



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:

We are writing on behalf of the Chronic Illness and Disability Partnership (CIDP). CIDP consists of national organizations representing people living with a wide range of chronic illnesses and disabilities, including cancer, cystic fibrosis, diabetes, HIV, Hepatitis B and C, multiple sclerosis, and mental health and substance use disorders. We represent the 117 million Americans estimated to be living with a chronic illness and/or disability, many of whom rely upon Medicaid to obtain needed care.<sup>1</sup> While our organizations are national in scope, we also affiliate with strong regional, state, and community based advocacy networks.

We appreciate the opportunity to provide comments on Kentucky's Section 1115 Demonstration Application (the "Kentucky Application") under Section 1115 of the Social Security Act. CIDP is very concerned that the work requirement policies, lockout provisions, and increased enrollee cost-sharing set forth in the Kentucky Application would substantially decrease meaningful access to care for low-income people living with chronic illnesses and disabilities. 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.

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<sup>1</sup> U.S. Centers for Disease Control and Prevention, Chronic Disease Overview (February 23, 2016), available at <https://www.cdc.gov/chronicdisease/overview/>.

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."<sup>2</sup>

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.<sup>3</sup>

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 illnesses and disabilities, and losing Medicaid coverage would be particularly harmful for these individuals.

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.<sup>4</sup>

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<sup>2</sup> 42 U.S.C. § 1396-1.

<sup>3</sup> Amicus Brief of Deans Chairs & Scholars, available at

<https://publichealth.gwu.edu/sites/default/files/downloads/HPM/Kentucky%20Medicaid%20Proposed%20Amici%20Curiae%20Brief.pdf>.

<sup>4</sup> 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).

## 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" 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<sup>5</sup> expansion enrollees and 20% of Michigan<sup>6</sup> 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 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.<sup>7</sup> 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.

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<sup>5</sup> 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>.

<sup>6</sup> 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>.

<sup>7</sup> 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>

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. This process is likely to be error-prone. 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.<sup>8</sup>

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 error prone, applied inaccurately, and led to eligible individuals being denied benefits.<sup>9</sup> 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.<sup>10</sup> Historical analysis of state experience implementing work requirements in TANF suggests that adding similar requirements to Medicaid could cost states thousands of dollars per beneficiary.<sup>11</sup>

Furthermore, Kentucky has not considered the impact of their application on children, particularly those living with chronic illnesses and disabilities that require a consistent caretaker. While the Kentucky Application contemplates exempting primary caregivers of minor children and adult dependents, as discussed above it is likely that the process of securing this exemption will lead to losses in coverage, at least temporarily. Particularly if parents and caretakers are not aware of or otherwise unable to obtain an exemption, their children stand to be negatively affected: research demonstrates that when parents lose Medicaid coverage, their children are at risk of losing it as well.<sup>12</sup>

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

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<sup>8</sup> 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>

<sup>9</sup> 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>.

<sup>10</sup> Mathematica Policy Research, Inc., Imposing a Time Limit on Food Stamp Receipt: Implementation of the Provisions and Effects on Food Stamp Participation (2001).

<sup>11</sup> 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.

<sup>12</sup> Karpman, M. and G. Kenney. "Health Insurance Coverage for Children and Parents: Changes Between 2013 and 2017" Urban Institute, September 7, 2017. <http://hrms.urban.org/quicktakes/health-insurance-coverage-children-parents-march-2017.html>.

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.<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup> 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 already works: 64% of non-SSI, nonelderly enrollees live in working families, 47% work full-time, and 14% maintain part-time employment.<sup>16</sup> 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 reasons for not working.<sup>17</sup> These individuals depend on consistent access to care and treatment in order to stay healthy. 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.

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<sup>13</sup> 42 C.F.R. § 431.412(a)(1)(viii).

<sup>14</sup> 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>.

<sup>15</sup> 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>.

<sup>16</sup> 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)

<sup>17</sup> *Id.*

#### **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.<sup>18</sup> 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.<sup>19</sup> A focus group conducted by the Kaiser Family Foundation found similar confusion.<sup>20</sup> 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 promote the objective of furnishing medical assistance on behalf of those that cannot otherwise afford it.

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<sup>18</sup> 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>.

<sup>19</sup> 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>

<sup>20</sup> 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>

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. With any further questions, please contact Robert Greenwald with the Treatment Access Expansion Project ([rgreenwa@law.harvard.edu](mailto:rgreenwa@law.harvard.edu)), Amy Killelea with the National Alliance of State & Territorial AIDS Directors ([akillelea@nastad.org](mailto:akillelea@nastad.org)), or Jean McGuire at Northeastern University ([j.mcguire@neu.edu](mailto:j.mcguire@neu.edu)) if we can be of assistance.

Respectfully submitted by the co-chairs of the Chronic Illness and Disability Partnership

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