

HRSA SPNS Improving Care and Treatment Coordination for Black Women with HIV:

An epidemic through the pandemic- Strategies to support women in Black communities during the COVID-19 pandemic

OVERVIEW

In 2020, the Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program Part F: Special Projects of National Significance (SPNS) funded the Initiative Improving Care and Treatment Coordination: Focus on Black women <https://targethiv.org/BlackWomen> . The launching of this initiative coincided with the onset of the COVID-19 pandemic, requiring demonstration sites to rethink and adapt their delivery of care to tackle the health inequities resulting from both pandemics. This article details innovative strategies adapted by the 12 demonstration sites delivering bundled interventions for improving health outcomes for Black women with HIV during the COVID- 19 pandemic.

Key Takeaways

- COVID-19 aggravated the many burdens faced by Black women with HIV.
- There is a need to invest and develop effective resources and interventions tailored to the needs of Black women to address both the HIV epidemic and COVID-19 pandemic.
- Ryan White grantees play a crucial role in providing services to the hard-to-reach population of Black women facing stigma, violence, multiple hardships, and co-existing health disparities thereby improving their access to quality care even in the post pandemic phase.

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Challenges

“These are the same issues that was around before COVID it just got worse”

- Housing instability and food insecurity are exacerbated due to job loss from the pandemic.
- In person health and social services are closed or reduced.
- Many women lost access to care and treatment and did not have access to appropriate technology (e.g., computer, smart phone, or Wi-Fi) to attend routine medical visits.
- Some women do not have private space in their homes to access telehealth services confidentially.
- Women are hesitant to attend in person medical visits due to lack of childcare, fear of exposing other family members to the virus while being in public or using public transportation.
- COVID -19 triggered memories of an early HIV epidemic for some women who experienced discrimination and poor treatment.
- COVID vaccine hesitancy stems from historical medical mistrust within Black communities and misinformation around vaccines including risk of infertility among women.

Impact of HIV and COVID-19 on Black women in the United States

Despite advances in HIV prevention and treatment, the HIV/AIDS epidemic disproportionately affects racial and ethnic minority groups in the United States. Black/African American women, in particular bear a heavy HIV/AIDS disease burden, accounting for more than half (58%) of new HIV infections compared to their White (21%) and Latinx (17%) peers, and experience greater overall disease prevalence and higher HIV-related mortality.[1] HIV is the 7th leading cause of death for Black women compared to 18th for their White counterparts. [1]. Among transgender women diagnosed with HIV, 44% identify as Black/African American compared to 25% Latinx and 7% White. [2] The rates of HIV diagnoses among Black/African American people are high across all geographic regions with highest rates in the South (24.6 per 100,000) and Northeast (23.5 per 100,000). [1] Given these inequities in HIV burden, the HIV National Strategic Plan 2021-2025 prioritizes efforts to reach and engage Black cis and transgender women to improve HIV health outcomes. [3]

The onset of the COVID-19 pandemic further elevated these inequities. Similar to HIV, COVID-19 disproportionately impacts communities of color due to the interplay of several factors related to social determinants of health, including structural racism.[4] For Black women, specifically those with chronic health conditions like HIV and who live in housing situations, such as multigenerational families or low-income and public housing there is increased risk for becoming infected with COVID-19 due to limited possibilities for physical distancing.[5] These women also face economic burdens while balancing multiple responsibilities including childcare, caring for parents or elders, active community roles and financial responsibilities that may increase their risk of poor health outcomes [6]

Black women, similar to women of all racial groups in the U.S., may also have experienced isolation, increased substance use, mental health challenges and intimate partner violence during the COVID-19 pandemic. Cis and transgender women of color with HIV, faced unemployment and COVID-19-related job losses. [7] Homelessness, poverty, food insecurity, limited access to transportation and medical care has put the lives of these vulnerable women at substantial risk during the pandemic.

Medical mistrust, stemming from systemic racism, also re-emerged with the COVID-19 pandemic impacting the uptake of preventive measures such as testing and the vaccine and other health outcomes. [8-16] A recent study among a convenience sample of Black individuals living with HIV found general COVID-19 mistrust was high and associated with greater vaccine hesitancy and treatment.[14] In addition, persons with greater negative COVID-19 impacts also exhibited lower adherence to HIV treatment.[14] While participants in this study identified as mainly Black cis males, identifying and mitigating these structural barriers and mistrust beliefs are crucial also for Black women to improve their health outcomes.

