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July 21, 2016

Commissioner Stephen Miller
Department for Medicaid Services
275 E. Main Street
Frankfort, KY 4062

*RE: Public Comments on Kentucky HEALTH
Section 1115 Medicaid waiver application proposal*

Dear Commissioner Miller,

On behalf of the Southeast Chapter of the American Academy of HIV Medicine, our members, and the patients they serve, we write to express our concerns with the proposed Section 1115 waiver application for the Kentucky Medicaid program, or “Kentucky HEALTH” program.

The American Academy of HIV Medicine (AAHIVM), is an independent organization of HIV Specialists and other medical care providers dedicated to promoting excellence in HIV/AIDS care and to ensuring better care for those living with AIDS and HIV disease. AAHIVM has a diverse membership composed of Infectious Disease, Internal Medicine, Family Practice and General Practice doctors as well as Nurse Practitioners, Physician Assistants, and also Dentists and Pharmacists. AAHIVM also has a Hepatitis C Institute, which is dedicated to promoting the care of patients with Hepatitis C virus (HCV), which is the most common co-infection with HIV.

As an organization of front-line HIV care providers, we strongly support initiatives that advance access to medical care and treatment for all people living with HIV disease. AAHIVM supports policies that provide affordable and stable access to the full range of health care services which contribute to effective management of HIV disease and co-occurring conditions. AAHIVM also supports policies that ensure HIV patients have access to the life-saving medications that are necessary for the treatment of their disease and for their overall health and wellness.

Since Kentucky's Medicaid expansion occurred in 2014 an additional 428,000 low income adults have gained access to healthcare in the state. This is a tremendous victory for public health efforts, and for medical providers on the front lines of treating HIV in the state. According to statewide data, roughly 80 percent of the HIV patients in the state of Kentucky became qualified for Medicaid under the expansion.¹ That means that an overwhelming majority of the state's HIV population benefits from coverage and access to care and treatment through that program. As such, we have a significant interest in seeing that success maintained, along with access to preventive screenings, medical care, and treatment for patients.

Medicaid has been a crucial program in the care and treatment of HIV patients in the U.S. since the beginning of the epidemic. Medicaid is estimated to be the single largest source of coverage for people with HIV in the U.S. While Medicaid enrollees with HIV represent less than 1 percent of the overall Medicaid population, they account for almost half of people with HIV in regular care.² HIV disease can be a disabling condition, which has qualified many HIV patients for the program's services. Many HIV patients qualify for the program because they are also low-income. Additionally, a significant share of Medicaid beneficiaries with HIV are also dually eligible for Medicare (approximately 30%). These "dual-eligible" are among the most chronically ill and medically vulnerable Medicaid enrollees, with many having multiple chronic conditions and requiring long-term care. The Medicaid program was designed to serve these individuals.

We write to express our concerns with several aspects of the "Kentucky HEALTH" proposal which we believe would have negative consequences on HIV patients in Kentucky who are eligible for Medicaid services. Although we, as an organization, generally support initiatives to improve the health system and support the cost-efficiency of public programs, we are concerned that some of the aspects of the Kentucky HEALTH proposal may have the unfortunate consequence of restricting access to necessary medical care, life-saving medications, and services that promote optimal care provision to vulnerable patients. In addition, we find that some of the aspects of the proposal are not in-line with the financial, social, and medical realities of the patient population served by this program.

We wish to address some of these points in further detail below:

- **Definitions of "Able-Bodied Adults" and "Medically Frail"**

Our reading of the proposal found that the term "able-bodied adults" was used multiple times in the document, but was never clearly defined. Many of the proposals of Kentucky HEALTH focus on this segment of the beneficiary population, while allowing exclusions for the "medically frail," and

¹ The HIV Specialist, "Despite Need, Medicaid Expansion is in Question," October 2012
<http://www.aahivm.org/hivspecialist>

² Kaiser Family Foundation, "Medicaid and HIV/AIDS," <http://kff.org/hivaids/fact-sheet/medicaid-and-hivaids/>

those with “complex medical conditions” which are also not defined in the proposal. We see a need for further clarification on the specific populations these proposals will affect.

