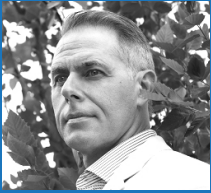




# Employing Consumer Workers

A Vital Strategy  
to End the HIV/AIDS Epidemic  
in New York State



# Message from Amida Care President and CEO Doug Wirth

**THE LATE, GREAT TONI MORRISON ONCE SAID,** “If you are free, you need to free somebody else. If you have some power, then your job is to empower somebody else.”

That is a poetic way of describing where we are in our fight to end HIV/AIDS.

In the darkest, early days of AIDS during the 1980s, an HIV diagnosis was a death sentence. Today, we’re in a very different landscape. With adherence to treatment, people living with HIV can achieve and maintain viral suppression—levels of HIV low enough to be “undetectable.” At those levels, HIV cannot be transmitted to others: undetectable equals untransmittable (U=U). Just as important, U=U status means that people living with HIV can stay healthy and live full, productive lives.

Nowhere is this seismic progress more evident than New York. Once the nation’s epicenter for HIV/AIDS, New York State is now poised to become the first state in the nation to end HIV as an epidemic by the end of 2020. New diagnosis rates continue to decline sharply. In 2018, the number of new diagnoses in New York State was down to 2,471, compared to 3,081 in 2015, the year Governor Andrew Cuomo’s Ending the Epidemic Blueprint was released.<sup>1</sup> In New York City, new diagnoses fell below 2,000 for the first time since annual HIV reporting began in 2001.<sup>2</sup>

Supporting the employment of people living with HIV at living-wage jobs is a critical component of ending the HIV epidemic. The health of many New Yorkers living with HIV has improved so dramatically, they are now physically able and mentally motivated to contribute to the workforce and their own livelihood by working again. As the details in this report demonstrate, “peer” or consumer workers—individuals with lived HIV experience—are uniquely qualified to provide support services to people with similar complex conditions. This not only gives people living with HIV an

opportunity to work, it also helps empower others living with HIV to take control of their health.

Investment in consumer (or peer) workforce development is a win-win proposition for everyone: the consumer workers, the people living with HIV and other complex conditions whom they serve and support, and New York State government agencies and taxpayers. That investment prepares people living with HIV for work and helps them find and keep living-wage jobs that enable them to remain healthy and fulfilled. Likewise, it improves engagement in care, because it means that people are getting support from workers who understand firsthand what they are going through. Finally, as the analyses that follow indicate, consumer workforce development will also ultimately reduce the cost of public assistance for New York taxpayers.

Amida Care health outreach worker and Brooklyn grandmother JoAnn is a prime example of how consumer work can give people living with HIV a renewed sense of purpose. In 2013, when an Amida Care staff member knocked on her door, JoAnn had been living with HIV for 15 years and was battling depression, homelessness, and substance use; that home visit helped her on her journey to recovery. Today, JoAnn has been sober for seven years and her HIV is undetectable. After completing Amida Care’s Workforce Initiative Network (WIN) job training program, JoAnn started knocking on doors herself as a Community Health Outreach Worker, connecting with members who had been lost to care. JoAnn sums up the arc of her journey best: “When I first started, I felt I couldn’t do this. At 56, I thought I was too dusty. But the counselor told me not to give up, and gave me the confidence I needed. I believe we all have a purpose for being here.”

To end the HIV epidemic, we need more stories like JoAnn’s. The rest of this report outlines details and recommendations for how we can get there, together.

## ★ Executive Summary

### ★ WORKING EQUALS WELLNESS FOR PEOPLE LIVING WITH HIV

Research shows that working addresses holistic needs and results in better health outcomes for people living with HIV.<sup>2</sup> People with lived HIV experience who are hired for and maintain living-wage jobs experience benefits and improvements across the continuum of physical, mental, emotional, and spiritual health.

### ★ WORKFORCE DEVELOPMENT PROGRAMS ARE A NECESSARY INVESTMENT

Effective employment programs for New Yorkers living with HIV prepare them for work and help them find and keep living-wage jobs that enable them to remain healthy and fulfilled. Investment in a trained peer workforce in the communities most affected by HIV improves engagement in care.<sup>4</sup>

### ★ A MODEL FOR EFFECTIVE CONSUMER (PEER) WORKFORCE PROGRAMS

Since 2003, Amida Care has hired over 500 of its members by developing and investing in two major consumer workforce programs: Workforce Initiative Network (WIN) and HIV Innovator Employment Project. Referred to as “consumers” of health care, individuals with lived HIV experience who seek employment are in a unique position to use their valuable experience and develop their skills to provide support services to people with similar complex conditions.

