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Department of Health & Human Services
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Comments on Kentucky HEALTH §1115 demonstration waiver proposal

Dear Sir or Madam,

Thank you for the opportunity to comment on the Kentucky HEALTH proposal. Kentucky Equal Justice Center is a non-federally funded poverty law advocacy and research center. We work with multiple community partners on issues affecting low-income Kentuckians.

Although we are a small, policy-oriented watch dog group, during implementation of the ACA we chose to register two staff become Certified Application Counselors for coverage. Almost three years later, we know beyond doubt that hands-on help to consumers made us better policy advocates.

It showed us what worked right, it enabled us to report glitches and problems, and it gave us eyes and ears in the community through outreach and enrollment at diverse sites including Lexington's Village Branch Library and New Life Day Center, a day center for homeless people.

We heard, and often documented in audio and video, the difference that new coverage made in the lives of people we met—from a life-saving cardiac procedure to long-delayed dental care to help for depression.

Given the diversity of people helped by Medicaid expansion, it was not a single story. But throughout, we found that Kentuckians already had the dignity that Kentucky HEALTH claims it will give them and that coverage empowered them rather than making them "dependent."

This letter restates and amplifies my comments during the state public comment period, taking into account minor changes made by Kentucky officials before submission to you. Its underlying premise is that health is infrastructure and coverage is both a foundation and an opportunity.

At its heart, this letter expresses concern about the waiver's increased consumer costs, reduced coverage and imposition of pre-conditions that make health care contingent on participating in a set of "learning activities," including features of the waiver proposal that:

- Impose premiums—even below the poverty line—and delay coverage pending payment
- Impose six month lockouts for failure to pay premiums or renew within a time window
- Eliminate dental, vision and non-emergency transportation from the Kentucky HEALTH plan
- Eliminate the protection of retroactive coverage
- Create work or community service requirements as a condition of coverage

Under the waiver, the consequences of a new set of "failures" to learn lessons that Kentucky HEALTH seeks to convey are not low grades on a quiz. Increase in cost and suspension of coverage make them matters of life and health and would place family income and assets in jeopardy.

Taken together, the lessons substitute a set of purposes outside of—and in the details of the waiver, inimical to—coverage and health. To highlight just one example, the notion of "on ramps" during lockout periods is not reassuring. It is an acknowledgement of the possibility of harm. And it places a complex game of chutes and ladders between patients and providers.

The 1115 waiver process is standards-based

Waivers under Section 1115 of the SSA are demonstration projects. They provide a means for states to try something new to better achieve the purposes of programs, with evaluation of the results. The purpose of Medicaid, KCHIP and Medicaid expansion under the ACA is to achieve coverage for low income adults and children who cannot otherwise afford it.

The Kentucky HEALTH waiver proposal is filled with declarations of purpose that are at least a step removed. Examples include statements that the goals are to:

> "provide dignity to individuals as they move towards self-reliability, accountability and ultimately independence from public assistance" Section 1. Page 4. Overview.
>
> "provide members the tools to successfully utilize commercial market health insurance and eventually transition off Medicaid" Section 1.2. Page 7. Program Summary.

We believe the "welfare dependency" model that pervades the waiver is misplaced. It ignores the diverse circumstances of Kentuckians newly eligible under the ACA, from entrepreneurs launching businesses, to students completing school, to adults on waiting lists for community-based long term care, to caretakers of other family members and Kentuckians working for employers who do not provide affordable coverage.

The model is misplaced in this sense, too: no one can "depend" on medical services. The payments go to providers (who may depend on them). They can't be spent on rent, food, clothing or school supplies. Because medical coverage does not generate income, it does not create a disincentive to work.

We suggest that the framers of the waiver consider a different premise: health coverage and care are work supports rather than work substitutes.

In our state comments, we pointed out that 1115 waivers are not simply the occasion for a battle of wills between states and the federal government. The waiver process is a standards-based process. CMS has published its standards for review on its website. These criteria include assessment of whether the demonstration will do any or all of four things:

1. increase and strengthen overall coverage of low-income individuals in the state;
2. increase access to, stabilize, and strengthen providers and provider networks available to serve Medicaid and low-income populations in the state;
3. improve health outcomes for Medicaid and other low-income populations in the state; or
4. increase the efficiency and quality of care for Medicaid and other low-income populations through initiatives to transform service delivery networks.

Taking just the first two—increase coverage and access—we suggest that multiple elements of this proposal would do the opposite, creating delays in coverage, suspending it and, in particular, creating barriers to dental and vision benefits proven vital to health and workforce participation.

We trust the waiver will be evaluated by CMS based on the merits. Recent CMS announcements about proposals in Ohio and Arizona reassure us that this is the case. Our Governor's statement that he would end Medicaid expansion if his plan is not approved is external to the proposal. It is responsive to none of the criteria above. And if the plan meets the standards on the merits, it's unnecessary.

