



**TECHNICAL BRIEF**

# **HIV Planning Councils**

Implications for Latinx Gay and Bisexual Men



Effective frameworks for community empowerment progressively ensure full participation of gay and bisexual men [MSM]. Programs should be designed to transition from doing programs/activities for gay and bisexual men [MSM] to doing them with gay and bisexual men [MSM], and ultimately to programs/activities done by gay and bisexual men [MSM].<sup>i</sup>

*“Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.”*

- Recommendations for People (Living) with AIDS, The Denver Principles

## Background

In 1990 the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provided funding for the first time to four of the most impacted cities early in the epidemic (SF, NYC, LA and Miami). It required for the inclusion of People living with HIV/AIDS (PLWHA) in the planning process for Title I (Part A) program for Eligible Metropolitan Areas (EMAs) and involved consumers in implementing the Title II (Part B) program for States and Territories.<sup>ii</sup>

On the HIV prevention front, community planning began as an innovative initiative between the Centers for Disease and Prevention (CDC), health departments and HIV prevention organizations in 1994.<sup>iii</sup> All 65 state, local and territorial health departments or project areas receiving prevention funds from the CDC had to partake in a planning process to identify and prioritize prevention needs involving community planning groups (CPGs). CPGs were intended to give community members a direct voice in allocation of HIV prevention funding.

Guidance for community planning processes prioritized evidence-based HIV prevention strategies and interventions, with a sound basis in behavioral and social science. According to the guidance, planning processes at the local and state levels should begin with an accurate assessment of the epidemiology of the current and projected future HIV epidemic.<sup>iv</sup>

Currently, there are 52 planning councils and bodies and 53 identified hard hit areas receiving Part A Ryan White funding.<sup>v</sup>

In the original guidance published in 1993, the main goal of CPGs was to improve the effectiveness of HIV prevention programs through the meaningful participation by people living with or affected by HIV and application of evidence-based interventions.

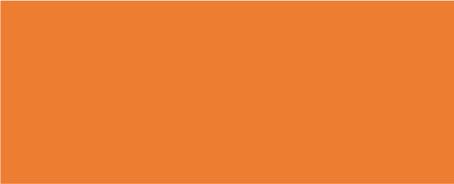
The three main tasks delegated to CPGs include:

- 1) Development of an **epi profile**, describing the impact of the epidemic in local jurisdictions;
- 2) Identification of prevention needs of population at risk for HIV infection and programs or interventions to address these needs (**needs assessment, community resource inventory, and gap analysis**); and
- 3) **Priority setting** which then determines the **allocation** of HIV prevention funding.

The **HIV Planning Guidance** has been updated three times. The latest 2012 version aims to<sup>vi</sup>:

- 1) Support the implementation of high-impact prevention programs;
- 2) Ensure that HIV planning is efficient and focused on results-oriented processes;
- 3) Encourage collaboration and coordination across HIV prevention, care, and treatment services;
- 4) Reduce reporting documentation for HIV Planning Group (HPG);
- 5) Engage a broader group of stakeholders; and
- 6) Focus on streamlining communication and coordination among Health Departments (HDs), HPGs, and community stakeholders, to ensure the implementation of needed services (e.g., mental health, substance abuse, and coinfections of viral hepatitis, STDs, and TB) across the continuum of HIV prevention, care, and treatment services.

The HIV Planning Guide contains sections dedicated to Stakeholder Identification and Results Oriented Engagement Processes. However, they do not delineate specific strategies for recruiting, training, engaging, and retaining marginalized populations overly impacted by HIV infection nor for disenfranchised people living with HIV (PLWH). This includes Latinx gay and bisexual men who may also be mono-lingual Spanish speakers, immigrants/asylum seekers, homeless, unemployed, sex workers, active drugs user and/or facing behavioral health issues. Although, these concerns are mentioned as part of the principles for both recruitment and engagement, there is no built-in monitoring, evaluation or enforcement mechanism to address effective implementation and resolve potential barriers to meaningful participation of the before mentioned community members.<sup>vii</sup> Consequently, if meaningful community engagement is the driving force behind these planning efforts, are we living up to those goals/standards through current processes and if not, what are the consequences?



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## **Structural Challenges**

Over the years, CPGs have experienced broader challenges around simplifying the process to enable full participation from lay community members. They include effectively addressing issues such as lack of time or resources to recruit, train and retain CPG members, conflict of interest with CPG members representing funded CBOs, conflict of interest of Health Department staff with CPG responsibilities and underrepresentation of impacted community members among Health Department staff, and in some rare cases mismanagement of resources by funded CBOs and/or public health administrators.

