will disproportionately harm individuals living with chronic health conditions

Individuals living with chronic illnesses stand to be disproportionately harmed by the combined effect of these proposals. Many individuals who live with a chronic illness that is not classified severe enough by the Medicaid program to be considered a disability but that make maintaining employment impossible would be subject to the work requirement. Chronic illnesses can produce symptoms or disabilities that are not visible, yet serve as impediments to steady employment. Additionally, some chronic conditions like multiple sclerosis produce periods of inability to work due to medication side effects or symptom flare-ups; employees with these conditions require flexible work arrangements that can be hard to find or keep. Episodic disabilities can produce an uneven work history, which in turn can make it more difficult for a person to find consistent employment. These burdens particularly affect people living with chronic illnesses or disabilities, as consistent access to medical care is key to the management of symptoms and overall long-term wellness.

While Kentucky's Application states that individuals determined "medically frail," including those living with HIV, will be exempted from the new work requirements, the definition of this term is narrow and will leave out many individuals living with chronic illnesses and disabilities that need consistent access to health services. For example, Kentucky estimates that 10% of its Medicaid population will be designated as medically frail. However, other states' data show that a higher percentage of enrollees have mental health conditions that negatively impact their ability to consistently work. Nearly 18% of Ohio[7] expansion enrollees and 20% of Michigan[8] expansion enrollees reported that they had a mental health condition that impaired their ability to function. Given that these percentages relate only to mental illness, it is likely that Kentucky had not

---

[6] *See, e.g.*, *Beno v. Shalala*, 30 F.3d 1057 (9th Cir. 1994) (striking down a section 1115 waiver due, in part, to an inadequate determination by HHS that the plan was likely to promote the Act's objectives). Furthermore, the law requires that the Secretary's decision is based solely on a substantive "judgment" as to whether the waiver "is likely to assist in promoting the objectives" of Medicaid. As the Supreme Court has made clear in *Massachusetts v. EPA*, "the use of the word 'judgment' is not a roving license to ignore the statutory text. It is but a direction to exercise discretion within defined statutory limits." 549 U.S. 497, 533 (2007).

[7] The Ohio Department of Medicaid, "Ohio Medicaid Group VIII Assessment: A Report to the Ohio General Assembly," http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Assessment.pdf.

[8] Renuka Tipirneni, Susan D. Goold, John Z. Ayanian, "Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan," *Journal of the American Medical Association*, https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2664514.

adequately considered the full range of individuals for whom complying with work requirements presents practical difficulties due to their conditions.

Further, even individuals that qualify for an exemption may be unable to prove that they do. Imposing additional paperwork requirements has been shown to reduce Medicaid enrollment overall, and individuals living with chronic health conditions will face added hardships in meeting these requirements.[9] Navigating the complex process of obtaining physician testimony, medical records, and other required documents may prove unduly burdensome, particularly if individuals do not have health coverage while securing an exemption.

Kentucky has not described the process by which enrollees must engage in to secure an exemption. Instead, Kentucky proposes to rely on its contracted managed care organizations operated by private insurers to collect the information necessary to make this determination. Even if people living with HIV and other chronic conditions are formally exempt, experience shows that the process of securing an exemption is likely to be error prone and potentially lead to gaps in coverage and treatment. The history of administering exemptions to work requirements in other public benefits, such as the Supplemental Nutrition Assistance Program (SNAP) and Temporary Assistance for Needy Families (TANF) programs shows that states often make mistakes and end up sanctioning beneficiaries that are not formally subject to the requirement, including individuals living with disabilities.[10]

The administrative challenges associated with implementing work requirements would be more pronounced in Medicaid than in the SNAP and TANF programs, which have struggled with implementation. SNAP and TANF require substantial interactions with participants, including interviews and frequent reporting. States have encountered numerous obstacles to accurately applying these policies. States' administration of these policies in the SNAP program was often applied inaccurately and led to eligible individuals being denied benefits.[11] When first implemented, the U.S. Food and Nutrition Service did a study and found that policies were "difficult to administer and too burdensome for the States." One of the biggest shifts was tracking benefit receipt over time, rather than circumstances in a single month, which was a fundamental change to program administration.[12] Historical analysis of state experience implementing work requirements in TANF suggests that adding similar requirements to Medicaid could cost states thousands of

[9] Margot Sanger-Katz, "Hate Paperwork? Medicaid Recipients Will Be Drowning in It," *The New York Times,* January 18, 2018, https://www.nytimes.com/2018/01/18/upshot/medicaid-enrollment-obstacles-kentucky-work-requirement.html

[10] LaDonna Pavetti, Michelle K. Derr, Heather Hesketh Zaveri, "Review of Sanction Policies and Research Studies: Final Literature Review," Mathematica Policy Research Reports, https://ideas.repec.org/p/mpr/mprres/acfb6f4539184fbf9847236c75f1fb36.html

[11] USDA Office of Inspector General, FNS Controls over SNAP Benefits for Able-Bodied Adults Without Dependents, September 2016, https://www.usda.gov/oig/webdocs/27601-0002-31.pdf.