Coverage is foundational and new coverage is the starting point for analysis

In public testimony on the waiver proposal before the Medicaid Advisory Council here, I pointed out that most of the Council's members were providers. When people are covered, providers can use their knowledge, skills, tools and practices to restore health, improve it, sustain and manage it. When they are not, it gets harder—or doesn't get done.

Kentucky has done a great job with coverage. The Commonwealth went from over 20 percent uninsured to less than 7 percent. Depending on the poll, we're ranked 1st or 2nd in the nation in the decline in the rate of uninsured. In Lexington and Fayette County, our home county, 22,951 people had enrolled in new coverage through Medicaid expansion, just about the capacity of Rupp Arena.

Kentucky was seen nationally as winner: an attractive "can do" state.

The administration here has tried in public statements to diminish the value of this success through use of the disparaging label of "welfare dependency," by evocation of a stereotype of "able bodied adults" and by casting doubt about sustainability. It argues that predictions of sustainability made by the previous administration are wrong but offers no comparable new analysis of its own.

One thing is clear: the federal funds that would be lost to Kentucky under the waiver far outweigh the state dollars saved. Most savings are predicted to come from drops in enrollment.

We suggest that CMS, by its own standards, must take Kentucky's success with coverage as the benchmark when evaluating whether the waiver would "increase and strengthen overall coverage of low income individuals in the state." Kentucky's success simply makes us categorically different from states proposing expanded coverage for the first time—even if limited—through waivers.

If the benchmark—an historic, game changing achievement—is accepted, the plan doesn't measure up. And, in any case, there is a better way to go than diminishing coverage.

Coverage creates the opportunity for health system transformation

In testimony July 20, 2016, before the Interim Joint Committee on Health and Welfare, representatives of the administration stated that the Kentucky HEALTH waiver is but one prong of a four-pronged strategy, as follows:

- The Kentucky HEALTH 1115 waiver proposal
- A Substance Use Disorder initiative
- New emphasis on disease management
- Reform of Medicaid managed care through renegotiated contracts

The irony of this approach is that three of its four strategic elements seize the opportunity of new coverage to manage toward health, while only one does not: the proposed Kentucky HEALTH waiver.

Along with Kentucky Voices for Health, we are fans and supporters of "Health Systems Transformation" that links payment and delivery reform in innovative ways. Examples include:

- Investing in Community Health Workers to help people navigate the health system
- Promoting prevention
- Targeting high utilizers and hot spots for smart management
- Paying to create health teams responsible for episodes of care
- Paying for outcomes rather than volume
- Enhancing oversight through data transparency, including a publicly accessible dashboard

It is true that, toward the back of the waiver proposal, managed care and payment changes are described in general terms. It is good that they are there. Many, perhaps all of them, can be done without a waiver through renegotiation of contracts and redesign of payment systems.

Through the waiver—the first prong of the strategy—the state would put a complex system of "chutes and ladders" between patients, coverage and care, requiring multiple new administrative systems for tracking premiums, work activity, the deductible account and the rewards account.

In short, the waiver would create administrative complexity around coverage. It would generate new costs for new systems. Why not keep coverage simple and go straight to delivery and payment reform?

New cost barriers create jeopardy for health and family assets

Cost barriers are a clumsy tool to manage health. They call on patients rather than providers to distinguish medically necessary from unnecessary care. They have been studied for at least 40 years, since the RAND Corporation Health Insurance Experiment of the 70s and 80s. It is difficult to imagine that anything new can be demonstrated. See Rand here.

RAND studied adult patients at multiple income levels. The research team found that most of the time, for most people, copayments did not reduce medically necessary care. People either found a way to pay them or skipped care without harm. But for low income people Rand found health effects:

> "free care led to improvements in hypertension, dental health, vision, and selected serious symptoms. These improvements were concentrated among the sickest and poorest patients."

Stand that on its head and it means that low-income and sicker people lost access to medically necessary and beneficial care in detectible ways when faced with cost barriers. (Given the removal of dental and vision care to a distance under the plan, the Rand findings appear particularly telling.)

Findings like these have influenced cost sharing policies to be smarter: we refrain from imposing copayments on children, or pregnant women, or for preventive services. But several aspects of the waiver are steps backward. Jeopardy like that found by Rand could occur when:

- Kentucky Health adults fail to pay premiums and are made subject to copayments
- Waiver of copayments is prohibited

- Older and sicker patients needing more services—particularly prescriptions—face multiple copayments each month

In our state comments, we expressed concern about imposition of copayments on medically frail individuals. We did so for a specific reason: we believe smart disease management means strategic removal of cost barriers to related care, even where federal law would allow them. (Some prescriptions in my own plan are free for just that purpose.)

In the waiver proposal submitted to CMS, Kentucky has removed the copayment requirement from individuals found to be medically frail. The change protects some people from unaffordable care, but "medically frail" remains a vague category. It is not clear that all adults who could benefit from disease management would fall into it. And delays in designations would expose patients to cost.

We believe that the ill-defined divide between "able bodied" and "medically frail" is an inadequate basis for imposing copayments or excusing patients from them. An income limit would be simpler. Flexibility for providers and MCOs engaged in disease management would be smarter.

