

# The Longstanding and Present-Day Challenges Contributing to Unmet Oral Health Needs among People Living with HIV/AIDS

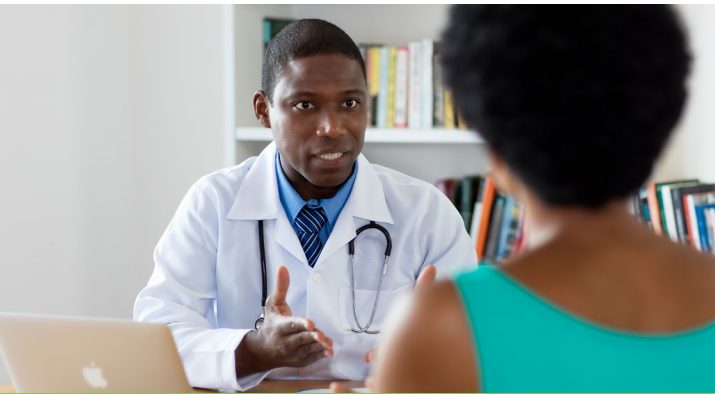
## Executive Summary

Oral health has a significant impact on overall health and quality of life. People living with HIV/AIDS (PLWHA) experience more oral health problems and complications compared to their non-infected counterparts, have greater difficulty accessing and using oral health care services, and as a result have greater unmet oral health care needs than the general population.

The Weitzman Institute convened a Taskforce of people living with HIV/AIDS and advocate in order to understand and address the current barriers to receiving oral care. The Taskforce, titled “Understanding Barriers to Oral Care for People Living with HIV/AIDS,” also serves to center and uplift the voices and lived experiences of these individuals, adding valuable context and nuance to help understand prior quantitative research.

The purpose of the Taskforce is to promote greater oral health care access and use. Taskforce members were key contributors to a three-part policy brief series, “Barriers and Opportunities for Improving Dental Healthcare Access, Utilization, and Outcomes through the Ryan White HIV/AIDS Program (RWHAP). The series highlights,

1. The longstanding and present-day challenges contributing to unmet oral health needs among PLWHA;
2. Opportunities for addressing social determinants of health and advancing structural change to decrease oral health care access and utilization gaps, and;
3. Recommendations for amplifying the vital role that patients and patient advocates play in influencing policy and reducing inequities.



## Ryan White HIV/AIDS Program (RWHAP)

The Ryan White HIV/AIDS Program (RWHAP) is the largest Federal program designed for people living with HIV/AIDS (PLWHA). RWHAP serves as the nation's safety net for PLWHA by providing outpatient HIV care and treatment to low-income, uninsured patients, and filling gaps in coverage and cost for those with insurance. According to the U.S. Department of Health and Human Services (HHS), more than 50% of people diagnosed with HIV, estimated to be half a million, receive services through RWHAP each year.<sup>6</sup> Moreover, the majority of clients served by RWHAP (73.6%) are from marginalized communities, including LGBTQ+ and racial/ethnic minorities, which has major implications for reducing disparities and moving the needle on health equity through RWHAP.<sup>5</sup>

Under Part F Dental Reimbursement Program, the RWHAP aims to improve access to oral health care services for PLWHA, and to support related education and training for the delivery of oral health care to PLWHA. PLWHA experience a higher incidence of oral health problems and complications compared to their non-infected counterparts. According to the RWHAP, 32% of PLWHA will develop at least one HIV-related oral health problem in the course of their disease. In addition, RWHAP estimates that between 58 to 64% of PLWHA do not receive regular oral health care. Research to date suggests that disparities in oral health care access and utilization persist among PLWHA with greater unmet oral health care needs among PLWHA, particularly women of color, than the general population.<sup>6</sup>

This brief addresses topic #1, barriers and challenges impacting unmet oral health needs among PLWHA. As with each brief in this series, the thoughts and opinions of Taskforce Members are featured prominently in order to increase understanding of the issues, their impact, and potential policy solutions.

## Introduction

More than 1.2 million people are living with HIV/AIDS (PLWHA) in the United States.<sup>1</sup> And for each of them, oral health is considered an unmet need, one that is often more prevalent than other unmet medical needs, specifically for those without dental insurance.<sup>2 3</sup> PLWHA experience a higher incidence of oral health problems and complications compared to their non-infected counterparts. Moreover, marginalized communities, including LGBTQ+ and racial/ethnic minorities, are overrepresented among PLWHA. HIV-related oral lesions are considered an early sign of HIV infection and are present in approximately one-third to one-half of PLWHA.<sup>4</sup>

The federally funded Ryan White HIV/AIDS Program (RWHAP) was developed to provide health and support services, including oral health care, to PLWHA. Yet, research to date suggests that disparities in oral health care access and utilization persist among PLWHA. One study noted that only 24 percent of persons served by RWHAP had obtained oral health services in the prior 12 months.<sup>5</sup> PLWHA report barriers including limited financial resources, shortage of dentists trained or willing to treat PLWHA, patient stigma within health care systems, lack of awareness of the importance of oral health, and lack of dental insurance. Additional work remains to be done to understand the scope of these barriers among PLWHA subgroups, particularly those from marginalized communities such as LGBTQ+, women, low-income individuals, and racial/ethnic minorities.

