

Confidentiality and Disclosure of HIV Status¹

RWHAP Part A Planning Councils



Disclosure of HIV Status

Whether people with HIV (PWH) should be required to disclose their status in order to serve as unaligned consumer representatives on a Ryan White HIV/AIDS Program (RWHAP) Planning Council is a complex question, about which there is no consensus.

The following factors should be considered in a discussion of confidentiality and disclosure:

- **The RWHAP legislation is silent regarding disclosure of HIV status.** The law requires evidence that at least 33% of voting members of the Planning Council are unaffiliated/unaligned consumers, but the HIV/AIDS Bureau (HAB) does not ask for disclosure of names, and does not require that they fill identified “unaligned consumer” seats. Consumers are often listed in “Category 8, affected communities,” which can include consumers, other individuals with HIV, and “historically underserved groups and sub-populations.” Consumers may also fill other seats such as “non-elected community leaders” or formerly incarcerated people with HIV (PWH) or their representatives.
- **HAB expects that at least two PWH members of a Planning Council will openly disclose their HIV status** so they can be public contacts and spokespersons for consumers of RWHAP services.² Many Planning Councils state this requirement in their Bylaws. For example, the Bylaws for one Midwestern Planning Council state that “at least two consumer representatives must publicly disclose their HIV status.” Having some publicly disclosed PWH members provides community access to HIV-positive Planning Council members.
- **Ideally, most PWH serving on the Planning Council will publicly disclose their HIV status,** since it is much easier for PWH to represent the community if their status is known. Disclosure enables them to serve as role models and gain the credibility of a consumer when speaking about service needs or program issues.
- **The difficulties of disclosure can be considerable.** Although the situation varies considerably by location and community, disclosure can contribute to discrimination in employment and housing, inability to obtain needed services, great strains for family members, and sometimes becoming unwelcome in a cultural group, school, or neighborhood. Fear of disclosure is often especially great in rural areas or smaller cities, although fear of discrimination can be a concern in any location.

¹ Based on information in the original 2001 version of the *Training Guide*, this resource has been updated by Mosaica and EGM Consulting, LLC many times. It was used in technical assistance to a Part A Planning Council in January 2022 under the JSI Planning CHATT project, and expanded by EGMC in April 2022.

² See the *Part A Manual*, Section X. Chapter 4. Planning Council Membership, p 109: “...at least two of these consumer representatives must publicly disclose their HIV status.”



- **Requiring disclosure can be inconsistent with maximizing diversity.** Being publicly identified as HIV-positive can be a special concern for some people of color, immigrants, and women, for whom family and/or community difficulties in accepting PWH can be especially severe. Requiring disclosure may make it difficult to identify diverse PWH willing to serve on RWHAP Planning Councils.
- **Planning Councils often require disclosure—sometimes limited disclosure—before an individual can be counted against the 33% of voting members who must be unaligned consumers.** Full disclosure may not be required if consumers are put into multiple membership categories, or into Category 8, “affected communities,” since this category can also include non-PWH. This decision is made by each Planning Council. Sometimes HIV status information is maintained by Planning Council Support and used in reporting reflectiveness and representation to the Planning Council and to HAB (Such reporting is required annually but without names). Sometimes individuals are willing to make their status known within the Planning Council or in certain community situations, with the understanding that the Planning Council will not divulge their status to the general public, send them letters identifying them as PWH members, or list them as such on letterhead or other public documents. A useful practice is to address them as “community representatives.” Some Planning Councils have a “Community Access Committee” instead of a “Consumer Committee” for similar reasons.
- **Some States and cities have sunshine laws that can make partial disclosure difficult.** Anything discussed in a Planning Council meeting is public information, and something as simple as announcing no conflicts of interest can suggest that a person may be a PWH. Where there is a sunshine law, meeting minutes and membership lists may identify status, although action can often be taken to avoid this, again by categorizing consumers as part of a larger group along with other community representatives. One Planning Council addressed this issue by changing the publicly disclosed membership category from “Unaffiliated Consumer” to “General Member.”
- **PWH sometimes find it easier to disclose status if there is an active PWH or consumer group to provide support.** Some PWH have been willing to disclose their status after participating in local or regional PWH training or becoming part of a PWH committee or coalition.
- **Some Planning Councils require members to sign a Confidentiality Pledge.** This is a written statement promising that they will not disclose the HIV status of another Planning Council member. Decisions about disclosure are left to the members themselves. The Bylaws of one large Part A Planning Council specify that Members must:

Follow the Council’s Confidentiality Policy, as stated in the Confidentiality Pledge signed by each member. This means not disclosing personal information about any Planning Council or committee or subcommittee member – such as the HIV status of anyone who is not publicly disclosed, or medical or personal/personnel information that would constitute an invasion of privacy – that was obtained through their Planning Council relationships and activities.



Multiple Views

- Discussions about disclosure of HIV status can bring out very strong feelings and varied perspectives on the issue.
- Some people feel very strongly that no one should be permitted to serve as a Planning Council member as an unaligned consumer without full public disclosure.
- Others believe equally strongly that women, people of color, recent immigrants, and/or rural residents can still face such serious potential discrimination for themselves and their families that disclosure must not be required, or that it is important to allow for limited disclosure in order to attract diverse consumer members.
- Some Planning Councils have found that limiting disclosure makes recruitment of unaligned consumers easier.
- HAB leaves disclosure requirements to the discretion of the Planning Council, but the Planning Council as a whole must provide community members access to at least some HIV-positive Planning Council members.

When discussing this issue, a Planning Council should acknowledge the complexity and lack of consensus, and establish an environment in which differing opinions can be stated and listened to.

Other Confidentiality Issues

Planning Council members and staff need to maintain confidentiality on some issues other than HIV status. For example, members may learn personal information about each other or hear very strong opinions during committee and Planning Council meetings. Many Planning Councils have Confidentiality Pledges as well as codes of conduct that require members not to disclose medical or other personal information or publicly repeat the individual views of members on controversial or personal topics. Planning Councils may know the health status or learn about family issues facing other members due to attendance requirements. This information should not be shared publicly.

Even if information is shared in a public Planning Council meeting, the member may still prefer not to have his/her opinions or personal situation shared more widely – just as many members disclose their status to the Planning Council but do not discuss it outside the Planning Council. Planning Councils should discuss such issues and then establish and enforce clear and consistent policies on confidentiality. Here is an excerpt from one Planning Council’s Code of Conduct:

Follow the Council’s Confidentiality Policy, as stated in the Confidentiality Pledge signed by each member. This means not disclosing personal information about any Planning Council or committee or subcommittee member – such as the HIV status of anyone who is not publicly disclosed, or medical or personal/personnel information that would constitute an invasion of privacy – that was obtained through their Planning Council relationships and activities.

These policies often apply to Planning Council Support and recipient staff as well. They help to create a comfortable environment for all members.