Given these challenges, improving care for Black women must also consider structural changes at the organization level as well as broader policy efforts to tackle social and economic inequity. COVID-19 placed an added burden, but it also created opportunities for organizational and policy change. Staff of the organizations funded through this initiative played a synergistic role in providing services to their clients who were striving through both HIV and the COVID-19 pandemic. Below are some of the strategies that are being implemented.

Strategies

Housing Support: SPNS grantees are leveraging emergency rental assistance via specialized funding to assist with housing needs and are making referrals for additional housing support services. University of California San Francisco (UCSF) Women's HIV program link patients with AIDS Legal Referral panel to prevent eviction from their homes. Alliance for Positive Change are working with clients to find new housing opportunities. Quality Comprehensive Health Center (QCHC) is assisting clients with emergency housing payment assistance during COVID-19. AIDS Foundation of Chicago is partnering with community organizations across metropolitan Chicago to link clients with emergency hotel and shelter housing for vulnerable clients.

Food and Emergency Assistance: AIDS Care Group is supporting their clients via their in-house food security program, where clients are provided daily hot cooked meals and access to a food pantry. Alliance for Positive Change organizes weekly food pantry services. Abounding Prosperity has worked with community partners to provide food boxes to clients in need. All demonstration sites are providing emergency utility assistance to clients based on assessed need.

Adapting new communication platforms for ensuring health care services: Virtual service delivery has been a primary mode of service delivery during the pandemic. Sites are innovative in their offering of technology to clients, *providing clients with hotspots, cell phones and/or recurring data plans to access virtual services and participate in telehealth and support groups.* Community events, focus group discussions and peer support groups are delivered virtually. Abounding Prosperity increased engagement through virtual educational events, social media, and awareness campaigns, and adapted their electronic health record (EHR) system to text clients about appointment reminders.

Grady Health Systems uses the Positive Links Cares (PL Cares) mobile app for appointment reminders, education and virtual community support with their clients. Positive Impact Health Centers has in office and telehealth services based on client's needs. Staff provide tele-medical health, tele-behavioral health, and tele-case management services to clients. Staff use social media to outreach and recruit clients for their bundled interventions and are sensitive to the importance of ensuring special protections around client privacy and stigma reduction. Clients call and text Access Matters Hotline for information, counseling, and referral resources. For ease with enrollment and engagement, sites have varied methods for client consent, such as regular mail of forms to collect PDF signatures, DocuSign, and texted consent.



COVID policies, testing and vaccination: Agencies are conducting targeted educational sessions around prevention of COVID-19. All 12 sites are supporting their clients with testing and vaccine resources. They developed policies and safety protocols for all activities conducted with the clients following CDC guidelines. City of Philadelphia modified their walk-in model schedule to an urgent care model requiring an appointment before being seen. As the “stay-at-home” mandate was declared, the Institute of Women and Ethnic Studies (IWES) leadership team and staff quickly developed remote work plans to continue carrying out program activities. AIDS Care Group conducts wellness checks via phone to clients every 10 days and refers patients for COVID-19 testing and administered vaccinations on site. Clients are provided with PPE and masks available through other funds. Mobile unit team reaches out to various communities to offer vaccination. AIDS Foundation of Chicago conducted COVID-19 grand rounds—a three-part training series about vaccines to increase understanding and reduce vaccine hesitancy for case managers so that they were prepared to educate clients. Alliance for Positive Change conducted a COVID -19 vaccination town hall event for Black women, had weekly drop-in zoom events addressing vaccination hesitancy and organized onsite testing and vaccination. City of Philadelphia provided PPE and COVID-19 vaccines for clients and IWES’ implementing partner, Priority Health Care, conducted community testing, offered vaccines, and developed risk mitigation plans. Additionally, IWES held community outreach events, at-home HIV self-test kits are distributed. Staff at UCSF helped schedule COVID vaccines for clients. City of Philadelphia providers increased medication prescription duration thereby minimizing client clinic visits during COVID.