Engagement and retention questions also arise, especially when community members are expected to participate in meetings lasting several hours to a full day plus participate in committees, all on a volunteer basis. Recent developments in HIV care and treatment have meant that PLWHA have returned to work, to school and/or to living full lives. Those struggling to survive the high costs of living in large urban areas or those with limited job opportunities in rural areas, at times need to work two or three jobs to make ends meet. Those underemployed, unemployed, homeless, struggling with substance use and or behavioral health issues may have competing priorities and may only be able to contribute on a limited basis to current community planning processes.

Meaningful community engagement must occur regularly, consult a range of impacted stakeholders, occur in a variety of venues and formats, accommodate the needs and preferences of community members, stretch our understanding and conventional wisdom and ideas about communities and occasionally make us uncomfortable.<sup>viii</sup>

Some local and state planning processes are currently operating using a crisis framework. Crisis frameworks are useful in rapid resource scale-up but detrimental to comprehensive and planned approaches. For example, crisis responses sometimes come at the cost of ongoing support for primary prevention, as evidenced by recent increases in HIV incidence among young Latinx gay men in some jurisdictions. Unfortunately, crisis frameworks can also sometimes pit communities against each other in fights over limited resources, instead of encouraging solidarity and coordination of effort or promoting intersectional responses to HIV.

The resulting mistrust and territorialism contribute to fractured HIV prevention, care and treatment responses and perceptions that local priority setting, bidding processes, and funding decisions are determined by the politics of crisis rather than ongoing assessment of local need.

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## **Evolving Planning Councils**

In the last ten years, due in part to shrinking planning budgets, cuts in prevention dollars, changing demographics of the epidemic, introduction of treatment as prevention and attempts to integrate services, several jurisdictions have opted to create Joint Planning Councils (JPC)<sup>ix</sup> and produce Integrated HIV Prevention and Care Plans. JPCs combine prevention and care funding streams and engage in similar planning process as Prevention Planning Councils.

Unfortunately, even before the integration, RWHAP advisory councils did not monitor their own membership demographics to ensure balance and to address disparities in their own recruitment processes. Ultimately, JPCs face similar challenges recruiting, training, engaging and retaining Latinx gay and bisexual men affected by and/or living with HIV.



In June 2015, CDC and HRSA published the Integrated HIV Prevention and Care Plan Guide including the Statewide Statement of Need CY 2017. Entities seeking funding are required to follow this guidance. It was released in order to align submission dates, reduce reporting burden, leverage resources for HIV prevention and care, utilize integrated epidemiologic profiles, and submit a multiyear plan that will cover a period of 5 years.<sup>x</sup> According to the guidance, the Integrated HIV Prevention and Care Plan is a vehicle to identify HIV prevention and care needs, existing resources, barriers, and gaps within jurisdictions and outlines the strategies to address them.

In 2019 funding to support Ending the HIV Epidemic plans was made available to the 57 entities (DC, San Juan, 7 states and 48 counties). Notice of Funding Opportunity (NOFO) PS19-1906 B highlights the importance of community engagement and requires entities to document the level of community engagement enacted in the development of their EHE plans.<sup>xi</sup>

The following recommendations are not only necessary but also timely in order to effectively address the increase in HIV infection among Latinx gay and bisexual men and the limited access to HIV care and treatment and consequently low viral suppression among Latinx PLWHA.<sup>xii</sup>

## **Recommendations**

### **CDC & HRSA**

- Create additional accountability mechanisms to ensure NOFO requirement and guidance are met and provide assistance to said entities to reach adherence.
- Provide adequate funding to Latinx specific CBOs that earmark funding to support leadership development and community education programming that include capacity building and trainings on planning councils and that allow for language access support and incentives to ensure the active participation of Latinx gay and bisexual men.
- Convene a national Latinx gay and bisexual men's advisory body to ensure EHE has meaningful Latinx gay and bisexual men participation.

Besides letters of concurrence. Accountability mechanisms should be integrated into all planning processes as this is at the core of the function of a planning body. When developing such accountability mechanisms, developers and implementers should ask themselves: Are communities able to provide meaningful input on resource allocation? If not, how can this be resolved?

## Health Departments

- Develop built-in monitoring, evaluation and accountability mechanism to address effective implementation and resolve potential barriers to meaningful participation.
  - Proactively address time or resources limitations to recruit, train and retain Latinx gay and bisexual men planning council members, making special considerations for those that are mono-lingual Spanish speakers, immigrants/asylum seekers, homeless, unemployed, sex workers, active drugs user and/or facing behavioral health issues.
  - As financial stewards of resources that are critical to addressing the HIV disparities in prevention, care and treatment among Latinx gay and bisexual men, distribution of said resources need to be monitored and evaluated to prevent mismanagement.
  - Proactively address crisis frameworks by encouraging solidarity and coordination of efforts that are inclusive of all communities impacted by HIV.
- Strengthen quality data collection and reporting efforts by capturing primary language, sexual orientation, gender identity, country of origin and key social determinants of health (housing, employment, food access, mental health needs, substance use treatment needs) in electronic health records and other relevant state funded surveys.<sup>xiii</sup>
- Linguistically competent and culturally humble Latinx gay and bisexual men should be considered when hiring staff at all levels of health departments. Relocation incentives, competitive salaries, student loan forgiveness programs should be considered when attracting Latinx gay and bisexual professional candidates to health workforce scarce communities.<sup>xiv, xv</sup>

