

Persistent racial disparities in HIV/AIDS treatment and care: the role of Ryan White planning councils in the United States.

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Abstract

Despite advances in care and treatment over the last 36 years, racial disparities persist in HIV/AIDS morbidity and mortality. The Federal Ryan White legislation funds HIV/AIDS services for persons who are unable to access treatment and care. Ryan White Planning Councils (RWPCs) inform planning and delivery of services by assessing the local needs of people with HIV/AIDS, allocating Ryan White funds to services that meet these needs, and developing long term plans for the delivery of care. Using qualitative editing analysis, we analyze the bylaws of RWPCs throughout the United States to assess purposefulness in confronting racial disparities in HIV/AIDS care and treatment. **Only 13% of RWPCs are explicit about eliminating racial disparities.** RWPCs should incorporate overt racial health equity language into their bylaws and in practice. Establishing “disparities committees” to ensure that processes and programs are inclusive, and do not have unintentional consequences for communities of color is essential.

Keywords: Ryan White legislation, Planning councils, Racial disparities in HIV/AIDS, Disproportionately affected populations, HIV/AIDS policy

Introduction

Despite tremendous advances in the treatment of Human Immunodeficiency Virus (HIV) and Acquired Immune deficiency Syndrome (AIDS) over the last 35 years, vast racial disparities persist in the incidence and prevalence of HIV, as well as in HIV/AIDS related morbidity and mortality [1,2]. For example, forty-four percent of new HIV infections in the United States (U.S.) in 2014 occurred among African Americans/Blacks, and less than half of Hispanics/Latinos with HIV were receiving treatment. Additionally, the age-adjusted death rates of HIV positive African Americans are more than two times higher than their White counterparts [3]. Racial disparities in HIV prevalence, morbidity, and mortality are paradoxical, not only because of advances of HIV/AIDS care, but also because African Americans are less likely than Whites to engage in sexual risk behaviors that increase exposure to HIV [4,5].

One of the greatest U.S. policy responses to HIV/AIDS is the enactment of the federal Ryan White legislation. The federal government through the Health Services and Resources

Administration (HRSA) and the HIV/AIDS Bureau (HAB) ensure that the Ryan White funds provide low income U.S. residents living with HIV/AIDS (PLWHA) with access to quality care including medical services and other related support services [6]. Ryan White Part A funds provide assistance in urban areas — Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) — that are disproportionately affected by HIV/AIDS. These grants are awarded to local governments which then allocate the funds to HIV/AIDS service providers based on local/regional service area priorities.

Service priorities are established by Ryan White Planning Councils (RWPCs). A planning council is a local community organizing group comprised of HIV/AIDS stakeholders (including a minimum of 33% Ryan White eligible recipients) who reside in the defined EMA/TGA geographical area. Planning councils assess the unique place-based needs of PLWHA in a given jurisdiction; identify core medical and support services that would best meet these needs; allocate Ryan White funds to the identified services; and develop long term plans for the local/regional delivery of HIV/AIDS care

[7]. While the establishment of planning councils is required for EMAs, planning councils are not required for TGAs. However, TGAs must demonstrate a process for community involvement in the planning of HIV/AIDS care and treatment, and as a result, most TGAs do have planning councils.

The federal government has established specific requirements to ensure that PLWHA who are consumers of Ryan White services are serving on planning Councils. For example, planning council membership should be reflective of the demographics of the HIV/AIDS epidemic in the jurisdiction [7]. Therefore community involvement, especially from disproportionately affected populations, is critical if planning councils are to effectively assess needs, prioritize services, appropriately allocate funds and ultimately reduce the burden of HIV/AIDS among the populations that are most affected.

