August 18, 2018

VIA Electronic Submission

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

RE: Kentucky HEALTH 1115 Waiver Application

Dear Secretary Azar:

Disability Rights Education and Defense Fund (DREDF) thanks you for the opportunity to submit comments on the latest Kentucky HEALTH application to the Centers for Medicare and Medicaid Services (CMS) for a 1115 waiver. DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives. DREDF has significant experience in Medicaid law and policy, given that disabled individuals disproportionately live in poverty and depend on Medicaid services and supports.

Kentucky’s application to CMS for significant changes to eligibility and ongoing enrollment in the state’s Medicaid program deeply concerns DREDF. The stated purpose of the Medicaid Act is to enable each state “to furnish [] medical assistance on behalf of [individuals] whose income and resources are insufficient to meet the costs of necessary medical services” and to provide “rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care.”\(^1\) Section 1115 of the Social Security Act (“SSA”) gives the Secretary authority to waive a state’s compliance with certain requirements of the Medicaid Act, but only for an “experimental, pilot, or demonstration project which . . . is likely to assist in promoting the objectives” of the Medicaid Act.\(^2\) The changes called for in Kentucky’s proposal apply to the state’s entire Medicaid program and apply to the working age adults who enrolled through Medicaid expansion, who in the third quarter of 2016 comprised approximately 78% of the over 650,000 working age Kentuckians in the state’s Medicaid program.\(^3\) A proposal for permanent changes that affect such a significant proportion of

\(^2\) Id. § 1315(a).
the state’s Medicaid enrollees cannot be called a “pilot,” nor experimental except in the euphemistic sense of lacking any documented connection between the waiver’s proposed actions and achieving the Medicaid Act’s stated purpose.

The Kentucky HEALTH program does not promote, and indeed will undermine, the objectives of the Medicaid program by decreasing access to “medical assistance” and “other services” that individuals, and in particular people with disabilities, depend on “for independence and self-care.” While the proposal purports to apply only to “able-bodied” Medicaid enrollees, it posits a fictional binary distinction between those who are able-bodied and those who are disabled, and relies on inflexible exemption mechanisms for people with disabilities that are still not fully developed.

A. Flawed Exemption of People with Disabilities from Kentucky HEALTH Program

The Kentucky HEALTH program seeks “to comprehensively transform Medicaid” by, among other factors, imposing work and community engagement requirements, premium mandates, and lockout penalties and eliminating retroactive eligibility and the non-emergency medical transportation (“NEMT”) benefit. Individuals who qualify for Medicaid on the basis of disability, such as individuals eligible for Social Security Income (“SSI”), 1915(c) waivers, and the Medicaid buy-in, are ostensibly not included within the Kentucky HEALTH population. However, SSI and the Medicaid buy-in program employ narrow definitions of “disability” that do not encompass all of Kentucky Medicaid’s enrollees with disabilities and chronic conditions. Indeed, a recent study of Kentucky Medicaid enrollees aged 19–64 who were not eligible for SSI showed that approximately 129,300 individuals have a disability (compared to 88,500 people qualifying for Medicaid on the basis of SSI).4 There will still be thousands of individuals with disabilities in the Kentucky HEALTH population who will bear the onus of qualifying for limited “exemptions” from the program.

i. The “Medically Frail” Exemption

Some of Kentucky HEALTH’s policies contain exemptions for people within the Kentucky HEALTH population that are deemed “medically frail.” “Medically frail” is defined by the state and at a minimum must meet the requirements of 24 C.F.R. 440.315(f). According to its waiver application, Kentucky intends to develop an “approval process” to determine whether an individual is medically frail “based on objective criteria established by the State,” and the process “will evaluate the severity of the member’s health conditions and assign a risk score[.] . . . Individuals with qualifying conditions and scores would be determined medically frail.” The state does not further elaborate upon what “objective criteria” it intends to rely on.

