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Comments on the "Path to Transformation" 1115 Medicaid Waiver before the Illinois House Human Services Appropriations Committee

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Good morning Chairman and members of the committee. My name is David Ernesto Munar and I am the President/CEO of the AIDS Foundation of Chicago (AFC).

AFC's mission is to lead the fight against HIV/AIDS and improve the lives of people affected by the epidemic. Founded in 1985 by community activists and physicians, we are a local and national leader in the fight against HIV/AIDS.

We read with interest the concept paper for the State's 1115 Medicaid waiver application to the federal Centers for Medicare and Medicaid Services (CMS). Illinois is right to pursue a cogent request to CMS seeking program simplification and enhanced flexibility within its Medicaid program. With a thoughtful system redesign, and authority to invest state and federal funds in an array of needed health promotion strategies, the health and wellbeing of low-income Illinoisans can be substantially improved.

We agree with the State's interests in advancing Medicaid transformation vis-à-vis a carefully crafted 1115 waiver application to the federal government. However, we were dismayed that the publically available concept paper fails to address the unique population needs of people with and at risk for HIV disease. We hope this will be more thoroughly examined in the forthcoming draft 1115 application.

Indeed, Illinois's multiple efforts to modernize Illinois's outdated fee-for-service Medicaid system have so far failed to prioritize HIV care and prevention strategies. Without a deliberate plan on HIV identification and culturally competent disease management, Illinois cannot turn the tide on the HIV epidemic.

HIV/AIDS in Illinois

Illinois is home to an estimated 42,500 people living with HIV, and about 1,760 people are newly diagnosed with HIV each year in the state.[1] According to the Illinois Department of Healthcare and Family Services (HFS), Medicaid insured 12,734 HIV-positive people in 2011.[2] AFC estimates that an additional 11,400 people will become newly enrolled in Medicaid in

[1] AFC estimate based on Chung Eui Kim & Fangchao Ma, "Community Viral Load and Social Determinants," Illinois Department of Public Health, presented at Illinois HIV Planning Group Meeting in Collinsville IL on September 14, 2012.

[2] Illinois Department of Healthcare and Family Services, special data request, received 4/30/2013.

Illinois by 2017, thanks to the Affordable Care Act. When fully enrolled, the number of HIV-positive Medicaid beneficiaries will have doubled to over 24,100. Medicaid will cover well over half of all people living with HIV in Illinois.

For public health advocates, HIV disease presents unique opportunities and challenges. Thanks to scientific advances, HIV can now be treated as a chronic health condition, with daily medication regimens to curb viral replication among those infected. While the treatment of HIV is akin to chronic disease management, HIV remains a lifelong incurable and communicable disease. The infectious nature of HIV and its adverse effects on individual and population health warrant intensified public health interventions, including dedicated strategies within the state's Medicaid program.

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Access to HIV treatment has enormous public health benefits and cost savings to public programs. Each HIV case prevented saves a minimum of $380,000 in lifetime treatment costs,[3] which are primarily incurred by government programs, including Medicaid. Every person with HIV who successfully manages HIV clinically has a substantially lower risk of transmitting HIV to others in the community. In fact, new evidence released by the National Institutes of Health (NIH) demonstrates that consistent adherence to HIV medications reduces the chances that HIV will be transmitted by as much as 96%.[4]

Too Few HIV-Positive Illinoisans Benefit from Medical Advances that will Achieve the Triple Aim

Despite medical gains, too few Illinoisans are benefiting from HIV care and prevention to slow the epidemic, and this will hamper the state's ability to achieve CMS's Triple Aim (better individual and population health at the lowest cost possible). Poor outcomes in HIV have been perpetuated by lack of access to public and private insurance and intractable socio-economic challenges, such as stigma, poverty, drug and substance abuse, among others. Unmitigated stigma of HIV also results in too few people accessing the care and prevention they need to avert HIV infection or improve survival.

An estimated 20% (1 in 5) of people with HIV are undiagnosed in Illinois and nationally, meaning they have HIV but do not know it.[5] Facing socio-economic challenges and persistent AIDS stigma, more than half of all people diagnosed with HIV do not receive routine HIV medical care.[6] Far too many people with HIV are diagnosed late in the course of the disease,

[3] *HIV Cost Effectiveness,* U.S. Centers for Disease Control and Prevention, January 5, 2012. Accessed 6/19/13 from www.cdc.gov/hiv/topics/preventionprograms/ce/index.htm.

[4] Cohen, Myron S., et al. *Prevention of HIV-1 Infection with Early Antiretroviral Therapy.* 2011 New England Journal of Medicine 493-505: V365, no 6, http://www.nejm.org/doi/full/10.1056/NEJMoa11052

[5] AFC estimate based on Kim & Mao.

[6] AFC estimate based on Kim & Mao.

requiring medical treatment that is nearly three times more expensive than early treatment ($36,352 per year for someone who has advanced HIV compared to $13,885 per year for someone with HIV who is healthy[7]).

Illinois Medicaid Must Prioritize HIV Care and Prevention in the 1115 Waiver

Unfortunately, without a cogent Medicaid response to the public health challenges presented by HIV, unacceptable outcomes and disparities will persist and could escalate.

Over the past 30 years, the federal government has invested more than $1 billion in a specialized safety net care-delivery system for people with HIV in Illinois. This network, created by the federal Ryan White Care Act—and enhanced by the state—provides culturally competent, high-quality care that integrates medical and social services to meet the unique needs of people with HIV.

As health reform is implemented, federal funding for the Ryan White Program will almost certainly decline. **The state and federal governments face a choice: leverage Medicaid to harness and modernize this proven expert infrastructure or squander the opportunity to maximize this specialty infrastructure and unique qualified workforce to reach those affected by HIV/AIDS**.

