

## HIV Health Care Access Working Group

April 10, 2014

### VIA ELECTRONIC SUBMISSION

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
P.O. Box 8016  
Baltimore, MD 21244-8016

**Re: Proposed Healthy Pennsylvania 1115 Demonstration Project and Other 1115 Waiver Proposals**

To Whom It May Concern,

We are writing on behalf of the HIV Health Care Access Working Group (HHCAWG) – a coalition of over 100 national and community-based HIV service organizations representing HIV medical providers, public health professionals, advocates, and people living with HIV who are all committed to ensuring access to critical HIV-related health care and support services. We thank you for your commitment to implementing the Affordable Care Act (ACA) in ways that ensure access to comprehensive HIV prevention, care, and treatment, and appreciate the opportunity to comment on the Pennsylvania Medicaid expansion waiver. As CMS reviews Pennsylvania’s and other state waiver requests, we urge you to consider the ACA’s intent to increase access to meaningful health care coverage, particularly for individuals living with HIV and other vulnerable populations who are largely dependent on Medicaid for health care.

Medicaid is currently a lifeline to care for more than 200,000 people living with HIV and thanks to the ACA many more will be gaining Medicaid coverage. If every state were to expand their program, nearly 50,000 would gain access to Medicaid, not including the additional numbers of individuals who are likely to be eligible but who are not yet connected to care.<sup>1</sup> To this end, we support state efforts to expand their Medicaid programs to the full extent allowed under the ACA, and understand that states may take different approaches to the expansion process.

However, to ensure meaningful health coverage for low-income people living with HIV and reduce the geographic health disparities that currently exist within the Medicaid program, it will be critical for CMS to hold firm to the comprehensive coverage standards and critical protections that have been a hallmark of the Medicaid program. These standards and protections have been established through a robust

---

<sup>1</sup> Kaiser Family Foundation, “Assessing the Impact of the Affordable Care Act on Health Insurance Coverage of People With HIV,” (Jan. 2014).

legislative and regulatory process and were put in place to protect the country's most vulnerable residents. In particular, we urge CMS to maintain firm standards with respect to:

- protecting the medically frail,
- preserving established premium and cost-sharing limits,
- maintaining comprehensive benefits, including adequate wrap-around services in premium assistance models,
- requiring robust provider networks, and
- ensuring a fair and just appeals process that maintains consumer protections.

While 1115 waivers are designed to encourage state innovation, such innovation cannot come at the expense of eroding the program's most important features and jeopardizing access to care. To ensure adequate access to health care for individuals living with HIV and other chronic illnesses in states that request Medicaid expansion and/or premium assistance waivers, we make the following recommendations:

- **CMS should require detailed information about state identification and outreach processes for the medically frail, and ensure that all medically frail enrollees are given the opportunity to make an informed choice between traditional and ABP Medicaid coverage in states where benefit packages differ.**

By definition, individuals who are medically frail have complex health care needs that make it especially important for them to have access to a robust and comprehensive benefits package that will meet their needs and ensure continued and uninterrupted access to any existing care providers. Particularly in states requesting waivers to implement premium assistance programs, it will be critical for states to have appropriate processes to identify the medically frail and ensure they are given the chance to make an educated choice between traditional Medicaid and the private market. States have three levels of flexibility in this area: (1) adding additional contours to the definition of medically frail, (2) creating processes used to identify medically frail individuals at the time of enrollment and throughout the year, and (3) outreach and education.

1. Defining the medically frail - We strongly support CMS' recent decision to expand the federal definition of what constitutes medical frailty to include for example, individuals living with chronic substance use disorders. This federal definition constitutes the floor of who must be considered to be medically frail, and CMS must monitor state proposals that attempt to curtail this definition, and encourage states to expand upon it. We also support use of the Medicaid Health Home eligibility criteria as a federal floor for the definition of medically frail. At a minimum, anyone living with HIV should automatically qualify as medically frail. For instance, while we were pleased by Pennsylvania's proposal to automatically designate any individual living with HIV/AIDS as medically frail, additional language included in the waiver proposal substantially limits the definition of other individuals considered to have serious and complex

medical conditions. In particular, Pennsylvania proposes to require individuals who do not suffer from a few specifically named illnesses to have had at least 2 or more inpatient admissions within 12 months, AND 3 or more emergency room visits within 6 months, AND have 4 or more prescription medications per month in order to qualify. Not only does this severely restrict the number of individuals who may be considered medically frail, it also penalizes individuals with complex illnesses who may be able to avoid hospitalizations and emergency room visits through extensive outpatient clinical management of their illness.