Kentucky HEALTH’s “medically frail” definition is underinclusive and underdeveloped, and it will inevitably exclude some people with disabilities from its purview. Kentucky’s

exemption will attempt to fit individuals with work-limiting disabilities into neat exclusive boxes of “able-bodied” and “medically frail” by using still-undefined “objective criteria.” The problem with this approach is that, in reality, disabled individuals experience far more nuanced, episodic, or compounding periods of functional impairment that cannot be neatly classified by a binary, inflexible exemption process. For example, individuals may have multiple chronic conditions such as diabetes, high blood pressure, high cholesterol, chronic obstructive pulmonary disease, hemorrhoids, cataracts, and glaucoma will likely have acquired these conditions over time. No one condition would qualify them for Medicaid on the basis of disability. Nonetheless, when any one condition flares up, it will likely exacerbate other conditions leaving individuals feeling unwell and facing difficulty breathing, pain, and bleeding. Worsening vision will affect their capacity to find work, and complicate the ability to transport themselves to needed health services. In reality, these people may periodically have great difficulty finding employment, and especially in rural areas of Kentucky where job possibilities for those with physical functional limitations can be limited, but they likely will not qualify for the “medically frail” exemption because such episodic symptoms are not typically viewed as “severe” or “persistent” enough for an exemption from the work requirements. They will very likely be subject to Kentucky HEALTH’s requirements, and if they cannot satisfy them, they will lose their health care benefits. Without benefits, these individuals will be unable to manage their health conditions, which in turn will make it even more difficult for them to find or maintain employment.

The problems with the “medically frail” exemption will be widespread. Indeed, in a recent survey of non-SSI, working age Kentucky Medicaid enrollees, 51 percent of respondents (approximately 65,310 people) indicated that their disability or illness was the reason they were not working. Under the binary, inflexible “medically frail” exemption that Kentucky HEALTH intends to employ, some of these people with disabilities will be subject to the program’s requirements for failing to satisfy the “objective criteria” that the state perceives to be “disabled enough.” For these individuals, their health care coverage and correlated potential to maintain independence and live productive and fulfilling lives, hangs in the balance.

ii. The “Acute Medical Condition” Exemption

Kentucky HEALTH’s “acute medical condition” exemption will do little to remedy the problems with the main “medically frail” exemption. When CMS granted Kentucky’s Section 1115 waiver, it imposed a number of Special Terms and Conditions (“STCs”) that were not included in Kentucky’s application. Among those relevant, it imposed an exemption to the work requirements for “[b]eneficiaries diagnosed with an acute medical condition that would prevent them from complying with the requirements (as validated by a medical professional).” CMS did not provide a definition of “acute medical condition” or include any further detail on the exemption in its Approval Letter, STCs, or

5 See, e.g., Sharon Parrott, Ctr. on Budget & Policy Priorities, The New TANF Requirements and Individuals with Disabilities (March 2007), https://www.cbpp.org/sites/default/files/atoms/files/3-1-07tanf.pdf (finding that individuals with “severe temporary disabilities” are usually not exempt from work requirements within the Temporary Assistance for Needy Families (“TANF”) program).

Dear State Medicaid Director Letter. Further, neither the Medicaid Act nor CMS' implementing regulations otherwise contain a definition of or use the term.

A plain language reading of the “acute medical condition” exemption suggests that it will not reach individuals with chronic disabilities who experience episodic symptoms or a gradual worsening of functional ability. Webster’s Dictionary defines “acute” in the medical context as “characterized by sharpness or severity;” “having a sudden onset, sharp rise, and short course,” or “requiring short-term usually immediate medical care (as for serious illness or traumatic injury).”7 Ballentine’s Law Dictionary defines “acute disease” as “[t]he antithesis of chronic disease; one which is severe, perhaps critical, as of the moment.” Ballentine’s Law Dictionary 26 (3d ed. 1969). Under any of these definitions, individuals who have a number of complex chronic conditions that periodically make it difficult for them to work, would not qualify. An acute medical condition is characterized by short-term, severe conditions such as a traumatic injury or a serious virus or infection; disabilities, which are largely characterized by chronic, long-term conditions, do not naturally fit within its purview. If the exemption also included acute medical symptoms, then perhaps episodic impairments caused by chronic conditions could be included; but as it currently stands, the exemption focuses on the what would likely be a diagnosis, not the symptoms or functional impacts. As such, it would not seem to reach many disabled enrollees.

