

HIV Health Care Access Working Group

November 20, 2017

Submitted electronically to CMMI_NewDirection@cms.hhs.gov

Centers for Medicare and Medicaid Services
Department of Health and Human Services
Baltimore, MD 21244-8016

Re: Request for Information regarding the Innovation Center's New Direction

To Whom It May Concern:

We are writing on behalf of the HIV Health Care Access Working Group. We appreciate the opportunity to submit comments in response to the Request for Information about the Center for Medicare & Medicaid Innovation's (CMMI) New Direction.

The HIV Health Care Access Working Group (HHCAGW) consists of national, state, and local organizations that represent people living with and vulnerable to HIV and those affected by HIV, public health and medical providers, HIV/AIDS service organizations, housing providers, and legal advocates from across the United States. We are committed to increasing access to affordable and comprehensive health coverage for people living with HIV and other chronic illnesses.

While CMMI's New Direction could lead to improved models of care for people living with HIV, we are deeply concerned that the Centers for Medicare and Medicaid Services' focus on "flexibility" will detract from the provision of high-quality, accessible health care.¹ We have provided examples below as to how flexibility in certain state-based models could lead to increased and harmful barriers to care and what additional principles CMMI should consider when developing alternate models of care.

State-Based and Local Innovation, including Medicaid-focused Models

As CMMI works with states to develop State-led, innovative models of care, HHCAGW urges CMMI to reject models that introduce patient restrictions as a means to lower costs. Specifically, CMMI should avoid the integration of work requirements, eligibility time limits, and drug testing. CMMI should prioritize transparency and ensure that any demonstration of new innovative models is supported by culturally- and linguistically-appropriate consumer assistance. New models of care should remain voluntary as to not disrupt continuity of care for people living with HIV.

CMMI should reject innovation models that include work requirements as a condition of care. While employment could be a helpful factor in improving a person's health in certain cases, a work requirement would harm the health and wellness of already-vulnerable populations and create a barrier to care.

¹ Remarks by Administrator Seema Verma at the National Association of Medicaid Directors (NAMD) 2017 Fall Conference, (Nov. 7, 2017) <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2017-Fact-Sheet-items/2017-11-07.html>.

Including work requirements or incentives in an innovative model of care would be a blatant disregard for people living with HIV and other chronic conditions. Chronic illnesses often produce symptoms or disabilities that are not visible, but still serve as impediments to steady employment. Additionally, some chronic conditions like HIV can produce periods of inability to work due to medication side effects or symptom flare-ups, thus requiring flexible work arrangements.² Episodic disabilities can produce an uneven work history, which would result in uneven coverage and access to medical care, and make it more difficult for a person to find future employment.

Work requirements are often introduced to address the inappropriate and false assumption that public insurance recipients are unemployed and unmotivated. This frames the requirement not as a tool to improve the health and wellbeing of vulnerable populations, but rather a tool to (unnecessarily) enforce a standard of behavior. The majority of Medicaid enrollees are in fact in families that either work full time (51%) or part time (2%) though.³ A work requirement would put the heaviest of burdens on unemployed enrollees, of whom 35% are disabled, 28% are taking care of their home or family members, and 18% go to school.⁴ A work requirement approved within a State-led model would be redundant – as most Medicaid enrollees work if able – and serve as a barrier to care for those who have difficulties maintaining long-term employment.

CMMI should also fervently deny proposals that incorporate eligibility time limits into models of care. Eligibility time limits encourage patients to delay accessing medically necessary care out of concern that they may need greater care later in their life. Sporadic care runs counter to recommended treatment for HIV and other serious and chronic health conditions. With consistent care and regular adherence to antiretroviral therapy (ART), people living with HIV can suppress their viral load such that the virus is barely transmittable.⁵ The Department of Health and Human Services' Panel on Antiretroviral Guidelines for Adults and Adolescents (a working group for the Office of AIDS Research Advisory Council) has recommended that in order to improve adherence to ART, patients should get support to “maintain uninterrupted access to both ART and appointments.”⁶ Imposing a lifetime limit on care as a means to cut cost or improve value, would instead cause patients to ration or delay their care, counter to both individual and public health goals.