2. Creating processes for identification of the medically frail -We are concerned by state waiver proposals that attempt to set “quotas” for the number of individuals to be identified and/or that do not provide enough information for CMS to meaningfully review the adequacy of their intended processes. In its waiver proposal, for example, Arkansas indicated that it would be using a screening tool “calibrated to identify the top ten percent expected costs among the newly eligible population.” Moreover, the state also anticipated that approximately 10% of the new adult population would qualify. This implies that the state will limit its identification of, and outreach to, medically frail individuals to only those who are within that tier and only until the state has identified a number of people that corresponds to about 10% of new enrollees, to the exclusion of additional individuals who may also qualify.

While we commend Iowa, Pennsylvania, and Arkansas for their assertions that that they will use both an initial screening tool and ongoing analysis of claims data to help identify the medically frail, these general assertions are not specific enough to allow for meaningful review of the adequacy of these processes. For instance, we urge CMS to require states to indicate the types of claims data that will be used and the processes in place for individuals who become medically frail to self-identify outside of the time of enrollment or redetermination. Pennsylvania in particular gives no indication of what the screening tool will look like. In addition, all state screening tools should be required to have a “catch-all” space for individuals who can self-identify as medically frail based on their own particular combination of medical conditions and health care needs, even if they are not able to answer the specific screening questions in a way that would qualify them as such.

3. Education and Outreach- In addition to screening processes, it will be important for states to have clear plans for education and outreach. In this regard, Iowa sets a good example by asserting that the state will provide education and outreach about medical frailty to navigators, certified application counselors, community mental health and other health care providers that see high-needs patients. By contrast, Pennsylvania gives no indication of what steps will be taken to help individuals understand why filling out the screening tool could be important. This is of concern especially because Pennsylvania makes clear that the screening tool will be optional, and individuals may not realize the benefit to completing it, and/or what additional choices may be available as the result of a medically frail designation. We therefore urge CMS to impose outreach and education requirements for all state waivers, similar to the Iowa plan.

Accordingly we strongly urge CMS to require more detailed information about states' processes for the medically frail to ensure that the processes are appropriate, and to require robust outreach and education components. This will be particularly important in the context of states applying for premium assistance waivers, where it will be especially critical for individuals to have a choice to opt out of private market plans that may be inadequate to meet their needs. It will also be important for CMS to ensure that all beneficiaries are aware that a determination that an individual is not medically frail is a decision that may be appealed and that the state provide enrollees with clear and accessible information on the appeal process.

- **CMS must not permit states to increase enrollee premiums and cost-sharing beyond the established limits.**

CMS has established important Medicaid cost-sharing limits and protections, explicitly exempting individuals below 150% FPL from premium requirements, limiting co-payment amounts, and setting maximum out-of-pocket caps at 5% of income. Allowing states to go above these established levels will discourage individuals from seeking needed care and treatment. This is particularly a concern for individuals living with HIV and other chronic illnesses who rely on routine medical care and multiple medications to maintain their health.

Numerous studies have demonstrated the detrimental effect of premiums and cost-sharing requirements on consumer access to care.<sup>2</sup> Individuals with HIV are particularly vulnerable to cost-sharing requirements, as they tend to need more services and require more medications than other populations. Moreover, discouraging individuals living with HIV from seeking treatment will ultimately result in much higher health care costs in the long-term due to the development of more complicated and costly health problems that could have been prevented by early interventions and consistent access to care.