In defining these terms, we urge you to refer to current programmatic definitions of “medically needy” patients across state Medicaid programs, as well as the Federal definition of disability as contained in the Americans with Disabilities Act (ADA), and the Social Security Administration’s disability insurance and SSI definitions of disability in order to determine which beneficiaries fall into the status of the medically vulnerable patients who should be protected from burdensome coverage requirements in order to maintain access to medical care and treatment.

More generally, we urge you to undertake an analysis of the overall percentage of program beneficiaries who would qualify as “able-bodied adults” under your proposal. The Medicaid program traditionally serves groups of patients who live with medical conditions that partially or fully incapacitates them medically, or impacts their ability to work, leave home, or participate in certain daily activities. Expanded Medicaid provides insurance coverage for the working poor which also present with chronic and complex medical conditions.

We urge your office to consider the needs of patients with chronic and complex medical conditions which can be burdensome to manage. HIV patients for example, have to maintain high levels of medication adherence and regular medical care in order to effectively manage their HIV disease. Disruptions to care and treatment access can have deadly consequences for HIV patients, escalating health care costs to the medical system when patient health declines requiring more expensive medications, hospitalizations, and interventions. Many HIV patients also experience common co-morbidities of HIV, such as such as cardiovascular disease, tuberculosis, hepatitis, mental health conditions and substance abuse /addiction disorders.

Therefore, we urge you to include HIV patients in your definitions of the “medically frail,” and those with “complex medical conditions” and aim to reduce burdensome requirements for these patients.

- **Monthly Premiums for Low-Income Beneficiaries**

The proposal to charge a monthly premium for Medicaid beneficiaries, ranging from \$1.00 per month up to a maximum of \$15.00 per month may seem to be insignificant fees on their face. However, to individuals and families whose income is below 138% of federal poverty level (FPL), even the smallest fees can be significant in their toll, creating financial decisions between health care and other basic services and requirements such as food and transportation.

For example, the proposal suggests that for an individual with an income of less than \$2,942 per year, a monthly premium be charged of \$1.00, and for a family of four with an income of \$12,125 per

year, a monthly premium of \$4.00 be charged.³ Although this may seem a nominal charge at first glance, consider the weight of basic daily expenses to individuals and families who live at these income levels. For example, the cost of a transfer from metro to bus within the Transit Authority of Northern Kentucky (TANK) is \$1.00⁴, and a Day-Pass for Metro is \$3.50.⁵ In Jefferson County, the cost per bus ride on Transit Authority of River City (TARC) is \$1.75.⁶ It is entirely conceivable that a family or individual subject to these daily realities might be forced to choose between paying the premiums required to access Medicaid coverage and purchasing access to needed transportation.

We urge you to consider the significant impact that even small expenses can have for low-income individuals. We urge you not to impose additional expenditures on low-income individuals in the state of Kentucky, and to ensure that those who qualify for Medicaid are not made to choose between health care and other necessary living expenses.

- **Non-Payment Penalties & Waiting Period for Re-enrollment**

We are deeply concerned over the proposed penalties for beneficiaries after 60 days of non-payment of premiums. The proposed penalty for individuals under 100% FPL that subjects a beneficiary to co-payments, could easily leave a beneficiary unable to afford the expenses for necessary medical services and vital life-sustaining drugs. For beneficiaries whose income is over 100% FPL, to after 60 days of non-payment be dis-enrolled from the program for up to six months. This proposal puts the health of many beneficiaries in direct jeopardy by eliminating their access to coverage care and treatment for half a year or more.

For HIV patients, and many others, disruptions in the continuity of medical care, and interruptions in adherence to treatment regimens pose a significant threat. HIV treatment regimens require a high level of adherence in order to be effective. Viral resistance can occur with even short interruptions in medications. HIV patients must be regularly monitored by medical providers for resistance, tolerability, and side effects of the antiretroviral medications as well as for opportunistic infections and other adverse events.