One of the main reasons for demographic reflectiveness in planning council membership is to ensure participation of affected populations — mostly communities of color — in the planning process: needs assessment, prioritization of services, allocations of funds, and the development of a comprehensive plan [7]. Inherent in these planning activities is the broader goal of confronting and reducing racial and ethnic disparities in the burden of HIV/AIDS. Community engagement in healthcare planning is a significant consideration for reducing disparities and is very meaningful in addressing gaps in HIV care and prevention [8,9]. We argue that such an outcome is hard to achieve if entities involved, namely planning councils, neither acknowledge existing disparities nor are intentional about addressing them in the process of planning local HIV/AIDS care and treatment services. The goal of this paper is to evaluate the role of RWPCs in addressing disparities in HIV/AIDS care and treatment. Specifically, we assess on a national level whether planning councils are committed and purposeful in confronting and eliminating racial disparities in HIV care and treatment.

Methods

From September 2015 to September 2016, we conducted a comprehensive analysis of the available bylaws of Part A Ryan White Planning Councils (RWPCs) within the United States and Puerto Rico. Information about the RWPCs was accessed using the TARGET Center website (<https://careacttarget.org>), a consortium that lists the websites and contact information for all Part A jurisdictions, and offers the Ryan White community with federally funded tools. Several RWPCs contained incomplete or outdated links for their contact information and website on the TARGET Center website. In these instances, a Google® search was utilized to locate accurate information. Bylaws for 45 of the 53 (~85%) RWPCs were publicly available and reviewed. These bylaws were analyzed for their inclusion of key terms that focus on addressing racial disparities in HIV care and treatment. The key terms include disparity/disparities, equity, social determinants, race/racism, ethnic/ethnicity, diverse/diversity, minority/minorities, culture, cultural competency and cultural sensitivity.

Using the qualitative research editing analysis style [10], RWPLC bylaws documents were examined and overarching

thematic constructs were identified and ascribed to each discrete written statement incorporating the aforementioned key terms. The unit of analysis in this study focuses on the code(s) that emerged from each discrete written statement observed. A major tenet of the editing analysis style includes the timing of classification through organizing data. In the chronology of editing style, text is first entered into a neutral rubric (Microsoft® Excel Spreadsheet) and is later evaluated for classification and coding. The editing analysis style is a validated approach that allows text units to be identified, arranged, rearranged, reduced and highlighted in such a way that connections and interpretations between data can be established. This allows the analyst to classify categories that emerge from the text through sorting and rearranging the text [10].

Our methodologies incorporate first highlighting the key terms or words emerging from discrete bylaws statements addressing racial disparities in HIV care and treatment. Next, organizing key terms into overarching categories. Finally, attributing thematic codes to the categories to elucidate trends within the data. In order to assure accuracy and to eliminate any potential interpretation bias, two reviewers separately interpreted the data and reached a consensus on categories, codes and final themes that emerged.

Results

In all, bylaws for 45 of the 53 (~85%) RWPCs jurisdictions were available for review. RWPC Bylaws were analyzed for their inclusion of key terms that focus on addressing racial disparities in HIV treatment and care. More than half of the available 45 EMA/TGA bylaws (75%) contained one or more of our search terms. Discrete sections of bylaws that incorporated these key terms encompassed the council mission/vision statements, as well as committee, co-chair and responsibilities and obligations statements. Three main themes emerged from our analysis: (1) addressing disparities, (2) eliminating racial and ethnic disparities, and (3) providing culturally appropriate services

1) Addressing disparities: Over two thirds (71%) of RWPC directly acknowledge their charge in addressing disparities in access to HIV care and treatment. By far, the majority of discrete planning council statements extracted from the bylaws focus on reducing or eradicating disparities in access to HIV care and treatment. These statements are overwhelmingly found in the portions of the bylaws that highlight the overall purpose of the planning councils, among the specific duties of its operating committees. For example, the Planning Council of the District of Columbia (Washington D.C.) EMA [11] states under its duties as follows:

“Determine the size and demographics of the population of individuals with HIV/AIDS and determine the needs of this population, with special attention to individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services, individuals with HIV/AIDS who do not know their status, and disparities in access and services among affected subpopulations and historically underserved

communities. This includes establishing methods for obtaining input on community needs and priorities.” (p. 4)

The conceptualization of disparities in most planning council bylaws is very broad and does not specify the group(s) most likely to experience unequal impact. For instance, the example above focuses on disparities in access to services among sub-populations but makes no specific distinction in terms of disparities by race, gender, age, mode of exposure, etc. In general, most RWPC, though explicit in their charge to address disparities, are not direct in targeting and eliminating group-specific disparities with respect to HIV treatment and care.