We strongly encourage the state to include specific provisions in its 1115 waiver application to maximize opportunities to integrate Medicaid with Ryan White and other grant-enabled services. With the assistance of the Department of Public Health, innovative HIV systems can be promoted to maximize Medicaid and other federal grant investments to achieve the best outcomes in HIV prevention and care.

The AIDS Home and Community Based Care Waiver is a Model of Service Integration

Illinois already has experience bundling and braiding funding streams to create better approaches to HIV care. For example, in the late 1980s, Illinois secured the AIDS Home and Community-Based Waiver program to help dying people with AIDS meet their needs in community-based settings, thereby averting preventable skilled nursing-home care. From the very start of the AIDS waiver over 20 years ago, Illinois has subcontracted with the AIDS Foundation of Chicago to nest waiver services within a service continuum created to efficiently coordinate Ryan White and other discretionary HIV grant funds.

Administration of the AIDS waiver alongside other HIV-related case management services provides clients a seamless continuum of case management, healthcare, and support services. Our system ensures that more than 5,500 clients with HIV are assigned to only one case manager at a time, regardless of the 12 different funding streams that support HIV-related case management in metro Chicago. In addition to creating a more efficient system, we believe this integration improves medical outcomes.

[7] Chen RY, Accortt NA, Westfall AO, et al. Distribution of health care expenditures for HIV-infected patients. *Clin Infect Dis.* 2006;42:1003–1010.

The HIV case management network uses Ryan White funds to provide wrap-around services for clients in the AIDS waiver, ensuring they receive the highest level of care possible. Through this process, AFC centrally coordinates program management with our 40 delegate agencies, creating an efficient system for the network of partner entities and the state. This unique approach to care maximizes scarce resources and ensures clients are able to seamlessly transition to needed services when their health status changes.

The historic investment over the past 30 years to develop a comprehensive HIV/AIDS case management system is a resource that Illinois Medicaid waiver should seek to harness, not dismantle.

Our unique model allows us to have 60 AIDS waiver case managers, housed in 21 community-based organizations in the Chicago area. This model of care allows us to standardize training requirements. We have created a standard training curriculum for all case managers, regardless of funding source. This ensures that if a client wishes to receive services from a different agency or moves to a new neighborhood, he/she will receive the same level of core competencies and services no matter the location. As the state increases use of care coordination for people with disabilities, this raises another question regarding maintenance of the proven HIV/AIDS case management system that has been in place for 20 years.

Unclear Benefits of Waiver Consolidation

The call for consolidation of home and community-based waiver services in the 1115 waiver concept paper raises concerns about the quality of services that will be available to people with HIV. Proposed consolidation should prioritize investments in the historic infrastructure of coordinated networks serving those affected by HIV/AIDS. With specific state regulations or legislation, managed care organizations could be required to leverage community resources and utilize established HIV service metrics to ensure attainment of improved health outcomes for Illinoisans affected by HIV.

The proposed 1115 waiver application is an opportunity for Illinois to fill gaps in the state's service delivery model. While we appreciate the move from volume-based to value-based payment models in Medicaid, without specific HIV quality metrics, a commitment to HIV-related culturally competent care, and specific strategies to deliver on the promise of HIV preventative care and screening services, the HIV epidemic will only continue to grow.

The historic investment over the past 30 years to develop a comprehensive HIV/AIDS service delivery system is a resource in Illinois that the 1115 waiver should seek to harness. The waiver should build on this infrastructure and the state public health department's expertise in HIV care and prevention to devise innovative Medicaid models to serve vulnerable people affected by HIV.

Recommendations for Medicaid Leadership against HIV/AIDS

AFC specifically requests consideration for the following provisions to maximize HIV care and prevention opportunities under the 1115 waiver application:

1. The State must **dedicate capacity building funds to help community-based organizations make the transition to billing for Medicaid**, including services previously not billable, such as prevention services and reimbursement for outreach and linkage to care.

2. The State must **evaluate the current structures established for the AIDS Waiver administration and consider the current opportunities the system affords to easily leverage other grant-funded services for people with HIV/AIDS**. Increased flexibility for HFS in the administration of the AIDS Waiver should enhance and not dismantle this efficient service delivery system.

3. Illinois should prioritize in the 1115 waiver application **provisions to ensure ready access to HIV clinical experts and other service providers with the cultural competency, training and certification to adequately engage and support people with HIV in care adherence.**

4. CMS has highlighted the potential role of state Health Home applications in addressing the unique service needs of people with HIV/AIDS. **Illinois should look to examples from New York, Florida and other states to replicate the development of HIV-specialty Health Home models to improve HIV-related prevention and care outcomes in Illinois.** Doing so could benefit the affected populations – principally African American and Latino men and women and gay and bisexual men of all ages, races and ethnicities – to harness the available service infrastructure developed with Ryan White and CDC prevention funds. Development of HIV-related Health Home models should originate from the Department of Public Health, which has led Illinois HIV responses since the epidemic first emerged in the early 1980s.

5. The 1115 waiver is an opportunity for Illinois to **establish enhanced HIV-related quality measures in managed care settings** and **require Medicaid managed care entities to enlist community-based HIV/AIDS organizations in their service networks and approaches** to ensure vulnerable Illinoisans with HIV benefit fully from Medicaid transformation.

On behalf of the AIDS Foundation of Chicago, thank you for this opportunity to testify on the 1115 waiver submission to CMS. We look forward to future dialogue and engagement that helps the state submit the strongest waiver application possible, and provide meaningful input into its implementation plan.