We are very concerned that the proposed non-payment penalties could potentially interrupt HIV patient access to life-saving medications and treatment and to necessary medical care. Other patient groups with chronic conditions, mental health conditions, and multiple co-occurring conditions also

³ KY Voices For Health “Major Changes Are Being Proposed for Medicaid in Kentucky” <https://www.kyvoicesforhealth.org/res/uploads/media/Medicaid-Waiver-Consumer-Handout-7.7.16-FINAL-WITH-REVISIONS-v2.pdf>

⁴ Transit Authority of Northern Kentucky (TANK), “Fare Structure,” 2016 <http://www.tankbus.org/fares/fare-structure>

⁵ Transit Authority of Northern Kentucky (TANK), “Passes,” 2016 <http://www.tankbus.org/fares/buy-passes>

⁶ Transit Authority of River City (TARC), “2016 Fares” <https://www.ridetarc.org/fares/>

have similar need for uninterrupted access to medical care and medicinal treatment. We cannot support any proposal which could limit access to vital medical interventions and pose a threat to patient well-being and lives.

These proposed penalties apply to the poorest of the poor, and create an escalation of costs that we believe would be insurmountable for many. For individuals with an income less than \$11,770 per year, and families with an income less than \$24,250 per year (<100% FPL), a simple unexpected household expense could easily render them unable to pay a premium for a period of more than two months. The imposed co-pays between \$3-\$50, could then add up to significantly more than the premiums owed, and create a cycle of financial costs that would be difficult for a patient to overcome in order to regain coverage.

We also have concern with the lack of provisions for retroactive coverage. Especially in situations of hospitalizations and long term care, the lack of retroactive coverage can have severe financial implications for individuals who are found to have qualified for the insurance prior to the event, but did not know it.

- **Emergency Room Penalty**

We are concerned about the proposed penalties for non-emergency use of emergency facilities. The proposed escalation of costs to patients in the form of co-pay penalties, and the waiting period for re-enrollment of beneficiaries after the proposed penalties stand to increase utilization of emergency rooms and hospitals among patients who have lost access to coverage for regular care.

Although this proposal would impose financial penalties for such “inappropriate” uses of Emergency Room facilities, in reality, there is no way that these penalties will offset the unpaid balances for emergency facilities.

We urge you to consider the impact of these proposals to providers and care centers. The cost of uncompensated care impacts the whole economy and health system. It is the lack of medical coverage and access to regular medical care for patients that drive this cycle.

- **Appropriate Utilization Incentive & My Rewards Account**

Although the state intends to fully fund the \$1,000 deductible for coverage plans through a Rewards account, the proposal to transfer 50 percent of unused deductible account balances to participants’ Rewards account at the end of the year for use in accessing so-called “enhanced benefits” such as dental, vision, over the counter medicines is extremely alarming.

This proposal put high-utilizer patients, such as HIV patients and others with chronic conditions in the position of being very unlikely to accrue account balances, and therefore unable to obtain basic medical services such as routine dental care and vision care.

Dental health is important for many patients, including those living with HIV disease. Dental care can affect transplants, stents, heart health, and diabetes care, just to name a few. It is not a negligible part of medical care, or a superfluous benefit. Dental care can also serve as an opportunity for HIV testing and other screenings, and an opportunity for early identification of a number of diseases and medical conditions. The same is true for basic vision care. We urge the state to consider the long-term costs of not providing coverage for these services.

At worst, even for patients who are not high-utilizers, we are concerned that the proposal could possibly serve to incentivize some patients into forgoing medical care in order to obtain dental and vision services. We cannot support a proposal that places coverage of basic benefits in a sort of competition or decision point.

- **Need for Case Management / Assistors**

We are concerned that the proposal does not seem to include provisions for case managers or assistors to help beneficiaries navigate the new system, process paperwork, or work within deadlines. We find these roles to be very important to patient understanding and adoption of new systems of coverage and to facilitating access and connection to services.