We were concerned by CMS' decision to allow Iowa to implement premiums for all individuals with incomes at or above 100% of FPL. Of greater concern is the most recent waiver request by Pennsylvania. That state has proposed a cost-sharing system that would in year 1, require all individuals with incomes above 100% FPL to pay a co-pay that would be collected by providers. Failure to pay the co-pay can result in providers refusing to provide medical services. In year 2, all individuals with incomes above 100% FPL would be required to pay a \$25/month premium, and failure to pay would result in progressively longer periods of lock-out from the program. Individuals above 100% FPL would also be required to pay a \$10 co-pay for non-emergent use of the emergency room (a similar request was made

---

<sup>2</sup> See, e.g., S. Artiga & M. O'Malley, "Increasing Premiums and Cost Sharing in Medicaid and SCHIP: Recent State Experiences," Kaiser Commission on Medicaid and the Uninsured (May 2005), available at <http://www.kff.org/medicaid/7322.cfm>; and L. Ku & V. Wachino, "The Effect of Increased Cost Sharing in Medicaid: A Summary of Research Findings," Center on Budget and Policy Priorities (July 7, 2005), available at <http://www.cbpp.org/files/5-31-05health2.pdf>.

and denied in Iowa's waiver). Moreover, Pennsylvania requests blanket authority to potentially impose premiums or other cost-sharing for individuals below 100% FPL in year 2, with no indication of what those amounts might be, and no mention of the services (such as family planning and pregnancy related services) that must be exempt from co-payment. Nor is there an exceptions process in either year 1 or year 2 for individuals who are determined to be medically frail or chronically ill, unless they can otherwise meet the very narrow criteria for exemption.

These proposed policies violate existing Medicaid law and are blatantly discriminatory against individuals living with HIV and other chronic health conditions who will have higher cost sharing expenses due to their need for more frequent medical services. Because of the structure of the waiver, individuals who are unable to pay their copays in year 1 and/or who do not participate in the Encouraging Employment initiative will be further penalized in year 2 when they will be ineligible for any premium discounts that are otherwise available to everyone else. Lock-out periods, in addition to being expressly prohibited under Medicaid law, are completely contrary to the stated goals in the waiver to reduce churn and promote continuity of care, as lock-out periods only serve to disrupt care and access to needed services. Pennsylvania's proposal to eliminate point-in-time eligibility and retroactive coverage is also at odds with these goals (and a similar request in Iowa's waiver proposal was rejected).

In addition, we strongly oppose Pennsylvania's proposal to implement a voluntary "Encouraging Employment" program. Work requirements have never been part of Medicaid and will only serve to enact additional barriers to coverage for low-income populations, particularly for individuals living with HIV and other chronic conditions who may be less likely to be able to participate in any kind of work incentive program due to illness.

Moreover, all of these provisions are contrary to the intent and spirit of the Medicaid expansion to promote access to health care for low-income people. CMS should be very explicit in denying these requests, and make clear that any increases in cost-sharing or premium obligations in the future would require additional waiver amendment requests that would include opportunities for public comment.

- **CMS must ensure access to comprehensive benefits for all individuals in Medicaid, including adequate wrap-around services for individuals in premium assistance plans.**

Mandates in existing Medicaid law for inclusion of specified benefits in ABPs, in conjunction with new essential health benefits and anti-discrimination provisions put in place by the ACA,<sup>3</sup> require that state Medicaid programs provide access to comprehensive benefits packages for both existing and newly eligible individuals living with HIV and other chronic illnesses. To this end, we urge CMS to uphold mandated benefits for enrollees in waiver states. An analysis of Medicaid premium assistance plans by the Government Accountability Office for example, noted a reported concern that there may be less access to benefits and cost-sharing protections as compared to those in traditional direct Medicaid

---

<sup>3</sup> See e.g. §1937 and §1302(b)(4)(B-D)).

coverage.<sup>4</sup> In particular, we urge CMS to reject proposals that attempt to limit access to needed services and medications, and that restrict or eliminate wrap-around benefits for premium assistance enrollees.

We urge CMS to ensure all waiver proposals provide meaningful access to the care and treatment people living with HIV and other chronic illnesses need to stay healthy without imposing restrictive limits. For example, Pennsylvania’s proposal to limit and cap visits to Federally Qualified Health Centers (FQHCs), mental health benefits, and laboratory services in both the high and low-risk benefit plans will have a particularly detrimental impact on access to HIV care and treatment and should be rejected by CMS. Laboratory tests, for example, are recommended every three to six months to assess an individual’s response to HIV therapies and to monitor disease progression. The restrictions proposed by Pennsylvania are therefore inadequate to meet the needs of the target populations and contrary to law. In addition to these limits and restrictions, Pennsylvania fails to provide chronic disease management, a required essential health benefit.