### ★ BARRIERS TO WORK FOR NEW YORKERS LIVING WITH HIV

Low-income New Yorkers with HIV are currently faced with choosing between working and being on public assistance, neither of which is financially viable on its own given the costs of living in NYC.

In addition, some employers are reluctant to hire low-income New Yorkers living with HIV because they may represent a larger and longer investment of time and other finite organizational resources.

### ★ HOW TO ADDRESS BARRIERS TO WORK

Enable low-income New Yorkers with HIV to maintain eligibility for public assistance support while working. This can be achieved by changing and updating outdated statutory and regulatory limits on New York State Office of Temporary and Disability Assistance (OTDA) Earned Income Disregard (EID).

Train state and non-governmental employees about cultural competency regarding gender identity and expression, to help prevent employment discrimination against members of the LGBTQ community, including transgender and gender non-conforming individuals.

### ★ CONSUMER EMPLOYMENT PROGRAMS WORK FOR PROVIDERS AND GOVERNMENT

Consumer employment decreases avoidable care and associated costs across the board. Amida Care estimates \$115 million in combined HIV/AIDS Services Administration (HASA) and Medicaid savings if HASA clients are supported in their efforts to return to work.<sup>5</sup>



## Why Working Means Wellness

### **STAYING HEALTHY WHILE LIVING WITH**

**HIV** is about more than doctor visits and taking pills. Resolving the ripple effects of social determinants of health (SDOH)—which drive up to 80% of health outcomes—is as essential to ending the HIV/AIDS epidemic as leveraging effective medical interventions.<sup>6</sup> In this way, HIV remains a social justice issue. Even with all the medical progress that makes it possible to treat and prevent HIV, it persists in communities struggling with socioeconomic disparities—the effects of poverty, homelessness and housing instability, unemployment and under-employment, food insecurity, and lack of access to affordable, culturally competent, and inclusive health care. The real work ahead is in addressing these SDOH drivers.

### **Chief among those drivers is access to empowering work that provides a living wage.**

Just as having a roof over one's head each night through access to affordable housing drives better HIV health outcomes, adequate employment and job stability promote treatment, adherence, and viral suppression. Data shows that the benefits of employment enable strong health outcomes: Research indicates that employed HIV-positive respondents have 27% higher odds of optimal adherence to anti-retroviral medication compared to those not employed.<sup>7</sup> People living with HIV (PLWH) who receive treatment to get and stay virally suppressed maintain their viral load at an undetectable level and therefore cannot transmit HIV to others through sex: Undetectable = Untransmittable.<sup>8</sup>

**Because employment addresses holistic needs, PLWH who obtain and maintain living-wage jobs experience benefits and improvements across the continuum of physical, mental, emotional, and spiritual health, including:**

- increased maintenance of physical health and self-care (e.g., monitoring of overall health, keeping medical appointments, and taking medications consistently) and greater incentive to remain healthy;
- supports for combatting addiction and substance use disorders, as well as depression and other behavioral conditions;
- increased economic independence and security and greater capacity to address other socioeconomic issues, like stable housing; and
- increased feelings of productivity, gratification, engagement, and community connection.<sup>9</sup>

For this reason, the Blueprint to End the AIDS Epidemic (ETE) in New York State by 2020,<sup>10</sup> launched by Governor Andrew Cuomo in 2015, singles out employment as a critical factor to maintaining health and provides extensive recommendations on how job creation can help minimize new HIV infections. Only by addressing the holistic needs of PLWH will we be successful in ending the epidemic once and for all.

# What Works?



**SUPPORTING EMPLOYMENT PROGRAMS FOR PLWH** helps them find and keep the living-wage jobs that enable them to remain healthy and feel fulfilled. Now more than ever, PLWH are able to access the medical care they need. Tools and programs that enable PLWH to achieve a consistent means of sufficient financial support for themselves are vital to achieving optimal health.

Workers from the communities most affected by HIV are especially effective at outreach and engagement.