Given that more than 50% of PLWHA—about a half million people nationwide—receive services through RWHAP, there is a great opportunity to explore how RWHAP can be better leveraged to serve the oral health needs and improve outcomes among PLWHA.

## Description of the Project and the Taskforce

The Weitzman Institute is interested in addressing and understanding current barriers faced by PLWHA in receiving oral care. Because previously published reports and research helped to identify and quantify disparities in oral health care, the Weitzman team sought to center the voices and lived experiences of PLWHA as a way to provide another dimension to the issue and seek patient driven solutions. As part of the project, we created a representative Taskforce comprised of PLWHA and patient advocates working closely with PLWHA

or familiar with HIV/AIDS advocacy and community work. Our goal was to hear from both PLWHA and those working closely with them about issues faced in receiving dental care and how we can improve access to routine oral care.

Recruitment for the Taskforce was nationwide, with our website receiving over 500 applications from which 11 members were selected. See below the profile of members.

Across eight meetings, Taskforce members identified longstanding and present-day structural challenges contributing to unmet oral health needs among PLWHA, as well as opportunities to address social determinants of health, advance structural change to increase oral health care access, and reduce utilization gaps. The first meeting was set as a general discussion where Taskforce members were asked why they think it is important to bring attention to the oral health issues presented by PLWHA. This time and space also allowed Taskforce members to become comfortable speaking with one another and learning a little about each other. Subsequent meetings (meetings second to seventh) followed a format where the issue was first presented at one meeting, with the next meeting focused on reviewing items identified and addressing potential solutions to the issue from the perspectives of the Taskforce. The last meeting (meeting eight) was a general discussion where everyone had an opportunity to share any pending issues or items they felt needed to be re addressed and discussed.

This brief draws on the meeting discussions to present feedback and opinions of Taskforce members related to the present-day challenges contributing to the unmet oral health needs among PLWHA.

## Oral Health Challenges Experienced by PLWHA

Taskforce members described several challenges they or their clients' experience as it relates to receiving oral health care while living with HIV. We have categorized their challenges into five categories:

1. Access Barriers and Lack of Providers
2. Stigma/Discrimination
3. Lack of Training and Capacity
4. Program Barriers
5. Challenges Specific to Populations and Geographic Locations
  - a. Substance Use
  - b. Immigrants
  - c. Puerto Rico

These challenges are also included in Table 3.

**Table 1. Demographics of Taskforce Members**

Demographic	#
<b>Gender</b>	
Female	5
Male	4
Non-binary/Third Gender	2
<b>Race</b>	
Hispanic	4
Black or African-American	3
Asian/Pacific Islander	1
White/Caucasian	2
Black Hispanic	1
<b>Sexual Orientation</b>	
Heterosexual or Straight	5
Gay	5
Queer	1
<b>Stakeholder Type</b>	
Community Advocacy	5
Case Management	6

**Table 2. Representation by State/Territory**

State/Territory	#
California	1
Illinois	2
Louisiana	1
Massachusetts	1
Florida	1
Minnesota	1
Iowa	1
Virginia	1
Texas	1
Puerto Rico	1

**Table 1. Summary of Challenges to Oral Health Care Experienced by PLWHA Presented by Taskforce Members**

Categories	Main Challenge 1	Main Challenge 2	Main Challenge 3
Access Barriers	Long wait times for appointments/Long distance travel for care	Providers not accepting Ryan White funding or accepting insurance	Limited locations/clinics to receive care
Lack of providers	Not willing to accept Ryan White funding or insurance	Long wait times for appointments due to lack of providers	Having to travel long distances or only getting appointments at certain times of the year
Stigma/Discrimination	HIV status being exposed by providers	Stereotyping and negative comments from providers	Mistrust/not wanting to see dentists
Lack of Training/Capacity for Providers and Administration	Providers not receiving HIV training/HIV not a part of dental school curriculum	Providers not comfortable treating patients with HIV or understanding health risks due to a lack of knowledge	Dentistry/states not knowing when or how services can be used/case managers and providers not giving referrals
Program Barriers	Limited funds/funds run out quickly	Limited locations or dental programs	Issues determining between cosmetic vs necessary procedures
Specific Population: (Substance use with HIV)	Stigma associated with substance use and messaging around “meth mouth”	Having to explain oral health issues because of substance use	_____
Specific Population: (Immigrants)	Issues navigating services as an immigrant	Language barriers	Lack of information
Specific Geographic Location: (Puerto Rico)	Lack of RWHAP funding to cover needs	Lack of providers to meet needs.	Lack of specialized services, much needed by patients in Puerto Rico.