Much of the Kentucky HEALTH proposal relies on significant beneficiary interaction and participation by the beneficiary. For example, the creation of the “My Rewards Account” and process by which premiums are utilized, is a proposal that may be very difficult for some beneficiaries to fully comprehend or effectively navigate. Health insurance and coverage literacy is historically low among low-income populations. Many beneficiaries will require assistance in understanding of how they will go about accessing coverage benefits, medical care and treatment, and meet the requirements of a new program.

The proposal contains a provision for a health literacy course explaining the system to be made available to participants. However, studies have shown cognitive dysfunction in almost 60% of AIDS patients in the state of Kentucky have a concurrent diagnosis of AIDS within 30 days of initial diagnosis.⁷ This indicates that many of the HIV patient population is likely to be cognitively impaired

⁷ Watkins, Crystal and Glenn Treisman. “Cognitive impairment in patients with AIDS – prevalence and severity” Kentucky HIV/AIDS Surveillance Report June 2015 Volume 15 number 1, http://chfs.ky.gov/NR/rdonlyres/984647A7-9C4C-4B3C-B33F-5369624B6132/0/AnnualReport_2015.pdf

by the time their HIV disease is diagnosed. Cognitively challenged patients are very unlikely to be able to understand the complexity of a medical system despite any offered educational training.

Furthermore, for individuals with complex medical conditions such as HIV, establishing routine care and monitoring with a qualified medical provider, and arranging for access to daily medication regimens is already a complex process. The assistance of medical case managers can be necessary to support HIV patients in accessing and routinizing their care and treatment needs. New and complex coverage systems only add to patient burden, and thereby increase need for assistance in coordination and understanding. We urge you to include provisions for case managers or assistants to help beneficiaries navigate the new system, process paperwork, and work within deadlines and also able to offer support in accessing and coordinating their benefits, care, and treatment.

We urge provision of outreach and assistance especially because the proposed penalties for non-compliance stand to take an extremely harsh toll on beneficiaries who struggle to comprehend or fully connect with the new Kentucky HEALTH system. Even for those who fully intend to comply with the new system, difficulties navigating, comprehending or connecting to the new systems could easily surpass the 60 day timeframe for connection and payment, and leave beneficiaries locked out of the new system for six months or more, despite best intentions. We also urge leniency of imposing penalties on those who have difficulties in navigating the new systems and for those who seek assistance but may surpass deadlines while receiving assistance.

- **Lack of Access to Internet**

Much of the Kentucky HEALTH proposal seem to rely on a presumption of access to internet in order to enroll in new systems, for payment of premiums, and in order to manage the proposed “My Rewards Account.” The Medicaid program serves a low-income population that may have no access or only limited to the internet within their home, place of business, or some other community area. Some beneficiaries may also have low or no technological literacy in order to navigate a predominately online system. We urge the state to consider how these beneficiaries will navigate the proposed systems, and to provide multiple methods of access for all components of the system.

We are very concerned that potential barriers to internet access could result even in loss of access to vital medical services. Again, the proposed penalties for non-compliance stand to take an extremely harsh toll on beneficiaries who, due to a lack of internet access, may struggle to interact with the online Kentucky HEALTH system despite best intentions. Those without regular secure internet access, could easily surpass the 60 day timeframe for connection and payment, miss out on open-enrollment periods, or lose accrued benefits.

- **HIV Testing**

Although the Kentucky HEALTH proposal contains provision that would intend to cover “preventative services,” without cost for beneficiaries, we are concerned about the lack of specific coverage for HIV testing. The CDC recommends routine HIV testing for all adolescents and adults ages 15 to 65 years for HIV infection. CDC recommends that individuals get tested at least once in their lifetimes and those with risk factors get tested at least annually. Additionally, CDC has recently reported that sexually active gay and bisexual men may benefit from getting an HIV test more often, perhaps every 3-6 months.⁸

Evidence shows that individuals who are tested and diagnosed early, and initiate early care and treatment, have better outcomes. Additionally, individuals who know their HIV-infected status are less likely to transmit the disease to others, and HIV patients in regular care and treatment substantially less likely to transmit HIV to others.⁹ The U.S. Preventive Services Task Force (USPSTF) gave a “Grade A” rating for routine testing for HIV infection in adolescents and adults aged 15 to 65 years.¹⁰ This grade effectively means that coverage of the service is highly recommended for all government payers, including Medicaid. We urge you to assure that Medicaid beneficiaries will have continued access to routine HIV testing under the proposed Kentucky HEALTH program.