In the Medicaid Innovation Accelerator Program's focus on substance use, CMMI should deny models of care that incorporate drug testing as a condition to care. Similar to work requirements, drug testing as a condition to care would not be tied to a public health goal, but instead be used as a way to enforce a standard of behavior or coerce a person into substance use treatment programs. This enforcement and coercion is not ethically (or at times, medically) appropriate. This requirement for care would instead serve as a deterrent to the very populations in need of screening and care.

² *Getting to Work: a Training Curriculum for HIV/AIDS Service Providers and Housing Providers: Module 1*, <https://www.hudexchange.info/trainings/dol-hud-getting-to-work-curriculum-for-hiv-aids-providers/>.

³ R. Garfield & R. Rudowitz, *Understanding the Intersection of Medicaid and Work*, (Feb. 15, 2017) <https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/>.

⁴ *Id.*

⁵ CDC, *HIV Prevention FAQs*, <https://www.cdc.gov/actagainstaids/campaigns/starttalking/prevention.html>.

⁶ *Limitations to Treatment Safety and Efficacy*, (Oct. 17, 2017) <https://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv/30/adherence>.

CMMI should also reject drug testing requirements as they are not financially or administratively efficient. Past examples of drug testing have shown little to no direct savings. In 2016, Tennessee reported that only 65 of over 39,000 residents applying for state cash assistance tested positive for illegal drugs.⁷ Also in 2016, Michigan ran a pilot program testing recipients of their temporary cash assistance program and found no positive test results.⁸

Any new State-led models of care should be assessed for full transparency and broad stakeholder participation in all stages of planning and implementation. Evaluation and review processes should be set in advance and intentionally include opportunities for stakeholder opinions to be heard. State-led models of care should also be supported by robust, free consumer assistance programs. To exercise informed choice, beneficiaries need easy-to-use and accessible tools that allow them to compare options. These tools should be culturally- and linguistically-appropriate and allow consumers the ability to review coverage of specific drugs and services prior to enrollment.

New State-led models of care should allow for consumer choice, such that participation would remain voluntary. People living with HIV and other chronic illnesses have often spent months or years developing provider teams that work well for the management of their condition(s). Consumers should always be given the option to remain in these networks and not disrupt the continuity of their care.

Patient-Center Comprehensive Care Models

Patient-centered care should be focused on designing delivery systems tailored to meet the needs of patients and that facilitate access to preventive services, medical care, and medications without barriers, such as higher than nominal cost sharing, prior authorizations, or other service restrictions. We urge CMS to look to the Ryan White HIV/AIDS Program to define patient-centered care and to support demonstrations that increase access to this care model under Medicare and Medicaid for people with HIV and others with chronic conditions through expansion of the Medicaid health home model or other similar care models.

The Ryan White HIV/AIDS Program has been a leader in supporting a patient-centered, comprehensive care model and was designed to ensure that individuals with HIV have access to the range of services that they may need to effectively manage HIV, including medical case management, mental health and substance use treatment, treatment adherence, and nutrition and dental services.⁹ Many of these services often are not covered by insurers or are not adequately covered by insurers, but, based on evaluations of outcomes at Ryan White-funded versus non-Ryan White-funded clinical sites, do contribute to improved health outcomes for people with HIV.¹⁰

HHCAWG strongly urges CMS to consider additional models for enhancing reimbursement of effective management and coordination of services for individuals with HIV and others with chronic conditions. We urge CMS to define consumer driven or directed care as a healthcare system designed to meet the

⁷ Anita Wadhvani, *Drug testing for benefits in Tennessee yields only 65 positives*, Tennessean (Feb. 7, 2016).

⁸ Ryan Felton, *Michigan's drug-testing welfare program has yielded zero positive results so far*, The Guardian (June 21, 2016).

⁹ Gallant, JE. *Essential Components of Effective HIV Care: A Policy Paper of the HIV Medicine Association of the Infectious Diseases Society of America and the Ryan White Medical Providers Coalition*, 53 Clin Inf Dis. 1043 (2011).