We urge CMS to ensure that any waiver proposal ensures access to lifesaving medication for people living with HIV and other chronic conditions by monitoring the following access issues:

- Medicaid beneficiaries must continue to have access to the 24-hour prior authorization decision timeline. Iowa, Arkansas, and Pennsylvania for example, all requested to extend the necessary time-frame for responding to requests for prior-authorization of medication from 24 hours to 72 hours. This 24-hour requirement was put in place to ensure that individuals would not go without access to potentially life-saving medications. Even with state assurances to make available emergency supplies, the proposal to extend the length of time erodes protections put into place to ensure access to critical prescriptions drugs and maintain a more efficient healthcare system. Under the current rules, providers report delays in care and burdensome processes that only serve to impede access to medically appropriate prescription drugs. It is particularly important to maintain the 24-hour turnaround time given that CMS has already waived traditional Medicaid prescription drug protections in favor of the EHB formulary standards.
- Monthly limits on prescription drugs should be prohibited. In addition to extending the time allotted for prior authorizations, Pennsylvania is proposing to limit prescription drug benefits in both packages to six medications per month. This limit will not meet the needs of many individuals who rely on multiple medications to treat their HIV and other common co-occurring conditions, such as mental illness, liver disease and diabetes.

It is particularly concerning that under Pennsylvania’s proposal, individuals with complex conditions and/or who have been designated as medically frail are not automatically exempt from these limits.

---

<sup>4</sup> Government Accountability Office, “Enrollment, Benefits, Expenditures, and Other Characteristics of State Premium Assistance Programs, GAO-10-258r at 2 (Jan. 19, 2010).

Specific exceptions are allowed only for individuals with “chronic systemic illnesses or other serious health conditions” who can also demonstrate that the denial of the exception will “jeopardize the life or result in the serious deterioration of the health of the recipient.” Otherwise, similar to all other individuals, the state must determine that granting such an exception would either be a cost effective alternative for the MA program or that granting the exception would be necessary to comply with federal law. Aside from being severely restrictive, this exceptions process is too vague to be adequate and it is unclear in what context and in what manner these standards will be applied. This complexity may also limit the willingness of providers to see patients with complex or chronic conditions, as this process will be quite burdensome.

Uphold provision of all mandated wrap-around benefits for enrollees in premium assistance plans. In previous guidance, CMS made clear that access to wrap-around services would be an essential component of any premium assistance waiver. Yet we were alarmed by CMS’ recent decision to waive non-emergency transportation for individuals in the Iowa Wellness plan. This is a critical benefit that addresses a common barrier to accessing medical care and treatment for low-income individuals living with HIV and other chronic conditions. This is of even greater concern for individuals living in rural communities, where access to HIV experts may be especially difficult and/or in communities that have been identified as areas with health professional shortages.

We are even more concerned by Pennsylvania’s explicit proposal to eliminate all wrap-around services for individuals in the premium assistance program, without even specifying services that may not be covered in the private market. Granting such a request to eliminate wrap-around benefits would seriously jeopardize access to care for individuals in the premium assistance plan in Pennsylvania as well as lower the standard for other states who are likely to request similar or even more harmful waivers. Even states such as Iowa and Arkansas, who made assurances of providing wrap-around services to individuals enrolled in the premium assistance plans, did not offer details as to how such processes will work.

Congress was explicit in enacting a Medicaid expansion under the ACA rather than authorizing a system of advanced premium tax credits for individuals with incomes below 100% FPL to purchase coverage in the private market. In fact, Medicaid has been designed for low-income and vulnerable populations largely because the private market has been inadequate to meet their needs. Medicaid enrollees who are placed in premium assistance plans are at risk for facing additional barriers to care if basic Medicaid protections and services are not maintained. Eliminating wrap-around services would be a complete abdication of the years of experience and expertise that the Medicaid program has developed with regard to the services low-income and vulnerable individuals need to ensure they can access needed health care and maintain health. CMS must therefore carefully monitor implementation in all premium assistance states to ensure ongoing access to wrap-around services and other benefit entitlements.

