## Ending the Epidemic Task Force Recommendation Form



#### **COMPLETE**

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#### PAGE 1

Q1: OPTIONAL: This recommendation was submitted by (please provide your first and last name, affiliation, and email address)

First Name Mark
Last Name Misrok

Affiliation National Working Positive Coalition

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Q2: Title of your recommendation

Expand Availability of Certified Benefits Advisement

# Q3: Please provide a description of your proposed recommendation

People living with HIV/AIDS and HIV service providers share inadequate access to accurate, current, comprehensive and individualized information about public benefits to intervene in income instability and inadequate access to health care and treatment, as well as the potential for increasing economic security, independence and community inclusion through employment. Increased availability of certified benefits advisement is needed to increase income, health care, treatment and housing stability for people living with HIV/AIDS (PLWHA), and prevent decrease of income, health care, treatment and housing stability for PLWHA entering/reentering employment.

An initiative to develop a statewide network of certified benefits advisors would address these needs and barriers by: 1) wide-spread, intensive training of service providers; 2) small class instruction and individualized counseling for PLWHA (including web-based benefits advisement for those without transportation, or otherwise unable to access on-location services) 3) establishing a cadre of experts to act as a continuing resource throughout the HIV services network and 4) starting an efficient infrastructure by which these experts can interact and cooperatively co-mentor their knowledge and practice.

Certified benefits specialists can directly assist people living with HIV for well-informed decisions about transitions to work and eligibility for economic and health care stability programs. Service providers lack and need training on benefits programs and policies to support well-informed decision-making of PLWHA and increase engagement and retention in care, initiation and adherence to antiretroviral therapy, and increased viral suppression. Accurate, individualized and accessible information about benefits program eligibility and work incentive programs is needed for PLWHA to make well-informed decisions about transitions to work, eligibility for income replacement, health insurance, medication access, subsidized housing, and other health and economic stability programs.

The belief that becoming employed will cause an individual to forfeit benefits is widespread among individuals, families and providers. The complexity of the system and the lack of accurate, current training about benefits and entitlements and their relationship to employment intensify this misunderstanding. Contributing to this barrier is the widespread lack of knowledge and the difficulty of providers maintaining current information for individuals to turn to regarding this in-depth area. Current training offers limited information on benefits counseling. The complexity of this issue also makes it difficult to maintain expertise without regular practice. There is inadequate availability of benefits advisors mandated to serve all disability communities across the

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state, and they are not equipped with comprehensive, current information about HIV care, treatment, services and programs, or trained to deliver culturally competent services to effectively engage and serve many communities disproportionately impacted by HIV infection and health disparities.

Research data shows that high percentages of PLWHA experience job loss following diagnosis, and also that the longer individuals are out of the workforce, the less likelihood that they successfully enter/reenter employment Current participants in Social Security Administration disability programs (SSI, SSDI, Ticket to Work) who consider employment are confronted with complex, hard to understand transition-to-work policies and work incentive programs. Few HIV supportive services practitioners are knowledgeable about these policies and programs, or able to provide individualized accurate benefits advisement.

Fear of losing benefits and inability to consider employment with an understanding of expectable stability or changes in benefits contributes powerfully to high rates of unemployment among PLWHA. Others implement transitions to work without the benefit of knowing if or what changes to critical resources may happen, risking negative and unexpected changes to their economic stability, access to health care and medications, and other supports.

Few agencies currently have on staff certified benefits specialists, with inadequate staffing in relationship to client population and needs. Availability of these specialists in the broader services community is largely limited to SSA's Work Incentive Planning and Assistance (WIPA) program, with inadequate number and accessibility of these providers, funded to serve all individuals with disabilities.

HIV service providers who are under-informed about benefits programs, work incentives and transition-to-work policies will be less likely to encourage or will actively discourage consideration of employment and transitions to work by PLWHA. Individuals living with HIV participating in financial, health care or housing support programs will avoid change related to employment status when accurate, individualized information is unavailable or inaccessible for their decisions about working.

Those proceeding into employment without planning these transitions risk falling out of care, losing access to medications and being assessed overpayments of SSI/SSDI. Those avoiding employment due to inadequate or inaccurate information lose opportunities to improve their benefits and economic status, as well as vocational development.

"The fear of losing Medicaid and/or Medicare is one of the greatest barriers keeping individuals with disabilities from maximizing their employment, earnings potential, and independence. For many Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries, the risk of losing health care through work activity can be a greater work disincentive than the risk of losing cash benefits through work activity." (Cornell 2010).

Q4: For which goal outlined in the Governor's plan to end the epidemic in New York State does this recommendation apply? (Select all that apply)

Linking and retaining persons diagnosed with HIV to health care and getting them on anti-HIV therapy to maximize HIV virus suppression so they remain healthy and prevent further transmission Q5: This recommendation should be considered by the following Ending the Epidemic Task Force Committee (Select all that apply) Care Committee: Develop recommendations to support access to care and treatment in order to maximize the rate of HIV viral suppression. The Committee will promote linkages and retention in care to achieve viral suppression and promote the highest quality of life while significantly decreasing the risks of HIV transmission. Recommendations will also ensure a person centered approach is taken and that access to culturally and linguistically appropriate prevention and health care services is available.

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Housing and Supportive Services Committee:
Develop recommendations that strengthen
proven interventions enabling optimal
engagement and linkage and retention in care for
those most in need. This Committee will
recommend interventions that effectively address
complex and intersecting health and social
conditions and reduce health disparities,
particularly among New York's low-income and
most vulnerable and marginalized residents.
These interventions will diminish barriers to care
and enhance access to care and treatment
leaving no subpopulation behind.

Q6: Does this recommendation require a change to an existing policy or program, or the creation of a new policy or program?

New program

Q7: Would implementation of this recommendation be permitted under current laws or would a statutory change be required?

Permitted under current law

Q8: Is this recommendation something that could feasibly be implemented in the short-term (within the next year) or long-term (within the next three to six years)?

Within the next year

#### Q9: What are the perceived benefits of implementing this recommendation?

It is critical that both providers and people living with HIV/AIDS understand the interplay of work earnings on benefits and entitlements, and the ability of SSI/SSDI, Medicaid/Medicare and HOPWA/Section 8 and SHP participants to work while retaining access to health insurance coverage. The proposed program will generate "benefits practitioners" with comprehensive and in-depth understanding of benefits and Medicaid/Medicare programs, and mentor them to stay current with this specialized knowledge. Employed individuals will become taxpayers and contribute to the economy. They will have the opportunity to experience the positive impact of employment on self-worth and self-esteem. The program will allow unemployed/underemployed persons living with HIV increased and more meaningful assimilation into their communities, reducing dependence on public programs and resources.

Q10: Are there any concerns with implementing this recommendation that should be considered?

Respondent skipped this question

# Ending the Epidemic Task Force Recommendation Form

Q11: What is the estimated cost of implementing this recommendation and how was this estimate calculated?	Respondent skipped this question
Q12: What is the estimated return on investment (ROI) for this recommendation and how was the ROI calculated?	Respondent skipped this question
Q13: Who are the key individuals/stakeholders who we People living with HIV/AIDS HIV Service Providers	ould benefit from this recommendation?
People living with HIV/AIDS	Respondent skipped this question