Holistic Wellness: All SPNS grantees ensure that clients have access to behavioral health and HIV medical services. IWES is organizes bi-weekly virtual individual and support group for clients to address grief and loss concerns and promote healing for clients impacted by the pandemic. Peers/patient navigators through regular check in with clients via phone or text, assess client needs especially being sensitive to occurrence of increased partner violence and isolation. Referral services were provided if this was a client need.

Transportation Support: All sites continue to provide transportation supports to women as they feel comfortable using various public transport systems. Bus and train passes to attend health appointments are available including for COVID-19 testing and vaccination programs. A few sites offer complimentary Lyft or taxi services for clients who are more wary of riding public transportation and in need of in-person visits for HIV or behavioral health care. All clinics have offered virtual therapy sessions and telehealth services to clients to support engagement in services.

Employment support and connection to financial resources:

QCHC and Positive Impact Health Centers are supporting clients by providing financial relief information. AIDS Foundation of Chicago partners with Rise Kit to work with justice involved Black women with HIV to build resumes, provide trainings in leadership and advocacy. Clients are connected to online employment systems, by their peer reengagement specialist.

Addressing the pandemic for staff: Task shifting at agencies was critical to address rapid development of new COVID-19 regulations and policies, redesigning workflows for program screening, referrals, and client engagement to services. All sites developed COVID-19 mitigation policies while providing services, such as limiting the number of patients in the waiting room, and followed CDC recommended guidelines. Alliance for Positive Change adapted a method where clients and staff were able to sign for gift cards through touchscreens. Institute for Women and Ethnic Studies conducted Trauma Informed Care trainings to staff who were impacted personally and professionally by the pandemic. Vaccines protocols were rolled out to all agency staff. Access Matters leveraged additional funding to provide COVID-specific support to their network providers.

Next Steps

- Housing insecurity is prevalent especially among Black trans women which can impact HIV care and treatment adherence. Continue to screen for and assist clients who fall behind on rent or mortgage payments with access to resources and subsidies. Develop cross sectoral partnership with housing agencies and ensure equitable housing to both cis and trans Black women with HIV.
- Continue to address food insecurity through provision of home delivered meals, healthy foods via food pantries or grocery cards to support women and their household. Implement approaches to tackling food insecurity among PLHIV.
- Increase capacity and leverage budgets for continued telehealth services for hard-to-reach clients. Ensure internet access for clients particularly those facing intimate partner violence, stigma, and isolation.
- Patient/peer navigators and case managers follow up with clients routinely as they progress towards viral suppression. Promote virtual HIV educational trainings and individual or group sessions as preferred for hard-to-reach clients.
- Identify the cracks in the system that prevent clients from reaching out to these organizations to receive care and treatment services. Continue ensuring safety and privacy of clients receiving services and continue supporting them with technology and devices to keep them engaged to care and treatment adherence.

*Out of the huts of history's shame
I rise
Up from a past that's rooted in pain
I rise*

*I'm a black ocean, leaping and wide,
Welling and swelling I bear in the tide.*

- *Still, I Rise, MAYA ANGELOU*



Efforts taken by the SPNS grantees

Although the organizational settings of these SPNS grant recipients delivering evidence based bundled interventions to clients varied, they were efficient in meeting the needs of their population even during the pandemic.

- Stigma and trauma are addressed in both the epidemic and the pandemic.
- Staff are investing a significant amount of their time to educate clients around technology to ensure constant contact with them.
- Community health workers, peer and patient navigators are playing a significant role to recruit, refer and follow-up with clients.
- Sites are making refinements to their intake to be conducted virtually or by phones and noted that their ability to meet the hidden population of women living with HIV were made possible due to the virtual communications.
- In efforts to provide services within restrictions due to the COVID-19 pandemic, these agencies were able to develop strategies for individuals to sign documents for care services, without being in person.
- Site staff are able to effectively educate women around COVID testing and vaccine that helped with their initial medical mistrust and provide resources to ensure a high vaccination rate amongst their clients.