- **CMS must ensure that individuals in Medicaid and premium assistance plans have access to adequate provider networks and should require states to provide detailed information on plan networks, including geographic access and inclusion of Ryan White Program and other specialty providers.**

While we recognize that Qualified Health Plans (QHPs) offered in marketplaces must meet existing network adequacy standards, there should be additional scrutiny of the QHPs available to Medicaid enrollees, as they are entitled to particular protections with regards to network adequacy that must be maintained. For example, Medicaid enrollees who are enrolled in managed care organizations (MCOs) are entitled to:

- the right to a choice between at least two physicians or case managers,
- the right to receive care from out-of-network providers as when the available in-network providers do not meet their needs,
- the right to change between MCOs within 90 days following enrollment, and
- the right to change plans at any time due to inadequate access to providers or services.

These rights are especially important in the context of new premium assistance waivers, and CMS must require states to provide enough information to assess the adequacy of provider networks and to ensure these rights and protections are enforced.

In addition, individuals in Medicaid also have the right to see any willing provider for family planning services. Access to sexual reproductive health resources, including family planning providers, is extremely critical. We urge CMS to reject Pennsylvania's request to waive statutory requirements that protect enrollee's right to freedom of choice in accessing family planning providers, services, and supplies. These protections were put in place in recognition of the heightened obligation of the state in protecting the privacy of enrollees while ensuring access to these critical services. As with Iowa, we urge CMS to categorically reject the requests of Pennsylvania and any other states to waive these rights.

- **CMS must ensure a fair and just appeals process that maintains protections for consumers.**

When individuals are unable to access needed benefits and services, there must be a just and efficient system to challenge adverse coverage decisions. As with Iowa, CMS should reject any state waiver requests to bifurcate and/or otherwise abdicate responsibility for maintaining the constitutional rights of Medicaid enrollees in appeals processes. CMS must also carefully monitor the processes states have in place to ensure individuals in premium assistance programs are made aware of these protections through adequate notice and education.

We thank you for your consideration of our comments, and for your continued efforts to ensure that Medicaid will continue to meet the needs of its most vulnerable enrollees. Should you have any questions about these issues, please contact Malinda Ellwood, [mellwood@law.harvard.edu](mailto:mellwood@law.harvard.edu), or the



HHCAGW Co-Chairs, Robert Greenwald with the Treatment Access Expansion Project ([Rgreewa@law.harvard.edu](mailto:Rgreewa@law.harvard.edu)); Amy Killelea with the National Association of State and Territorial AIDS Directors ([AKillelea@nastad.org](mailto:AKillelea@nastad.org)); or Andrea Weddle with the HIV Medicine Association ([aweddle@idsociety.org](mailto:aweddle@idsociety.org)).

Respectfully submitted by the Steering Committee of the HIV HealthCare Access Working Group, and others,

ActionAIDS | AIDS Action Baltimore | AIDS Action Committee of MA | AIDS Alliance for Women, Infants, Children, Youth & Families | AIDS Foundation of Chicago | The AIDS Institute | AIDS Project Los Angeles | AIDS Treatment Data Network | AIDS United | American Academy of HIV Medicine | Community Access National Network | Communities Advocating Emergency AIDS Relief (CAEAR) Coalition | Gay Men's Health Crisis | Georgia AIDS Coalition | Harlem United | Health and Disability Advocates | HealthHIV | HIVictorious, Inc. | HIV Medicine Association | HIV Prevention Justice Alliance | Housing Works | L.A. Gay & Lesbian Center | Metropolitan Area Neighborhood Nutrition Alliance | Moveable Feast | National Alliance of State and Territorial AIDS Directors | National Minority AIDS Council | The National Working Positive Coalition | Project Inform | San Francisco AIDS Foundation | South Carolina Campaign to End AIDS | Treatment Access Expansion Project | Treatment Action Group | VillageCare.