¹⁰ Weiser J, et al. *Service Delivery and Patient Outcomes in Ryan White HIV/AIDS Program-Funded and Nonfunded Health Care Facilities in the United States*, 175 JAMA Intern Med. 1650 (2015).

comprehensive needs of individuals with HIV and other chronic conditions and to ensure ready access to services that prevent disease progression and development of co-occurring conditions.

We urge attention to evaluating systems of care that are designed around the needs of patients and that provide enhanced reimbursement to providers for ensuring patients receive the appropriate care and treatment when and where they need it. A key component of a comprehensive system of care is for healthcare teams to have the resources and flexibility to take a holistic approach that meets medical needs and also ensures patients' basic living needs are met, including housing and nutrition.

Physician Specialty Models

People living with chronic conditions, such as HIV, face deep systemic disparities that negatively affect health outcomes. Specialty provider shortages often limit a patient's ability to seek out care. Research has proven that patients with HIV who are managed by experienced HIV medical providers have better health outcomes and receive more cost effective care.¹¹ A majority of HIV care is provided at Ryan White-funded clinical programs and people living with HIV receiving care at Ryan White-funded clinical sites have better health outcomes.

In developing specialty physician models, CMMI should ensure that people living with HIV will have the option to remain with their current team of providers. Changes in providers can produce unnecessary interruptions of care, resulting in a negative impact on health outcomes. CMMI should instead focus on increasing the pool of skilled providers that are familiar with HIV and other chronic disease management. CMMI should consider expanding networks to include advanced practice practitioners with the appropriate HIV experience and expertise.

Mental and Behavior Health Models

Mental and behavior health services have and continue to be vital for people living with HIV. People living with HIV are at a greater risk of developing mood, anxiety, and cognitive disorders, including certain disorders specifically associated with HIV (such as Asymptomatic Neurocognitive Impairment, Mild Neurocognitive Disorder, and HIV-associated Dementia).¹² The treatment of mental and behavioral conditions require consistent, reliable access to specialized providers who are familiar with the treatment of HIV and associated illnesses.

In exploring potential models on behavioral health for people with HIV, we urge CMMI to only consider models that intentionally include mental and behavioral health providers who specialize in treating people living with HIV. Specifically, we urge broader evaluation of the integration of behavioral health services into HIV clinical programs. Certain mental health conditions, such as depression, can have a negative effect on HIV treatment adherence.¹³ Expanding care to providers knowledgeable of HIV-specific characteristics can bolster a patient's ability to manage their chronic illness. Additionally,

¹¹ M.M. Kitahata, et al, *Physicians experience with the acquired immunodeficiency syndrome as a factor in patients' survival*, 334 N Engl J Med 701 (1996); M.A. Horberg, et al, *Influence of provider experience on antiretroviral adherence and viral suppression*, 4 HIV AIDS 125 (2012); R.D. Moore, et al, *Improvement in the health of HIV-infected persons in care: reducing disparities*, 55 Clin Inf Dis 1242 (2012).

¹² National Institute of Mental Health, *HIV/AIDS and Mental Health*, (November 2016) <https://www.nimh.nih.gov/health/topics/hiv-aids/index.shtml>.

¹³ S. Choi, et al., *Adequacy of Mental Health Services for HIV-Positive Patients with Depression: Ontario HIV Treatment Network Cohort Study*, 11 PLoS e0156652 (2016) <https://dx.doi.org/10.1371/journal.pone.0156652>.

specialized providers can serve as a conduit for patients to connect with more comprehensive care.¹⁴ Thus, models considered should integrate mental and behavioral health within the larger picture of treating chronic illnesses, rather than separating this type of care.

In addition to improving access to providers, CMMI should consider models that innovatively expand access to needed and covered services. Social determinants such as geography, housing, childcare, and employment can serve as additional barriers to mental or behavioral health treatment.¹⁵ Models that utilize innovative tools, such as telemedicine, can improve patients' access to care particularly in rural areas where health professional shortages already exist.¹⁶ Additionally, community-based benefit expansions, such as supportive housing, can promote stability (and improve treatment adherence) and ultimately lower health care costs.¹⁷ However, models that provide these benefits and innovative tools should do so equitably, without stigma, and with no barrier to entry.