2) Eliminating racial and ethnic disparities: The Los Angeles County Commission on HIV contextualizes its relevance by describing disparities that exist in HIV prevalence and access to treatment by race and ethnicity in Los Angeles and in the U.S. But ultimately, much fewer (6 of 45) planning councils make a direct commitments to addressing racial and ethnic disparities in HIV treatment and care in their bylaws. But within the bylaws of the RWPCs that do, there are several distinct statements which overtly name the groups that are disproportionately affected, and for which extra effort are needed to achieve equity in care in order to reduce the impact of the virus. For example, the RWPC of Hartford, Connecticut [12] has a Continuum of Care committee that is:

“Addressing disparities in care...and reducing unmet needs of special population’s especially racial and ethnic minorities...” (p.12)

Similarly, the RWPC of Palm Beach County EMA13 has a Community Awareness Committee that helps to:

“Identify ways to reach People Living with HIV/AIDS (PLWHA) communities served [13], including minority and other special populations.” (p.13)

It is important to note that an additional four RWPCs mention addressing racial and ethnic disparities in their bylaws but only within the context of the Minority AIDS Initiative (MAI) funds. MAI is an additional funding stream to “improve access to HIV care and health outcomes for disproportionately affected minority populations, including black/African Americans” [14].

3) Providing culturally appropriate and accessible care: Of the 45 planning councils, 19 have bylaws with discrete statements around ensuring that Ryan White funded HIV services are culturally sensitive and appropriate. Most of the RWPCs that commit to addressing racial and ethnic disparities in their bylaws are also dedicated to making sure that they identify cultural barriers to HIV treatment and care, and support programs and policies that help to reduce such barriers. For example, the Collaborative Community Planning Council of the Oakland/Alameda TGA [15] states as its vision:

“...to provide services that are linguistically and culturally appropriate that: Outreach to the underserved; Educate all communities; and Reduce HIV stigma.” (p. 4)

There is not one best way to provide care for disproportionately affected populations. Several RWPCs

demonstrate awareness of the fact that the mere availability of services is not enough if these services are not delivered in ways that respect or are consistent with the context within which each specific person needing such services lives. The Planning Council of the Boston EMA [16] elaborates on this concept in its bylaws:

“The mission of the Planning Council is to improve the quality of the lives of persons with HIV/AIDS by responding to their existing and emerging needs. This is accomplished by supporting and encouraging a range of culturally appropriate health and social services. Moreover, the Council efficiently responds to the changing face of the epidemic with regards to all affected sub-populations and impacted regions within the Boston Eligible Metropolitan Area (EMA).”

Acknowledging that context is changing is equally relevant. Different populations experience different kinds of unmet needs. Similarly, models of service delivery that might work for White men who have sex with men (MSM) may not work for Black or for Latino MSM or for women of color who are also disproportionately affected.

Discussion and Implications

The objective of this study is to assess the degree to which RWPC Planning Councils are committed to and purposeful in confronting racial and ethnic disparities in HIV care and treatment. To our surprise, very few planning councils specifically demarcate racial and ethnic disparities in their bylaws, and these are by far the greatest domains where disparities exist regardless of mode of exposure to HIV [1,17,18]. Even fewer mentioned disproportionately affected communities of color such as African American and Latino populations in the context of the Minority AIDS Initiative — a program that was created specifically improves care and treatment among these populations.

While greater than two thirds of the available 45 RWPC bylaws contain verbiage committing to address racial disparities in HIV/AIDS care and treatment, only 10 specifically mentioned racial and ethnic disparities in HIV treatment and care. This is indicative — to some degree — of a generic commitment to addressing these disparities, especially since 4 of these ten planning bodies only do so in the context of the MAI. Planning and allocation of MAI funds should explicitly and rigorously focus on addressing racial and ethnic disparities. More importantly, the MAI should not be the only context within which RWPCs address racial disparities in treatment and care. We hope that the gaps in care among communities of color are taken seriously during planning. Needs assessment and allocation of all Ryan White funds.