Conclusion

The COVID-19 pandemic further exposed the gaps in the health and social service system impacting the wellbeing of Black women living with HIV. Despite these challenges of the pandemic, Black women are staying resilient, prioritizing employment, family, and housing over their individual needs. Supporting women who are in survival mode as they address both COVID-19 and HIV is essential. This current initiative is exploring innovative strategies to outreach, engage and support women in mitigating the structural barriers to care, including stigma and structural racial and gender discrimination. A key focus is building trust through the provision of resources and training to medical and service providers is offering culturally responsive care for Black women. These SPNS grantees encourage Black women with HIV who have similar experiences to share their stories and discuss topics to create awareness and a sense of community through regular virtual support groups. Agencies are also developing and implementing policies and strategic plans to combat racial and structural inequities faced by Black women living with HIV.

References

1. Centers for Disease Control and Prevention, HIV Surveillance Report, 2018 (Updated) vol.31. 2020: May 2020.
 2. Clark, H., et al., Diagnosed HIV Infection in Transgender Adults and Adolescents: Results from the National HIV Surveillance System, 2009-2014. *AIDS Behav*, 2017. 21(9): p. 2774-2783.
 3. U.S. Department of Health and Human Services. 2021. *HIV National Strategic Plan for the United States: A Roadmap to End the Epidemic 2021–2025*. Washington, DC.
 4. . Millett GA. New pathogen, same disparities: why COVID-19 and HIV remain prevalent in U.S. communities of colour and implications for ending the HIV epidemic. *J Int AIDS Soc*. 2020;23(11):e25639.
 5. Artiga S, Garfield R, Orgera K. Communities of color at higher risk for health and economic challenges due to COVID-19: Kaiser Family Foundation. 2020. <https://www.kff.org/coronavirus-covid-19/issue-brief/communities-of-color-at-higher-risk-for-health-and-economic-challenges-due-to-covid-19/>
 6. Chandler R, Guillaume D, Parker AG, Mack A, Hamilton J, Dorsey J, Hernandez ND. The impact of COVID-19 among Black women: evaluating perspectives and sources of information. *Ethn Health*. 2021 Jan;26(1):80-93. doi: 10.1080/13557858.2020.1841120. Epub 2020 Nov 5. PMID: 33153287; PMCID: PMC8542278.
 7. Simien, M. Evelyn. 2020. COVID-19 and the ‘Strong Black Woman’ - Gender Policy Report. <https://genderpolicyreport.umn.edu/covid-19-and-the-strong-black-woman/>
 8. Price-Haywood EG, Burton J, Fort D, et al. Hospitalization and mortality among Black patients and white patients with COVID-19. *N Eng J Med*. 2020; 382:2534–2543.
 9. Centers for Disease Control and Prevention. Weekly Updates by Select Demographic and Geographic Characteristics: Provisional Death Counts for Coronavirus Disease 2019 (COVID-19) 2020. Available at: https://www.cdc.gov/nchs/nvss/vsrr/covid_weekly/index.htm .
 10. Stokes EK, Zambrano LD, Anderson KN, et al. Coronavirus disease 2019 case surveillance—United States, January 22–May 30, 2020. *MMWR*. 2020; 69:759–765.
 11. Chicago City Department of Public Health. Chicago, IL: Latest data. 2020. Available at: <https://www.chicago.gov/city/en/sites/covid-19/home/latest-data/2020-05-17.html>. Accessed July 10, 2020
 12. Poteat TC, Reisner SL, Miller M, Wirtz AL; American Cohort to Study HIV Acquisition Among Transgender Women (LITE). Vulnerability to COVID-19-related Harms Among Transgender Women with and Without HIV Infection in the Eastern and Southern U.S. *J Acquir Immune Defic Syndr*. 2020 Dec 1;85(4): e67-e69. doi: 13.1097/QAI.0000000000002490. PMID: 33136755; PMCID: PMC7722524.
 14. Bogart LM, Wagner G, Galvan FH, et al. Conspiracy beliefs about HIV are related to antiretroviral treatment nonadherence among African American men with HIV. *J Acquir Immune Defic Syndr*. 2010;53: 648–655.
 15. Armstrong K, Rose A, Peters N, et al. Distrust of the health care system and self-reported health in the United States. *J Gen Int Med*. 2006;21: 292–297.
 16. Kinlock BL, Parker LJ, Bowie JV, et al. High levels of medical mistrust are associated with low quality of life among Black and white men with prostate cancer. *Cancer Contr* 2017; 24:72–77.
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