[12] Mathematica Policy Research, Inc., Imposing a Time Limit on Food Stamp Receipt: Implementation of the Provisions and Effects on Food Stamp Participation (2001).

dollars per beneficiary.[13]

Kentucky has not adequately considered the disproportionate effect these harmful policies will have on individuals living with chronic illnesses and disabilities, despite numerous state comments speaking directly to this issue. Accordingly, Kentucky has not satisfied the requirement that issues raised during the public notice procedure are considered during development of the final application.[14] It is clear from this Application that Kentucky is not adequately protecting the health needs of its most vulnerable citizens.

III. Work requirement policies threaten to worsen people's health and make it harder to find and keep work

Conditioning Medicaid eligibility on satisfying new work requirements would not achieve the objective Kentucky sets out in its application, let alone the objectives of the Medicaid program. Kentucky states that in implementing work requirements, it seeks to promote economic self-sufficiency. While we agree that this is a noble goal, it is not a permissible objective for an 1115 demonstration. Furthermore, the policies contemplated have been shown to be ineffective at promoting economic mobility. Forcing individuals to find and maintain employment to receive health coverage does not promote economic self-sufficiency, but rather leaves already vulnerable individuals without the health care they need.

A robust body of research shows that tying Medicaid eligibility to work or work-related activities would fail to increase long-term employment or reduce poverty.[15] In fact, Kentucky's application could even end up keeping people from gaining employment, because without health services, it will be more difficult for them to find and hold a job. Ohio's Department of Medicaid found that three-quarters of Medicaid expansion enrollees who were looking for work reported that Medicaid made it easier to do so, and more than half of those who were working said that Medicaid made it easier to keep their jobs.[16] It is precisely *because* Medicaid meets enrollees' health needs that they are able to focus on finding and keeping employment.

Furthermore, an analysis of Kentucky's Medicaid enrollees reveals the majority of the program already works: 64% of non-SSI, nonelderly enrollees live in working families, 47% work full-time, and 14% maintain part-time employment.[17] Further, among non-SSI, nonelderly enrollees that do not work, most face some significant barrier to work, with 51% citing an illness or disability as

---

[13] Gayle Hamilton et al., "National Evaluation of Welfare-to-Work Strategies: How Effective Are Different Welfare-to-Work Approaches? Five-Year Adult and Child Impacts for Eleven Programs," Manpower Demonstration Research Corporation, December 2001, Table 13.1.

[14] 42 C.F.R. § 431.412(a)(1)(viii).

[15] LaDonna Pavetti, "Work Requirements Don't Cut Poverty, Evidence Shows," Center on Budget and Policy Priorities, June 2016, https://www.cbpp.org/research/poverty-and-inequality/work-requirements-dont-cut-poverty-evidence-shows.

[16] Ohio Department of Medicaid, "Ohio Medicaid Group VIII Assessment: A Report to the Ohio General Assembly," http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Assessment.pdf.

[17] Rachel Garfield, Robin Rudowitz, Anthony Damico, Kaiser Family Foundation, *Understanding the Intersection of Medicaid and Work* (http://files.kff.org/attachment/Issue-Brief-Understanding-the-Intersection-of-Medicaid-and-Work (Updated Jan. 2018)

reasons for not working.[18] These individuals depend on consistent access to care and treatment in order to stay healthy and lead productive lives. The policies contemplated by the Kentucky Application will place access to these services in jeopardy, worsening health outcomes for those affected and removing any chances of economic mobility.

IV. Premiums will decrease Medicaid coverage and should not be approved

Kentucky's proposal to require beneficiaries to pay monthly premiums up to 4% of monthly income would be the highest amount ever approved for a Medicaid program. This policy has been demonstrated to achieve a result directly counter to the objective of Medicaid: decreased enrollment. Extensive research shows that premiums significantly reduce low-income people's participation in health coverage programs.[19] These studies show that the lower a person's income, the less likely they are to enroll and the more likely they are to drop coverage due to premium obligations. People who lose coverage most often end up uninsured and are unable to obtain needed health care services.