One reason why HRSA mandates demographic reflectiveness in RWPCs is to make sure that racial and ethnic minorities are represented in decision-making process of planning bodies. But one unintentional consequence of this directive is that demographic reflectiveness might lead to tokenism in planning council operations where disproportionately affected people of color with lower status and privilege are brought on planning councils simply to meet the numbers, rather than to fully and

continuously engage them in all stages of the HIV/AIDS care planning process. Creating an avenue for engagement and representation of people of color within the leadership of RWPCs is important. Because most planning councils and committees have co-chairs or tri-chairs rather than a single chair, writing into the bylaws that at least one of co-chairs (of the full council and committees) is a person of color might make a difference. Of course implementing this by creating an atmosphere that is responsive to the needs of people of color and that values their contribution will facilitate retention in planning council leadership positions. Without the leadership of people of color, identifying and meeting their prevention, treatment and care needs might be challenging.

This brings us to another important step that might make a difference — council bylaws might incorporate as an objective, building and maintaining strong relationships with communities of color. Providing measurable activities for this objective and monitoring its progress throughout each grant year has the potential for making a difference in the engagement of communities of color within the planning body.

In general, planning bodies should review bylaws to make sure that addressing and eliminating racial and ethnic disparities are not only alluded to, but are boldly and clearly detailed in their duties and responsibilities. One way of explicitly embracing the goal of confronting racial and ethnic disparities is to assign each committee a role in the process. For example, the committee that is tasked with conducting a local needs assessment ought to consider ways in which they can address racial disparities in their processes and the allocations and prioritization committee can do the same. Another approach might be to create a “disparities” committee that does the work of planning and monitoring efforts to address racial and ethnic disparities by the planning body, and fosters participation, engagement and leadership among people of color.

Since these original analyses were completed, some RWPCs are becoming more intentional in addressing racial and ethnic disparities. For example, the planning body of the Minneapolis St. Paul TGA has created a Disparities Elimination Committee that is tasked with monitoring and informing how racial and ethnic disparities in HIV/AIDS prevention, care and treatment are addressed by the council [19]. Creating this kind of structure is very important, but we argue that it is even more essential to document and evaluate how a committee such as this can reduce local racial disparities in HIV/AIDS treatment and care. We intend to explore this in the future and assess whether this model can be successful for all planning bodies.

These findings should be interpreted in light of important limitations. First, activities, programs, and discussions around eliminating racial and disparities in HIV treatment and care may not be included in RWPC bylaws — our primary source of data. It is possible that additional RWPCs are doing more to address disparities, which is not articulated in their bylaws. Second, the outcome of allocations, assessments, and programs are not often listed in bylaws. Documents such as yearly grant applications, program reports, and meeting minutes might be more relevant sources of information useful to assess planning body commitments to confronting disparities. Third, search

term identification may be limited by variations in how different regions understand and use these terms. For this investigation, we assumed that the use of “disparities” included several domains such as gender, age, sexual orientation, geography, race and ethnicity. In some circles, “disparities” might be used refer to racial disparities, and not as broadly as we assumed. Despite these limitations, the study highlights the role of language and purposefulness within RWPC bylaws in their important commitment of eliminating disparities.

Conclusion

In conclusion, RWPCs should become more intentional and proactive in ensuring that their activities are addressing racial disparities in HIV/AIDS and state these activities clearly in their bylaws. Recommendations include making sure that people who belong to racial and ethnic minority groups are involved in planning council leadership, building and maintaining strong relationships with communities of color as a measurable outcome and going beyond membership reflectiveness by race. Finally, RWPCs should consider establishing disparities committees that monitor activities and ensures that processes and decisions are inclusive, free of racial bias and do not have unintentional consequences for communities of color.

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