There is another reason to choose a different approach: as we argue below, the category "medically frail" is simply an artifact of an impermissible plan to require the "able bodied" to engage in work activities.

If one can observe the adverse health effects that Rand found with small point-of-service costs, imagine the effect of the two six-month lockouts in this proposal:

- One for participants above poverty who don't pay premiums
- One for participants who don't re-certify within a window of time

Not just a service here and there but all services will be lost. The chance that *medically necessary care* will be lost skyrockets. It's impossible to imagine how that meets the criteria of "improve and strengthen coverage." CMS should not approve lockouts. DMS should remove them. As well, the elimination of retroactive coverage for low-income Kentuckians simply to "teach a lesson" about private coverage falls in the same category and adds financial jeopardy for both providers and patients.

Activity requirements pose a big challenge to nonprofits and communities

CMS has said it will not approve work or other activities requirements that make coverage conditional upon performance. It is unclear what is achieved by including them in Kentucky HEALTH, other than to heighten an element of brinksmanship in negotiations. And, as stated above, it gets things backwards: coverage supports work.

Meanwhile, the activity requirements pose a big challenge to nonprofits and communities. It's true that under the plan, the requirements would roll out slowly, from pilot counties to more counties. That's probably because a bigger approach defies implementation.

Here's a quick "back of the envelope" calculation:

- About 1.3 million people receive Medicaid
- About 400,000 are adults in the expansion population
- More than half are working

- Many may be exempt as medically frail

Let's say that 100,000 Kentuckians statewide are covered for a year and have a 20 hour work requirement. That's 2,000,000 hours of work activity in a single week to arrange, track and enforce. And even at a tenth of that size—a small start-up scale of 10,000 Kentuckians faced with the requirement—where do we find:

- 10,000 nonprofits to take 1 volunteer
- 5,000 to take 2
- 2,000 to take 5
- 1,000 to take 10

What will be nonprofits' staff costs, liability costs and administrative and reporting time? Even if nonprofits wanted to do it, it's a huge challenge. The pilot may start small but in a microcosm the nature of the challenge for each participating nonprofit is the same. We should be concerned about an unfunded mandate on nonprofits, schools, churches and local governments—and about the administrative cost to the state.

As well, an injunction to tens of thousands of people to engage in compulsory volunteer activities raises the risk of displacement of employees or distortion of market wages. This is especially true in areas of Eastern Kentucky with both high unemployment and high Medicaid enrollment.

Finally, we note that the category "medically frail" appears to be a creature of the desire to label other adults as "able bodied" and impose work requirements on them. Should work requirements be found impermissible, the problematic designation of medically frail would be unnecessary. Cost sharing could be excused more broadly or shaped more creatively to steer utilization.

The public hearing process was flawed

It is hardly a secret that the U.S. Supreme Court left the decision to expand Medicaid to states. CMS can neither impose Medicaid expansion nor bar it. Yet Governor Bevin has said that CMS will be responsible for the demise of Medicaid expansion in Kentucky should it not approve his plan.

The Governor's statement may represent a "strong" negotiating tactic over a waiver, or a bravura public display of resistance to the federal government. But we suggest that its "take it or leave it" stance may have rendered the state hearing process a nullity—or at least compromised it. The Governor said he had already made up his mind and would greatly diminish coverage if he does not get his way.

We do not know whether low-income people, providers or advocates refrained from comment due to the threat of loss of coverage. Anecdotally, we hear that some did. But we know that the hearing process was troubling in other ways:

- Two of three state hearings were held within a week and a day of release of the waiver, limiting time for thorough analysis or careful crafting of comments
- None of the three hearings were held in major urban centers of the "Golden Triangle" formed by Louisville, Lexington and the Northern Kentucky suburbs of Cincinnati, where tens of thousands of people received coverage

- In Frankfort, public testimony was not taken until the “fourth quarter” of the announced two hour schedule from 1:00 to 3:00 p.m. Though the hearing proceeded into overtime, many of the people who had signed up to speak had left.

In Frankfort, the state agency also dominated the first hour and a half of the two-hour scheduled hearing by engaging in lengthy explication of the plan followed by reading of multiple statements from state legislators, all of them from the Governor’s own party and all reciting similar talking points.

We acknowledge that at the next hearing, in Hazard, Secretary Glisson said that all comments would be considered. We do see a handful of changes in the plan. We were troubled, however, by the—briefly—unpublicized extension of the deadline for comments.

CMS should evaluate whether a hearing process made under a “take it or leave it” threat can be considered genuine. And, in any case, it should evaluate the proposal on the merits under the standards it has set.

We are pleased that our advocacy partners at Kentucky Voices for Health scheduled hearings in eight locations around the state during the federal comment period. And we are deeply impressed by the eloquence and courage of ordinary Kentuckians who spoke up in public forums when given the chance. They painted a picture of a diverse, dignified population already deeply engaged in health care.

Sincerely,

Richard J. Seckel
Director