For example, under Indiana's waiver, fifty-five percent of people eligible to make a premium payment during their enrollment didn't do so at some point during their enrollment. Three-quarters of those below the poverty line who didn't make premium payments said they missed the payment because it was unaffordable, they were confused about how to pay, or they didn't know a premium was required.[20] A focus group conducted by the Kaiser Family Foundation found similar confusion.[21] Beneficiaries at all income levels said they didn't know whether they owed a premium and thought they would be dis-enrolled from coverage if they missed a payment.

Individuals with greater health needs, such as those living with chronic illnesses and disabilities, are more likely to pay premiums due to their increased dependence on health services (assuming they are initially aware that premium are required). However, this means that already low-income individuals may be forced to choose between premium payments and other basic necessities like food, housing, and childcare. In neither case does imposing additional costs on this population promote the objective of Medicaid to furnish medical assistance. Kentucky states that imposing premiums is ostensibly to "help prepare members to transition to Marketplace coverage." However, preparing individuals for an uncertain transition to private insurance coverage by charging premiums is not a permissible use of Section 1115's waiver authority, as it does not

---

18 Id.

19 Samantha Artiga, Petry Ubri, and Julia Zur, "The Effects of Premiums and Cost-Sharing on Low-Income Populations: Updated Review of Research Findings," The Kaiser Family Foundation, June 2017, http://files.kff.org/attachment/Issue-Brief-The-Effects-of-Premiums-and-Cost-Sharing-on-Low-Income-Populations.

20 The Lewin Group, "Healthy Indiana Plan 2.0: POWER Account Contribution Assessment," March 31, 2017, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-POWER-acct-cont-assesmnt-03312017.pdf

21 MaryBeth Musumeci, Robin Rudowitz, Petry Ubri, and Elizabeth Hinton, "An Early Look at Medicaid Expansion Waiver Implementation in Michigan and Indiana," The Henry J. Kaiser Family Foundation, January 2017, http://files.kff.org/attachment/Issue-Brief-An-Early-Look-at-Medicaid-Expansion-Waiver-Implementation-in-Michigan-and-Indiana

promote the objective of furnishing medical assistance on behalf of those that cannot otherwise afford it.

We appreciate the opportunity to provide comments on the Kentucky Application. Our comments include numerous citations to supporting research, including direct links to the research for the benefit of HHS in reviewing our comments. We direct HHS to each of the studies cited and made available to the agency through active hyperlinks, and we request that the full text of each of the studies cited, along with the full text of our comments, be considered part of the administrative record in this matter for purposes of the Administrative Procedure Act.

For the reasons described above, we urge HHS to reject the Kentucky Application in order to ensure that the 1115 waiver program promotes, rather than undermines, the objectives of the Medicaid program, and that vulnerable populations retain access to crucial medications and health care services. Please contact Robert Greenwald at rgreenwa@law.harvard.edu with the Center for Health Law and Policy Innovation, Amy Killelea with the National Alliance of State and Territorial AIDS Directors at akillelea@nastad.org, or Andrea Weddle at aweddle@hivma.org with the HIV Medicine Association with any questions.

Respectfully submitted by the undersigned organizations:

ADAP Educational Initiative
African American Health Alliance
AIDS Action Baltimore
AIDS Alabama
AIDS Alliance for Women, Infants, Children, Youth & Families
AIDS Foundation of Chicago
AIDS Research Consortium of Atlanta
AIDS Resource Center of Wisconsin
AIDS United
American Academy of HIV Medicine
APLA Health
Bailey House, Inc.
Communities Advocating Emergency AIDS Relief (CAEAR)
Community Access National Network (CANN)
Georgia AIDS Coalition
Harm Reduction Coalition
HealthHIV
HIV Medicine Association
Housing Works
Legal Council for Health Justice

Michigan Positive Action Coalition
Minnesota AIDS Project
National Alliance of State and Territorial AIDS Directors
National Black Justice Coalition
National Latino AIDS Action Network
National Working Positive Coalition
NC AIDS Action Network
NMAC
Open Door Clinic of Greater Elgin
Positive Women's Network - USA
Project Inform
Rocky Mountain CARES
San Francisco AIDS Foundation
SisterLove
Southern AIDS Coalition
Southern HIV/AIDS Strategy Initiative
The AIDS Institute
Thrive Alabama
Treatment Access Expansion Project