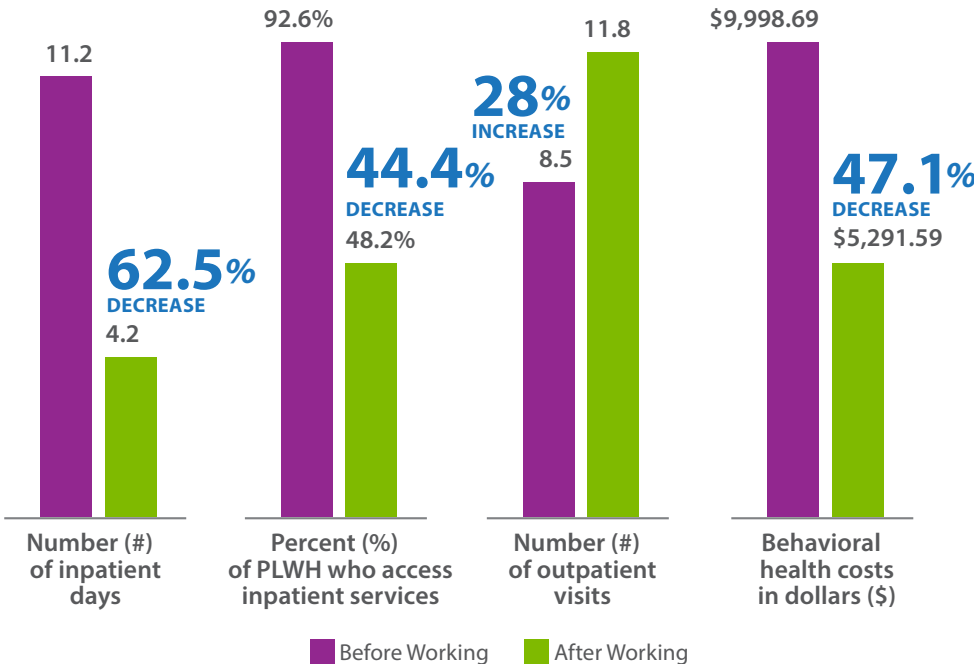
Working results in significant health care cost savings. Consumer employment decreases avoidable care and associated costs across the board.

“We’ve heard from community members about what we need to do. Having staff that reflects the population being served is a good start.... Investing in developing a workforce of folks who are from impacted communities is really important so that people can walk into a CBO or a clinic and feel like they belong there.”

– Dr. Oni Blackstock, Assistant Commissioner for the Bureau of HIV/AIDS Prevention and Control, NYC Department of Health and Mental Hygiene

## EMPLOYMENT & AVOIDABLE CARE

Researchers have found the following improvements correlate to employment:<sup>11</sup>



# Amida Care's Leadership in Workforce Development

**SINCE 2003, AMIDA CARE HAS HIRED OVER 500** of its plan members as outreach workers by developing and investing in two major consumer workforce programs: Workforce Initiative Network (WIN) and the HIV Innovator Employment Project.

## Workforce Initiative Network (WIN) Overview

**WHAT:** Since its 2014 launch, WIN has equipped Amida Care members with **marketable job skills through completion of a multi-week training program** at one of two CBOs, Housing Works and the Alliance for Positive Change.

**WHY:** WIN was a **direct result of our members' interest in working.** Amida Care's Member Advisory Council (MAC) proposed "more employment opportunities" as a priority. Once members in treatment become virally suppressed and healthy, they want opportunities to work and be productive.

**HOW:** Skills covered in the WIN program include **job skills training, life skills development, and wellness and workforce preparation.** Members receive vocational training and employment at Amida Care and other CBOs.



**"As a peer worker, my experience living with HIV is an asset not only to the clients I interact with but also to my employer. There is nothing more valuable than speaking with individuals on a person-to-person level and helping connect them to health care."**

- Deborah Stanton, Amida Care member and HIV Innovator Employment Project participant

### PROGRAM SUCCESSES SINCE 2014

**90** Amida Care members have graduated from WIN.

**38** have received job placement at Amida Care and other CBOs.

**GRADUATES HAVE FOUND EMPLOYMENT** as health navigators, outreach workers, or administrative assistants.

## HIV Innovator Employment Project Overview

**WHAT:** Amida Care's HIV Innovator Employment Project supports job training and placement at community health care providers for individuals living with HIV.

**WHY:** HIV Innovator Employment Project goals are to **prepare and empower health care consumers as workers** and to show that community providers benefit when they employ PLWH.

**HOW:** Made possible with **funding from the New York City Council** since 2016, the Project provides participants with the **training, technical skills, and work experience** needed to obtain

New York State Peer Certification and gain and keep living-wage jobs. The project's transition-oriented funding structure shows health care providers that **hiring consumer workers is sustainable:**

- Participating providers receive 50% of the total annual costs of employing and retaining consumer workers for Year 1 of employment, and 25% in Year 2.
- As of Year 3, workers' positions are fully funded by the provider sites through the increased revenue derived from clients re-engaged in care.