Even it did include people with chronic conditions, however, the exemption lacks the definition and specificity needed for effective implementation. When CMS created this vague exemption for Kentucky HEALTH, numerous questions arose as to whom Kentucky will apply this exemption to and what procedures it will develop to receive and process “validat[ions] by a medical profession.” To date, these definitional and procedural questions remain unanswered. The “acute medical condition” exemption cannot be relied upon to exempt individuals with disabilities from Kentucky HEALTH’s requirements.

iii. The “Reasonable Modification” Requirement

When CMS granted Kentucky’s Section 1115 waiver, it also imposed “reasonable modification” requirements on Kentucky HEALTH’s redetermination and reporting processes, work and community engagement requirements, and premium obligations. However, these additions, like the “acute medical condition” exemption, lack the definition and specificity needed for effective implementation and protection of the rights and health care coverage of people with disabilities.

By and large, the reasonable modification provisions in the STCs merely consist of one repeated, general statement: “the state must provide reasonable modifications to beneficiaries with disabilities protected by the [Americans with Disabilities Act (“ADA”)], Section 504 of the Rehabilitation Act, and Section 1557 of the Patient Protection and Affordable Care Act” in the program’s processes and procedures. The provisions relating to annual redeterminations, change-in-circumstance reporting, and premium obligations contain no meaningful detail that either describes or provides examples of what reasonable modifications may look like in those contexts. Thus, there is significant

concern that Kentucky does not have the implementation mechanisms in place—or even a guideline or example available—to ensure that the rights of disabled enrollees will indeed being effectuated.

The “reasonable modification” requirement in the work and community engagement provisions does contain slightly more detail, including the following statement: Reasonable modifications must include exemptions from participation where an individual is unable to participate for disability-related reasons, modification in the number of hours of participation required where an individual is unable to participate for the required number of hours, and provision of support services necessary to participate, where participation is possible with supports.

While a step in the right direction, the problem with this statement is that Kentucky, who did not originally include this requirement in its waiver application, does not currently have the procedures in place or the additional resources allocated to process and provide these “modification” exemptions, reductions of hours, and support services. There are also no guidelines that explain, for example, how an enrollee is to prove they cannot participate in employment activities for “disability-related reasons;” whether and how often they are to re-verify this status; and whether and how they can appeal an adverse decision. Additionally, it is unclear whether this “modification” exemption is really a separate exemption for disabled enrollees or merely a reference to the “medically frail” and “acute medical condition” exemptions that are more explicitly discussed throughout CMS’ Approval Letter and STCs. With so many implementation details still unclear and the stakes for disabled Medicaid enrollees so high, the “reasonable modification” requirements cannot be relied upon to shield individuals with disabilities from Kentucky HEALTH’s requirements.

B. Kentucky HEALTH’s Work and Community Engagement Requirements Will Cause Disabled Individuals to Disproportionately Lose Access to Medical Assistance, Contrary to the Purposes of Medicaid.

Kentucky HEALTH will require all non-exempt beneficiaries to engage in at least 80 hours of employment or community engagement activities per month. For the disabled enrollees who do not qualify for exemption, it will be disproportionately more difficult to satisfy these harsh work requirements. People with disabilities face more difficulties finding and maintaining employment than people without disabilities. This reality is reflected in Kentucky’s employment statistics: In 2016, the employment rate of non-institutionalized working-age people with disabilities in Kentucky was 31 percent, compared with 77.6 percent of people without disabilities. This disproportionate employment rate is due in large part to external factors that disabled individuals have no control over. People with disabilities continue to face discrimination in the workplace. Whether it is explicit or implicit biases in the hiring process, an adverse employment action (e.g., firing, failure to promote, or demotions) based on misguided assumptions, or a failure to provide reasonable accommodations to an employee, disability

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discrimination in employment remains pervasive. In 2016, the U.S. Equal Employment Opportunity Commission reported 325 complaints of workplace disability discrimination in Kentucky alone; while the state-equivalent agency, the Kentucky Commission on Human Rights, received 99 disability complaints, a historical high that accounted for the largest volume of complaints than any other form of discrimination.\(^9\)