## 1. Access Barriers and Lack of Providers

The access barriers Taskforce members described are often associated with a lack of providers. Lack of providers leads to longer wait time to get an appointment, traveling longer distances to receive care, or only receiving care during certain times of the year. The lack of providers may also be exacerbated by providers not willing to accept Ryan White funding or insurance, and limited dental programs or clinics in the area. One Taskforce member named three specific barriers related to access, “Lack of providers that are available. Traveling is 1 hour and 45 minutes and you’re there for 4 hours. Hav[ing] to pay to park and gas.”

Providers not willing to accept Ryan White funding also emerged as an issue of concern for PLWHA with one Taskforce member stating, “Our problems with the AIDS Drug Assistance Program (ADAP) in Chicago, in regards to dental care, is the lack of providers. Many providers are not comfortable receiving Ryan White money so they simply decline patients.” Two other Taskforce members agreed with this statement adding, “That is the same problem here in Baton Rouge. Lack of providers willing to accept,” and, “So true... here in Sioux City as well.”



### Policy Recommendations:

Taskforce members offered the following policy solutions to address these general barriers and lack of providers:

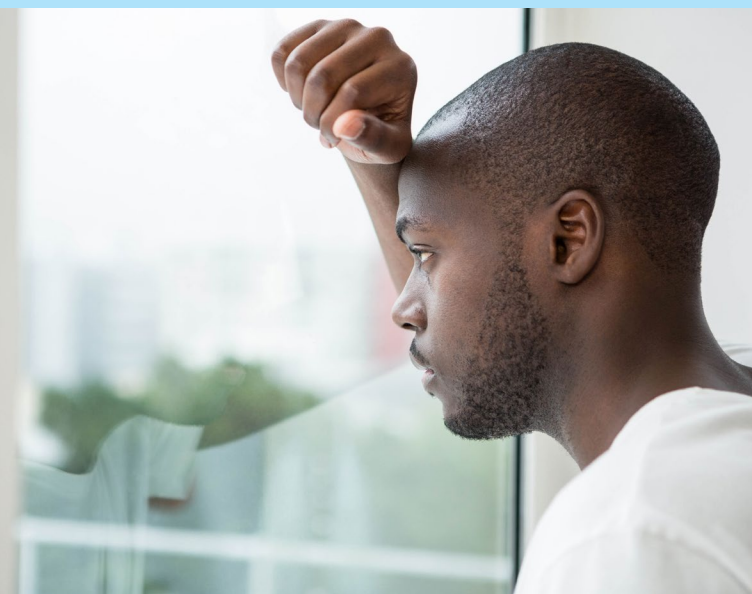
- Provide incentives to oral health care providers to work with HIV/AIDS programs and PLWHA.
- Encourage providers to set aside appointment slots specifically for PLWHA, which ensures availability and the option for patients to receive expedited care by being referred to nurses. One Taskforce member cited this practice as working well at a federally qualified health center (FQHC) and proposed it be expanded to the Ryan White program.
- Allow PLWHA to see a dental hygienist for primary care/maintenance (i.e., cleanings, addressing concerns, and referrals).

## 2. Stigma/Discrimination

Taskforce members described instances of stigma and discrimination including being stereotyped, receiving negative comments from providers due to their HIV status, or having their HIV status exposed by providers, all of which leads to medical distrust and not wanting to receive care from providers. One Taskforce member described their experience with stigma/discrimination saying,

### Taskforce Perspectives on Stigma/Discrimination

*“As a person who is HIV positive, there is a lot of stigma, and comments dentists make about teeth, and stigma with effects stimulants can have on oral health. Feelings of belittling when going to the dentist. Negative oral care experiences [are] a reality for those with HIV and those who use drugs. Sometimes (sic) put off going to the dentist.”*



### Policy Recommendations

To combat stigma/discrimination, Taskforce members provided the following:

- Make providers aware of cultural humility/competency
- Provide HIV/AIDS training for providers and those who work with PLWHA to combat misconceptions

### 3. Lack of Training and Capacity

Lack of training and capacity among providers and administration staff further contributes to issues of stigma. Often stigmatizing behaviors are driven by a lack of knowledge regarding HIV and oral health care, and when and how services can be used. Two Taskforce members gave their perspectives on providers' lack of HIV and oral health knowledge:

Regarding lack of training for administration staff, Taskforce members reported that this oftentimes resulted in inadequate advice with consequences for access to care. In situations where case workers do not have the right or most updated information regarding programs and funding, PLWHA may receive incomplete or inaccurate information, impacting access to services.