**“The HIV Innovator Employment Project is allowing me to develop my skills while helping others. I have a job I am passionate about, where I can use my own life experience of living with HIV for over 35 years to help others get the care they need. I wish I was linked to a peer when I first received my HIV-positive diagnosis.”**

– Kerry Jackson, Morris Heights Health Center employee and HIV Innovator Employment Project participant

### PROGRAM SUCCESSES SINCE 2016

**35** Medicaid beneficiaries have been employed as a result of the program.

**20** have accepted permanent employment.

**6 FQHCs** (Federally Qualified Health Centers) and **1 CBO** have participated in the program.<sup>12</sup>

**12 CONSUMER WORKERS** in the last fiscal year's program cohort helped improve care for **771 UNIQUE CLIENTS** between Nov. 2018 and Sept. 2019.<sup>13</sup>

Since the project began, it is estimated that **providers have received a total of \$393,000** in New York City Council funding to employ consumer workers.

# Barriers to Working for People Living With HIV

**LOW-INCOME PLWH STILL HAVE DIFFICULTY** attaining viable employment that provides a living wage. New York State Social Services Law and policies of the New York State Office of Temporary and Disability Assistance (OTDA) limit eligibility for public assistance based on income and assets. Unfortunately, eligibility requirements are not structured to help recipients move off of public assistance. The current structure discourages recipients from earning income or accumulating savings, and they are essentially trapped because they cannot earn enough to support themselves.

For example, a single PLWH in New York City can receive housing and other public assistance through the HIV/AIDS Services Administration (HASA), a program overseen by the NYC Human Resources Administration (HRA).<sup>14</sup> To qualify, they must meet the state's guidelines for Cash Assistance, which includes having less than \$2,000 in resources.<sup>15</sup> When HASA clients without dependent children start working again, even at very low levels of earned income—levels inadequate for financial self-sufficiency in NYC—they quickly earn too much to retain cash assistance for rent and other supports.

Most HASA clients need significant training and other workforce development and transition supports to re-enter the workforce, and the corresponding pay for those re-entry jobs is often too low to cover their living expenses without any public assistance. This results in barriers to employment:

- Potential employers tend to be reluctant to hire HASA clients because they represent a larger and longer investment of time and other finite organizational resources.
- Many HASA clients are hesitant to risk losing HASA housing assistance and other benefits by obtaining employment. As of September 2017, out of 33,390 cases comprising 44,240 people served by HASA, only 1,936 people reported any earned income (5.7% of all clients), while 26,125 cases received Safety Net Assistance (78.2% of all cases).<sup>16</sup>

## EMPLOYMENT DISCRIMINATION TOWARD TRANSGENDER INDIVIDUALS



**Poverty, unemployment, and employment discrimination remain prevalent for transgender New Yorkers.**

- **Transgender communities remain disproportionately affected by HIV as a major health issue.** A recent finding showed that transgender women are 49 times more likely to be living with HIV compared with the global general population.
- **According to the 2015 U.S. Transgender Survey, in New York State, 34% of trans respondents reported living in poverty, and 18% were unemployed.** Additionally, 30% of trans respondents who had jobs experienced mistreatment, including being fired and denied promotion due to being transgender.<sup>17</sup>

**“People see me as an example. They know what I went through and how well I’m doing today. That helps encourage them to get services and prevent the spread of HIV.”**

– Nicole Teyuca, Translatinx Network employee and HIV Innovator Employment Project participant

## ADDRESSING EMPLOYMENT BARRIERS

**Transgender and gender non-conforming (TGNC) individuals are now guaranteed protections against discrimination in employment under New York State law.**<sup>18</sup>

**Amida Care is committed to innovations that advance access to the full continuum of care and services for transgender individuals.** We’re proud to help our more than 1,200 transgender members—who comprise 15% of our total membership—access respectful, culturally competent care and support for housing, employment, and legal issues.



# Creating Employment Opportunities

**THROUGH THE WIN PROGRAM, AMIDA CARE AND ITS PARTNERS** help plan members living with HIV find and keep living-wage employment, drawing on their lived experience to help others in similar circumstances.