Program Integrity

CMMI should proactively and meaningfully engage beneficiaries, consumer advocates, and providers in the development and evaluation of potential models. Officials should include people living with HIV and advocates at the start of these discussions, and continuously engage these stakeholders as models are approved, tested, and improved. CMMI should set aside distinct opportunities for stakeholders to submit formal comments, and respond to specific consumer concerns.

To promote program integrity, CMMI should aggressively collect and report data on the adequacy and performance of new models. For individuals with HIV, one of the primary clinical goals of HIV treatment is to achieve and sustain viral suppression for the individual's health and to virtually eliminate his or her risk of transmitting HIV. Demonstrations that include beneficiaries with HIV must at a minimum include the HIV Viral Load Suppression measure (National Quality Forum #2082) as part of the evaluation plan. Too often, quality of care becomes compromised in an attempt to lower costs. A rigorous evaluation and analysis period focused on quality of care measures (instead of strictly cost measures) will help confirm whether a model demonstration is successfully improving care for people living with HIV and other chronic illnesses.

People living with HIV cannot afford to experiment with models of care that are designed to present barriers to medically-necessary treatment. CMMI should not allow flexibility in areas that will decrease access and coverage by shifting greater costs and care management responsibility to beneficiaries. Instead, CMMI should focus on developing alternative models of care that expand a patient's access to

¹⁴ As an example, in addressing the opioid use epidemic, specialized providers could help connect patients with screening and follow up care for diseases associated with opioid use, such as Hepatitis C.

¹⁵ J. Pellowski, *Barriers to care for rural people living with HIV: A review of domestic research and health care models*, 24 J. Assoc. Nurses AIDS 422 (2013).

¹⁶ Approximately 53% of Mental Health Professional Shortage Areas (reaching over 26 million people) are in rural areas of the United States. Bureau of Health Workforce, Health Resources and Services Administration, *Designated Health Professional Shortage Areas Statistics*, (Nov. 2017) <https://datawarehouse.hrsa.gov/Tools/HDWReports/Reports.aspx>.

¹⁷ E. Dohler, et al., *Supportive Housing Helps Vulnerable People Live and Thrive in the Community*, (May 31, 2016) https://www.cbpp.org/research/housing/supportive-housing-helps-vulnerable-people-live-and-thrive-in-the-community#_ftn18.

integrated, comprehensive coverage, that supports whole health, and that continuously engages appropriate stakeholders in evaluation and continued approval.

Thank you for the opportunity to provide information on how CMMI can use innovative models of care to improve care for people living with HIV. Please contact Amy Killelea with the National Alliance of State & Territorial AIDS Directors (akillelea@nastad.org), Andrea Weddle with the HIV Medicine Association (aweddle@hivma.org), or Robert Greenfield with the Treatment Access Expansion Project (rgreenfield@law.harvard.edu) for additional information.

Respectfully submitted,

ADAP Educational Initiative | AIDS Alabama | AIDS Action Baltimore | AIDS Alliance for Women, Infants, Children, Youth & Families | AIDS Foundation of Chicago | AIDS Research Consortium of Atlanta | AIDS United | American Academy of HIV Medicine | APLA Health | AIDS Resource Center of Wisconsin | Black AIDS Institute | Communities Advocating Emergency AIDS Relief (CAEAR) | Community Access National Network (CANN) | Dab the AIDS BEAR Project | Equality California | Georgia AIDS Coalition | God's Love We Deliver | Harm Reduction Coalition | HealthHIV | HIV Medicine Association | Housing Works | Legal Council for Health Justice | Michigan Positive Action Coalition | Minnesota AIDS Project | National Alliance of State and Territorial AIDS Directors | National Latino AIDS Action Network | NMAC | Positive Women's Network – USA | Project Inform | Rocky Mountain CARES | San Francisco AIDS Foundation | SisterLove | Southern AIDS Coalition | Southern HIV/AIDS Strategy Initiative | The AIDS Institute | Treatment Access Expansion Project