PRIVACY, DOMESTIC VIOLENCE, AND HIV: A GUIDE FOR ADVOCATES

Victims of domestic violence have higher chances of acquiring HIV than people who are not experiencing domestic violence. And people living with HIV are more likely to experience domestic violence or fear physical abuse upon disclosure. Domestic violence survivors who are living with HIV face a unique set of challenges in navigating privacy issues when seeking support related to domestic violence, HIV, and other aspects of their lives. This document explores why it’s important for domestic violence programs to be prepared to support the unique needs of survivors living with HIV and understand how to protect their privacy. (Check out NNEDV’s HIV/AIDS & Domestic Violence toolkit for more).

HIV STATUS & PRIVACY – THE BASICS

First, it is important to make sure that all advocates at your program know that survivors do not need to disclose their HIV status in order to receive services. There are very few situations in which a person living with HIV is legally obligated to disclose their status, and seeking domestic violence services is not one of them.

Questions about HIV status should not be routinely asked during intake. Some survivors may choose to voluntarily disclose their status. If a survivor decides to share that information, the program cannot under any circumstance discriminate against that person, and is legally obligated to keep that information confidential.

- Discrimination is prohibited against people living with HIV or AIDS under federal law by Section 504 of the Rehabilitation Act and the Americans with Disabilities Act.
- Programs funded by the Violence Against Women Act (VAWA), the Victims of Crime Act (VOCA), or the Family Violence Prevention and Services Act (FVPSA) are required to keep information shared by survivors confidential.
- In healthcare settings, the privacy of survivors’ HIV status is governed by the Health Insurance Portability and Accountability Act (HIPAA).

1 Centers for Disease Control and Prevention (CDC). Intersection of IPV and HIV in Women; Women and HIV/AIDS: Confronting the Crisis; and Population Reports.
Best practices encourage programs to collect the least amount of information needed to provide the service(s) requested, and to keep that information for the shortest period of time necessary, based on survivor needs and funder requirements. This includes information about HIV status. As with other personal information, records about HIV status could be harmful to survivors if shared. The less your program collects and stores, the less risk of harm to a survivor’s privacy and safety. Learn more from our Why Privacy and Confidentiality Matters to Victims of Domestic Violence resource, and from our Record Retention and Deletion resource.

If a survivor chooses to disclose their HIV status, that should not negatively affect the services they receive from your program. Here are some basic guidelines for how to respond:

- Don’t share information on their status with other survivors at your program, including in shelter.
- Don’t share information with other organizations in the community unless the survivor requests that you do so. But first, consider ways to help survivors share their own information about their HIV status with other organizations. Read more here about How to Work with Survivors Regarding the Release of Personal Information.
- Keep to an absolute minimum the number of people in your program who have access to information about a survivor’s HIV status. It is not necessary to tell other staff or volunteers about someone’s HIV status. A survivor should be able to choose who knows about their HIV status, just as with any other personal information.
- Do not control access to a survivor’s medications related to HIV status or any other medical condition. Check out NNEDV’s Guide for Medication Storage and Access resource for more information.

SURVIVOR CENTERED SERVICES

As in all other aspects of a survivor’s life, advocates should listen without judgment and without making assumptions. Offer resources, listen to the survivor about the priorities in their lives, and follow their lead on identifying needs and setting goals.

Connecting survivors to support and services can help decrease isolation and increase their chances of finding safety. Technology can also be used to connect survivors to services, which in turn can help them heal from their trauma, reconnect socially, find employment and educational opportunities, and develop a support network.

Advocates should be trained to help survivors make informed choices about HIV risk and risk reduction, HIV testing and treatment, disclosure of HIV status, and strategies for privacy in small
Communities (both online and in real life). Share this resource on Privacy & HIV with survivors. For more information on discussing HIV with survivors, checkout NNEDV’s Conversation Guide: Starting the Discussion About HIV/AIDS.

COMMUNITY PARTNERSHIPS

Build partnerships in the community to refer/connect survivors to for support and medical needs, and to share information about domestic violence and HIV. Learn from each other. Educate HIV service providers and partners in your community about domestic violence. Learn from them about HIV. It is important that advocates and service providers from the HIV and domestic violence fields work together. Each field needs to understand the many unique and varied privacy and safety related challenges experienced by survivors of domestic violence who are living with HIV, and the added risks related to the technology we use to store information about and communicate with them.

ADDITIONAL RESOURCES

★ Positively Safe DV & HIV/AIDS Toolkit, from NNEDV
★ Privacy, Confidentiality and Disclosure, from Lambda Legal
★ Laws Protect People Living with HIV and AIDS, from HIV.gov

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