**Since 2016, NYC Council Ending the Epidemic (ETE) funding for Amida Care’s HIV Innovator Employment Project has helped support 35 consumer workers at 6 community health care centers and 1 CBO. To date, 20 of them have accepted permanent employment.**

**Amida Care is working with NYS OTDA and NYC HRA to change and update regulatory limits on OTDA’s Earned Income Disregard (EID):<sup>19</sup>**

- Under the project, HASA will have authority to omit or “disregard” over 50% of a client’s income when calculating eligibility for housing and other supports.
- To aid transition to work for low-income PLWH, the demonstration project extends income disregard for a period of five years instead of the current limit of one year.
- The project will allow more HASA clients to return to work and earn a living-wage without losing their housing support, which is critical to positive health outcomes and ability to succeed in the workplace.
- The changes will also realize savings by flexibly supporting PLWH as they move from public assistance to greater financial independence and self-support.
- Amida Care has asked OTDA to grant state approval to expand and evaluate an existing HRA HASA-administered income disregard program as a demonstration project.

**“Being perinatally diagnosed as HIV-positive, adopted, and transgender, I could not find acceptance around me. Today I can say that I am a better person because of this program, and I can pursue my life’s mission to help others until they’re able to help themselves.”**

– Monique Mackey, WIN program graduate and Amida Care Community Health Outreach Worker

## Recommendations Addressing Barriers to Work for New Yorkers with HIV

**STAKEHOLDERS ACROSS CITY AND STATE GOVERNMENT**, health care providers, CBOs, and employers need to work together to provide flexible support that increases opportunities for PLWH. Enabling PLWHs’ transition to living-wage employment and self-support is crucial to ensuring their financial, physical, and emotional well-being and independence, which will in turn reduce the cost of public assistance for New York taxpayers:<sup>20</sup>

- Providing more flexibility to PLWH as they move from public assistance to greater financial independence and self-support can realize cost savings for New York City and New York State. Amida Care conservatively

estimated the impact if just **1,450 HASA clients were successful in their efforts to transition out of public assistance. In the first year, New York City would save over \$26 million from HASA housing assistance. New York State would save up to \$97 million (\$89 million from Medicaid, and \$8 million from HASA housing assistance).**

**Stakeholders must collaborate to increase access of PLWH to living-wage employment that provides opportunities for advancement, competitive wages and benefits, and environments free of discrimination and harassment.**

### YEAR ONE SAVINGS

**1,450 HASA Clients** Transitioning Out of Public Assistance:

**NEW YORK CITY** **\$26 MILLION**  
HASA housing assistance

**NEW YORK STATE** **\$97 MILLION**  
\$89 million from Medicaid + \$8 million from HASA housing assistance

**Stakeholders can work to implement statutory changes to OTDA's EID**, such that PLWH who receive public assistance and are working are allowed to keep more of their earnings as savings:

- **The current \$2,000 limit on resources (money in the bank, IRAs, CDs, etc.) PLWH can have when receiving public assistance must be increased.**

<sup>21</sup> That increased savings will serve as a financial cushion, facilitating the transition from public assistance to self-sufficiency (e.g., enough to pay a deposit on apartment rent).

- OTDA's EID program parameters need to be updated in NYS Social Services law to allow more income to be disregarded on a sliding scale. The EID currently exempts only 53% of the earned income of a family with dependent children.

**Stakeholders must work to implement administrative changes to OTDA's EID to extend the one-year time limit for HASA clients.**

This change will enable HASA clients to transition from reliance on public assistance to self-sufficiency in a realistic timeframe.

- HASA's existing Work Opportunity Program enables single and multiple adult cases to qualify for the EID, but only for one year in the client's lifetime. Amida Care is working with OTDA and HRA to implement and evaluate a five-year demonstration project. During this timeframe, all HASA clients who are working would be eligible for the EID program without a lifetime limit.<sup>22</sup>

**To improve health outcomes, stakeholders need to break down the barriers that keep health care out of reach for many in the transgender community, including violence, lack of employment opportunities, housing instability, and discrimination. Health care providers must work to create transgender-inclusive environments for patients and employees.**<sup>23</sup>



## Conclusion

Increased investment in workforce development is not only the right thing to do for the health of New Yorkers living with HIV—it will also be a game-changer for state and city budgets.

Amida Care anticipates that providing more flexibility to PLWH as they move from public assistance to greater financial independence and self-support would generate at least \$115 million in combined New York City and New York State savings.<sup>24</sup>

In pursuing these innovations, New York City and State have a unique opportunity to serve as the visionary leader in workforce development for PLWH that the global HIV movement has long awaited. With New York's 2020 goal of ending the HIV/AIDS epidemic now in our sights, it is time for New York to make that dream a reality by facilitating and supporting transition to work for low-income PLWH.

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