- **Medical Transportation**

Currently in Kentucky, all Medicaid recipients get free transportation to medical appointments with three days’ notice. Medical transportation services are an important part of access to medical care, and the loss of this benefit would create a significant barrier to timely, consistent health care for some beneficiaries. For the medically frail, medical transportation services may be the only means of access to medical appointments. For low-income patients, medical transportation services may offset other prohibitive transportation costs. Patients without access to medical transportation are also more likely to use the ambulance services to get to a hospital during acute care instances.

We urge the state to provide mechanisms for transport for those without transportation access to attain regular medical care services, and for the acutely ill to access medical care sites other than

⁸ CDC “HIV Testing in Clinical Settings” <http://www.cdc.gov/hiv/testing/clinical/>

⁹ CDC “Prevention Benefits of HIV Treatment” <http://www.cdc.gov/hiv/research/biomedicalresearch/tap/index.html>

¹⁰ USPSTF “Human Immunodeficiency Virus (HIV) Infection: Screening” <http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/human-immunodeficiency-virus-hiv-infection-screening>

emergency rooms. We urge you to retain medical transportation services within the Kentucky HEALTH program.

- **Community Engagement and Employment Initiative**

Under the proposed Kentucky HEALTH plan, all “able-bodied working age adults” members without dependents will be required to participate in the “Community Engagement and Employment Initiative” to maintain enrollment. Engagement activities include volunteer work, employment, job training, job search or educational activities, and failure to meet required engagement hours will result in a suspension of benefits until the member satisfies the requirement for a full month.

We are very concerned that this proposed requirement presents yet another barrier to health coverage for individuals that need coverage the most. This requirement could be exceptionally burdensome for some beneficiaries, requiring time commitments, travel, travel costs, and energy expenditures which may be difficult for some to meet.

While we are pleased that the plan does allow for exemptions for the medically frail and some others, beneficiaries who are unable to meet the requirements would be dis-enrolled from the program, until the requirement has been fulfilled for a full month. This disenrollment penalty could potentially interrupt HIV patient access to life-saving medications and treatment and to necessary medical care.

- **Access to HIV Specialists**

We are generally concerned with access to qualified medical care providers for HIV patients. The Kentucky Health proposal does not contain any requirement for coverage plans to ensure access to certain types of providers. However, access to HIV-specialized providers is extremely important to this vulnerable patient population. Furthermore, a large body of evidence indicates that the two best predictors of high-quality, cost-effective HIV care are experience and medical education and ongoing training.¹¹

The Center for Disease Control and Prevention (CDC) has developed a statistical model that shows the continuum of effective HIV care and treatment¹² which shows that one of the biggest failures in addressing the HIV epidemic in the U.S., is in the area of retention in care. After Kentucky expanded the Medicaid program under the ACA, 428,000 new patients were brought into coverage and able to access care, an estimated 80% of HIV patients in the state.

¹¹ AAHIVM Policy Platform, 2015 www.aahivm.org/policyprincipals

¹² The Center for Disease Control and Prevention (CDC) “Understanding the HIV Care Continuum” http://www.cdc.gov/hiv/pdf/DHAP_Continuum.pdf

It would be a terrible step back in combatting HIV in Kentucky if those patients were lost to care or suffered interruptions in access to qualified HIV providers under the Kentucky Health proposal. We urge the state to consider requiring access to HIV providers and other essential community providers for the plans that will cover the Kentucky Medicaid population.

We thank you for consideration of our comments. We urge you to consider the medical and daily needs highly vulnerable populations, such as HIV patients, who rely on the coverage and services provided by the Medicaid program, and to seek to provide for their medical needs and general well-being.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Krigger', with a stylized flourish at the end.

Karen Krigger, MD, MEd, FAAFP, AAHIVM(S)

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