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# PAID LEAVE IS CRITICAL FOR PEOPLE LIVING WITH HIV

“ As a person living with HIV, I am always reflecting on my health care needs and the long-term viral suppression of my HIV. Having paid leave gives me a feeling of economic security. It's reassuring to know that if I got sick, I would still be able to help support myself and my family. ”

– **Venton H.**, living with HIV since 2007

## OVERVIEW

Under the Family and Medical Leave Act (FMLA), many people living with HIV (PLWH) in the U.S. are currently eligible to receive up to 12 weeks of unpaid, job-protected leave to manage their health and medical conditions, including their HIV-positive status.<sup>1</sup>

However, not all PLWH are in a position to take advantage of this important workplace protection. Some PLWH do not work in jobs that qualify for the rights conferred by FMLA, which does not cover workers of businesses with fewer than 50 employees nor part-time employees.<sup>2</sup> Even if they do qualify, many PLWH, particularly those who are LGBTQ people of color, simply cannot afford to take off the time needed to see a doctor, adjust to a new medication, or grapple with a recent co-infection.<sup>3</sup> With lifetime treatment costs of HIV now exceeding \$350,000 in the U.S.,<sup>4</sup> the enactment of inclusive paid leave policies would benefit PLWH and their caregivers in real and meaningful ways.

## PAID LEAVE CAN PROVIDE A VITAL HEALTH SAFETY NET FOR PLWH

Even if they are eligible to claim unpaid FMLA leave, many PLWH simply cannot afford to take time off from work without pay to manage their health. PLWH disproportionately live at or below the federal poverty level, including:

# 67%

of PLWH residing in Los Angeles County, Calif., who receive HIV care and treatment funded by the federal Ryan White HIV/Aids Program, which provides support services for PLWH who are uninsured or underinsured. This figure also includes **84** percent of transgender PLWH.<sup>5</sup>

# 50%

of PLWH residing in the District of Columbia Eligible Metropolitan Area receiving Ryan White-funded services, including **56** percent of such individuals who are Washington, D.C., residents.<sup>6</sup>

<sup>1</sup> Employment and Living with HIV/AIDS: A Resource Guide. <https://www.dol.gov/odep/topics/hivaids/EmploymentLivingwithHIVAIDS.pdf>

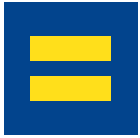
<sup>2</sup> United States Department of Labor: FMLA (Family and Medical Leave). <https://www.dol.gov/general/topic/benefits-leave/fmla>

<sup>3</sup> Ibid.

<sup>4</sup> HIV Cost-Effectiveness. <https://www.cdc.gov/hiv/programresources/guidance/costeffectiveness/index.html>

<sup>5</sup> Los Angeles County Comprehensive HIV Plan (2017-2021). <http://publichealth.lacounty.gov/dhsp/Reports/Publications/LAC-Comprehensive-HIV-Plan2017-2021.pdf>

<sup>6</sup> 2017-2021 District of Columbia Eligible Metropolitan Area Integrated HIV/AIDS Prevention and Care Plan. [https://doh.dc.gov/sites/default/files/dc/sites/doh/service\\_content/attachments/DC%20DOH%20INTEGRATED%20PLAN\\_FINAL.pdf.pdf](https://doh.dc.gov/sites/default/files/dc/sites/doh/service_content/attachments/DC%20DOH%20INTEGRATED%20PLAN_FINAL.pdf.pdf)



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## CURRENT REALITIES OF PLWH

According to the Centers for Disease Control and Prevention (CDC), there are approximately 1.1 million Americans currently living with HIV, and more than 40,000 people are newly diagnosed every year.<sup>7</sup> While HIV and AIDS continue to affect Americans from all walks of life, certain members of the LGBTQ community remain disproportionately affected. For example, even though gay and bisexual men comprise approximately 2 percent of the nation's total population, they make up 70 percent of all new HIV infections.<sup>8</sup> The disparity only worsens when viewed by race; if current trends continue uninterrupted, 50 percent of all Black gay and bisexual men living in the U.S. will contract HIV in their lifetime (as compared to 25 percent of Latinos and nine percent of Whites).<sup>9</sup> HIV is also especially prevalent among transgender women in the U.S., who report living with HIV at rates far higher than their non-transgender counterparts.<sup>10</sup> Given over-representation of LGBTQ people among PLWH, it is clear that no conversation about paid leave for PLWH can be had without discussing the needs and concerns of LGBTQ people in general and LGBTQ people of color in particular.