Disparities in health care access and health outcomes among people with disabilities also contribute to disparate employment rates. A recent study commissioned by the National Academies of Sciences, Engineering, and Medicine confirmed that “[c]onscious and unconscious biases and stereotypes among health care providers and public health practitioners about . . . people with disabilities[] contribute to observable differences in the quality of health care and adverse health outcomes among individuals within [that] group[].”\(^10\) The documented disparities in quality of health care can have a tangible impact on the capacity of disabled individuals to work, as many rely on health services to support their employment activities. People with disabilities depend on health services such as pain management treatments, mental health supports, glucose monitors, respirators, or mobility aids to function and go to work. Indeed, there have been several studies on the impact that increased access to health care—and specifically the expansion of Medicaid—has had on employment rates. Most studies show a significant positive link between Medicaid expansion and employment rates; none show a negative correlation.\(^11\)

These factors, among others, compound to make it disproportionately more difficult for people with disabilities to find and maintain employment. For the disabled individuals who do not qualify for an exemption, Kentucky HEALTH’s work requirements will create a large and potentially insurmountable barrier to Medicaid eligibility. Some will simply not be able to meet its parameters and will consequently lose eligibility for Medicaid. The Secretary only has authority to grant a Section 1115 waiver when the program “is likely to assist in promoting the objectives” of the Medicaid Act, which are, in part, “to furnish [] medical assistance” and to provide “services to help [individuals] attain or retain capability for independence or self-care.”\(^12\) Kentucky HEALTH’s work requirements will not promote these goals. Instead, they place a disproportionately large burden on disabled enrollees and risk decreasing access to the medical assistance that they rely to maintain health, independence, and livelihoods. For many people with disabilities, health care services and supports—benefits as simple as a wheelchair, physical therapy, prescription medications, or an accurate glucose monitor—are critical to maintaining employment, raising families, participating in communities, or even getting out of bed. Without them, an individual’s “capability for independence or self-


\(^12\) 42 U.S.C. §§ 1315(a), 1396-1.
care” can be severely diminished and some can even be at risk of institutionalization. Thus, by approving a waiver that runs contrary to these principles, as articulated in the Medicaid Act, the Secretary has exceeded his Section 1115 authority.

C. Kentucky HEALTH’s Elimination of Non-Emergency Medical Transportation Will Cause Disabled Individuals to Disproportionately Lose Access to Medical Assistance, Contrary to the Purposes of Medicaid.

The Kentucky HEALTH program waives the state’s requirement to provide non-emergency medical transportation (“NEMT”) to and from any Medicaid services for non-exempt beneficiaries in the new adult population. It also waives NEMT for methadone treatment services for nearly all Medicaid beneficiaries, including those deemed “medically frail.” For disabled enrollees, it will be disproportionately more difficult to access health care services without the NEMT benefit.

Research has consistently shown that access to reliable, affordable, and physically accessible transportation is one of the most common barriers to health care for low-income people with disabilities. Estimates show that at least 3.6 million Americans each year either miss or delay medical care due to transportation issues. Studies have consistently found that individuals who are unable access medical care because of transportation barriers are disproportionately poor, elderly, disabled, and/or have chronic health conditions. By one measure, approximately 12.19% of disabled people face difficultly obtaining needed transportation, as compared with 3.32% of people without disabilities.

The NEMT benefit is a critical component to ensuring that people with disabilities can access needed health care services. Enrollees with disabilities and chronic health conditions often have a thinner margin of health. Their capacity to maintain their health, employment, family responsibilities, and community involvement depends on getting timely access to needed medical care. The risk of institutionalization or hospitalization also increases when individuals are not able to access medically necessary treatment, which negatively impacts health outcomes and results in higher overall health care spending. Unfortunately, many low-income people with disabilities simply lack the financial resources to own a vehicle or hire a transportation service, and some lack access to affordable and reliable public transit. These issues—when compounded with still widespread physical accessibility barriers—make the NEMT benefit particularly critical for disabled and elderly enrollees, many of whom may have conditions that affect their mobility. As the U.S. Government Accountability Office (“GAO”) recently explained

15 Wallace, supra.
in a report studying states’ efforts to eliminate the NEMT benefit: “Medicaid's NEMT benefit can serve as an important safety net for program enrollees.” 16“[E]xcluding the NEMT benefit would impede . . . enrollees’ ability to access health care services, particularly individuals living in rural or underserved areas, as well as those with chronic health conditions.”17

Therefore, for the disabled enrollees who do not qualify for an exemption (and even for individuals who are deemed “medically frail,” for purposes of NEMT to and from methadone treatment services), Kentucky HEALTH's elimination of the NEMT benefit will create new barriers to health care. The purpose of Medicaid is, in part, “to furnish [] medical assistance” and to provide “services to help [individuals] attain or retain capability for independence or self-care.”18 Kentucky HEALTH will not promote these objectives; instead, it will risk decreasing access to the medical assistance that many disabled individuals need to live independently and work. As such, the Secretary has exceeded his Section 1115 authority by approving a waiver that is contrary to the purposes of the Medicaid Act.