## Planning Councils

- Need to allocate financial resources to provide training sessions in Spanish, to develop and update training material that incorporates adult learning principles, to utilizes multi-media to engage young Latinx gay and bisexual men, to promote mentorship opportunities and to provide incentives for participants in need of assistance to actively participate.<sup>xvi</sup> These suggestions can complement already established best practices utilized by planning councils that ensure smooth onboarding such as streamlining and simplifying the application process, continuously identifying potential council members, scheduling trainings at times that meet the need of

potential council members and provide annual and ongoing training throughout the year.<sup>xvii</sup>

- Investment in culturally and linguistically competent interpretation and translation services, also known as Language Access to limited English proficient (LEP) individuals, should be part of every planning council budget.<sup>xviii</sup> Expecting bilingual planning council members or bilingual health department staff to serve as interpreters limits their active participation in meetings and in decision-making processes. One strategy to consider is to partner with Latin-America consulates and or Latinx CBOs that may be able to provide interpretation and translation services in-kind/low cost and investing in interpretation equipment. Furthermore, back translation should be the standard in translating material into regional appropriate Spanish.<sup>xix</sup>
- Strategic engagement of marginalized and/or under-represented Latinx gay and bisexual men via social media, social media influencers, incentivized online surveys on dating/hook up apps, incentivized surveys at bars/sex clubs/underground parties/drag performance venues. Listening sessions at rehab centers, detox centers, criminal justice facilities, and immigrant detention facilities, listening sessions in collaboration with immigrant rights organizations, social justice organizations, community and state colleges and Latinx gay and bisexual specific CBOs should be also considered. Planning councils need to be clear about the level of involvement and amount of participation needed from Latinx gay and bisexual men to ensure the appropriate strategy is implemented.<sup>xx</sup>
- Develop mentorship/coaching guidelines to ensure retention and encourage Latinx gay and bisexual men planning council members to take on leadership roles in committees and/or at the larger planning council level. Continue identifying potential council members in collaboration with Latinx CBOs and CBOs serving predominately Latinx gay and bisexual men.
- Recognition and celebration events ensure that the volunteer work performed by the Latinx gay and bisexual men as planning council members is valued and remains critical to the planning councils. For those council members on a limited income or facing financial hardships, free transportation, meals and childcare/elder care should be the standard to ensure attendance at committee and general council meetings.<sup>xxi</sup>



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## **Community Based Organizations**

- Latinx CBOs and CBOs serving predominately Latinx gay and bisexual men need to be actively engaged in the identification of potential planning council members.
- Leadership development and community education and engagement programming at Latinx CBOs and CBOs serving predominately Latinx gay and bisexual men should include in-house trainings/workshops on the history of planning councils, on understanding epi data, on needs assessments, on the allocation processes, on meeting procedures, on decision making practices and on the importance of community input and participation at all levels of the process.
- As part of leadership development programming and community education and engagement curricula, Latinx CBOs and CBOs serving predominately Latinx gay and bisexual men should create check-in/follow up mechanisms for Latinx gay and bisexual men planning council members. This will allow for the provision of further training opportunities and to discuss and strategize around barriers to continuing their full participation in the planning council process. Additionally, this can also serve as an opportunity to connect Latinx gay and bisexual men planning council members with health profession pipelines or job training opportunities available in-house or at partnering agencies.

## ***WHAT CAN YOU DO?***

As funding for planning purposes from the Ending the HIV Epidemic initiative arrives into local jurisdictions there is a unique opportunity to engage or reengage Latinx gay and bisexual men in this critical process. This document was put together in close consultation with members of the National Latinx Gay and Bisexual Men's HIV Prevention and Treatment Coalition.

We are committed to support cis-gender Latinx women, Translatinx community members, and Latinx injection drug users that may have more specific needs not addressed by this document and stand in solidarity as recommendations are developed by individuals and organizations advocating on their behalf.

***Latinx gay and bisexual men advocates need to demand A SEAT AT THE TABLE, in prevention planning councils, in joint planning councils, in integrated planning councils, in health departments, in EHE planning efforts and at the level of CDC and HRSA.***

***Advocates should demand for the RESOURCES TO ENSURE FULL AND MEANINGFUL PARTICIPATION OF LATINX GAY AND BISEXUAL MEN in prevention planning councils, joint planning councils, integrated planning councils, EHE planning councils, health departments and at the level of CDC and HRSA.***

**For more information, please contact:**

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