Paid leave is important for people living with HIV like me, as it provides an added sense of security should the worst happen and one develop HIV and/or an HIV-related illness. Over the course of the epidemic, people living with HIV have struggled to be healthy enough to remain in the workforce. Paid leave policies help us address that problem.

– **Alex G.**, living with HIV since 1996



## BENEFITING THOSE NEWLY DIAGNOSED WITH HIV

While almost all PLWH stand to benefit from the adoption of LGBTQ-inclusive paid leave policies, the newly diagnosed are among those who stand to gain the most. According to the World Health Organization, those newly diagnosed with HIV should start treatment immediately in order to stop the virus from weakening the immune system further.<sup>11</sup> Early treatment allows PLWH to quickly get the virus under control, maintain good health, and prevent sexual transmission of HIV to a partner. Unfortunately,

getting connected to care can often take several days or even weeks. Reasons for the delay range from fear of rejection because of HIV-related stigma to a lack of available health care providers in the area. In any case, time off from work can mean lost wages, which only adds to the stress and anxiety facing those newly diagnosed with HIV. Paid leave policies would reduce the economic and emotional costs of pursuing care. This assistance is especially crucial for those newly diagnosed with HIV, since PLWH are at the greatest risk of passing the virus onto others in the period following seroconversion, which generally occurs within weeks of initial infection.<sup>12</sup>



<sup>7</sup> HIV in the United States. <https://www.cdc.gov/hiv/statistics/overview/ataglance.html>

<sup>8</sup> HIV among Gay and Bisexual Men. <https://www.cdc.gov/hiv/group/msm/index.html>

<sup>9</sup> Ibid.

<sup>10</sup> 2015 U.S. Trans Survey. <http://www.transequality.org/sites/default/files/docs/usts/USTS%20Full%20Report%20-%20FINAL%201.6.17.pdf>

<sup>11</sup> World Health Organization to recommend early treatment for everyone with HIV. <https://www.nature.com/news/world-health-organization-to-recommend-early-treatment-for-everyone-with-hiv-1.18017>

<sup>12</sup> The Stages of HIV Infection. <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/19/46/the-stages-of-hiv-infection>



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## BENEFITING THOSE CHANGING TREATMENT REGIMENS

Although HIV medications today are simple, safer and more effective than ever before, side effects can still occur, especially when beginning a new HIV treatment regimen.<sup>13</sup> Some of the most common side effects of HIV treatment medications include fatigue, nausea, diarrhea, muscle pain and dizziness.<sup>14</sup> Since many of the aforementioned side effects can last several weeks while the body adjusts, paid leave policies are an important way to enable PLWH to focus on their immediate health care needs without sacrificing their economic security.

## BENEFITING CAREGIVERS OF PLWH

Caregivers of PLWH routinely express similar concerns about the need for unpaid leave. The issue is especially salient for caregivers of older PLWH. According to the CDC, “people aged 50 and over account for an estimated 45 percent of Americans diagnosed with HIV.”<sup>15</sup> The CDC notes further that aging with HIV “presents special challenges for preventing other diseases because both age and HIV increase risk for cardiovascular disease, bone loss and certain cancers.”<sup>16</sup> Providing caregivers of PLWH with paid leave would make it easier for them to take care of their families – a worthy goal, according to the American Association of Retired Persons, since “people who have family caregivers tend to have shorter hospital stays, while the absence of a family caregiver has been linked to hospital readmissions.”<sup>17</sup>

## CONCLUSION

The enactment of LGBTQ-inclusive paid leave policies would benefit PLWH and their caregivers in real and meaningful ways. They would help provide a level of economic stability for people living with HIV – an easily treatable but still serious and costly medical condition – and it would enable those who care for PLWH to aid in their recovery without sacrificing their workplace security.

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<sup>13</sup> How to Manage Side Effects of HIV Treatment. <https://www.everydayhealth.com/hs/hiv-health/manage-hiv-treatment-side-effects/>

<sup>14</sup> Ibid.

<sup>15</sup> HIV Among People Aged 50 and Over. <https://www.cdc.gov/hiv/group/age/olderamericans/index.html>

<sup>16</sup> Ibid.

<sup>17</sup> Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update. [https://assets.aarp.org/rgcenter/il/i13\\_caregiving.pdf](https://assets.aarp.org/rgcenter/il/i13_caregiving.pdf)