D. The New Administrative Burdens Created by Kentucky HEALTH Will Cause Many Disabled Individuals, Including Those Who Qualify For An Exemption, To Wrongfully Lose Access to Medical Assistance, Contrary to the Purposes of Medicaid.

The Kentucky HEALTH program will impose onerous new requirements on disabled individuals, who must either demonstrate that they satisfy its mandates or prove qualification for an exemption. While the specific details are still undefined, Kentucky HEALTH requires non-exempt beneficiaries to pay monthly premiums and submit monthly documentation proving compliance with the work and community engagement requirements. Likewise, it requires exempt, “medically frail” individuals to recognize that they qualify for the exemption, “self-identif[y]” this qualification or ensure that their managed care organization (“MCO”) or health care provider has done so, and then, provided the MCO’s claims history is insufficient to demonstrate the individual’s qualifying condition (as is common for new members, newly diagnosed members, and members with mental health conditions, untreated conditions, or multiple chronic conditions), obtain and submit documentation sufficient to prove their “sever[e]” health condition.

There has been extensive research on the impact that new paperwork and documentation requirements, specifically in the context of work requirements, have had on the enrollment of people with disabilities in public benefit programs. Research has consistently demonstrated that Temporary Assistance For Needy Families (“TANF”) recipients with disabilities are more likely to lose their benefits for failing to meet work requirements than individuals without disabilities.19 This disparity has been linked, in

16 GAO, supra.
17 Id.
part, to the added administrative burdens placed on disabled enrollees, who often must obtain appropriate assessments and documentation and follow complex procedures to prove their initial and ongoing qualification for an exemption. These administrative obstacles, when compounded with the added cost and time that agencies must put towards verifying and tracking enrollees’ employment activities or exemption qualifications, can produce unintended consequences.20

Similar disparate results have been documented within the Supplemental Nutritional Assistance Program (“SNAP”). For example, a comprehensive evaluation of Ohio’s SNAP work requirement found that 32.6 percent of individuals who were subject to the requirement had physical or mental health conditions that limited their ability to work and should have—but did not—exempted them from the requirements.21 Moreover, a recent nationwide report from the U.S. Department of Agriculture found that implementing SNAP work requirements was an “administrative nightmare” that was “too burdensome” and “error prone” in multiple states.22 In several instances, the Department found that states were “improperly applying the [rules]” and terminating individuals’ SNAP benefits “despite qualifying for an exemption.”

Based on these consistent findings, it is reasonable to conclude that the administrative complexities created by the Kentucky HEALTH program and particularly its work requirements will cause some disabled individuals, including people who should technically qualify for an exemption, to wrongfully lose health care coverage. Therefore, Kentucky HEALTH will not “promot[e] the objectives” of the Medicaid Act by “furnish[ing] medical assistance.” Indeed, it will run contrary to these objectives by decreasing access to the medical assistance that many disabled individuals depend on for their health, independence, and livelihoods.

E. Conclusion

We would like to be very clear that nothing in our comments speaks against the desire and capacity of people with disabilities to be gainfully employed. DREDF fully supports the understanding that such activities as appropriate job training, part and full-time employment, and volunteering work can be economically, socially, and psychologically beneficial to people with and without disabilities. But those benefits cannot be obtained through the loss of medically necessary, consistently available healthcare. The thousands of Kentuckians enrolled in Medicaid who have disabilities and chronic conditions need greater resources devoted to effective job training and on-the-job

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supports, they need stronger enforcement of state and federal employment discrimination laws, they need reasonable accommodations and policy modifications in all state employment and assistance programs, and they need access to reliable healthcare so they can remain well enough to work and live productive and independently in their communities.

Thank you for the opportunity to comment on the Kentucky HEALTH proposal.

Yours Truly,

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