#### Policy Recommendations:

Taskforce members gave their recommendations to address the lack of training and capacity for providers and administration staff.

- Mandate that providers work with PLWHA as part of their certification and that continuing education includes HIV/AIDS, so that providers are updated on changes in treatment and infection control
- Create a text line or a resource database to share up-to-date information
- Train case managers on oral health for PLWHA
- Direct The Health Resources and Services Administration (HRSA) to provide states with training on oral health services for PLWHA

### Taskforce Perspectives on Lack of Training and Capacity

*"I have had the chance to advocate for many clients/patients, and many times, unfortunately the sad reality is providers not feeling comfortable providing care for patients with HIV. Stigma, lack of knowledge, etc. etc."*

*"Dentists don't want to sit in an educational seminar on HIV/AIDS and want to avoid certain types of clients. Dentists think people with HIV/AIDS look a certain way and there is a stereotype..."*

*"Case manager talked me out of getting marketplace dental insurance, and the services that I need are not covered under Ryan White."*

*"In Minnesota working with the state, it is like we need to push the state for them to have trainings in order for it to come down to staff. We have had issues with dentistry with the state not knowing how and when services can be used..."*

## 4. Program Barriers

Taskforce members cited funding quantity and sustainability as the main barrier within the Ryan White and Alternative Dental Assisting Program [ADAP]. Other program barriers included limited locations or few dental programs, not receiving care because procedures are deemed cosmetic and not necessary, and issues finding providers with whom to contract.

Taskforce members spoke at length about the effects of lack of funding or funds running out quickly:

### Policy Recommendations:

Taskforce members offered the following solutions to address funding issues regarding the Ryan White program and improve oral health and HIV services for PLWHA.

- Utilize Ryan White/HIV Care Councils to prioritize oral health, help with lack of funding, and identify providers who can work with the county and state to create greater access
- Ensure Ryan White funding is allocated to organizations of different sizes and scope. Funding shouldn't only be allocated to bigger organizations. There are opportunities to extend Ryan White funding to smaller community-based organizations to incorporate oral health
- Incorporate Ryan White representatives at community health centers and primary care clinics to assist with patient navigation
- Establish central eligibility, like Minnesota is trying to establish, where individuals do not have to reapply to programs and cause re-traumatization
- Establish different levels of Ryan White funding for different cases. For example funding for restorative care and funding for preventative, lower cost care. This can help address coverage issues regarding cosmetic vs necessary procedures
- Tailor funding per patient to address the different needs of each patient

### Taskforce Perspectives on Program Barriers

*"I know from experience in Louisiana, previously, when I first seeked [sic] out general services, I was told I had two cavities and two broken teeth. I was told I needed dentures. They pulled all my teeth, but then they ran out of money. Then they moved to dentistry schools, and you were sent there. To me, if you're trying to expand the quality of folks living with HIV, do you really think it's best to send them to a dental school?"*

*"Our ADAP program does pay for marketplace plans, but dental insurance sucks. I have yet to find a better plan for people. The average cost is around \$8,000, in my opinion we have fairly decent resources in my state, we just run out of money fast. For me money is such a big piece in this, we run out of money every year for people. Our program has been able to get grant funding. By month nine or ten we have spent our money. Most of our folks finish existing treatment plans, others have to wait to grant funds come in to finish treatment."*

*"I've struggled with marketplace plans covered by Ryan White, dental plans are bad. It's because in addition, the dental is part of the entire plan but it's bad. We should consider including a better health plan for the client that covers more. Include a gold plan that is more expensive and can cover more. It's unpredictable when funds are going to run out, patients have to wait six months to be able to utilize funds."*



## 5. Challenges Specific to Populations and Geographic Locations

Challenges to specific populations and geographic locations were also discussed by Taskforce members. These include co-occurring issues like substance use disorder and demographic differences such as immigration status.

### Substance Use

Stigma was the main challenge discussed by Taskforce members as it relates to substance use. Taskforce members expressed the stigma from substance use as an added layer to the stigma associated with having HIV status.

The intersection of HIV, oral health and substance use is not acknowledged by providers. For PLWHA who have or are currently struggling with substance use, having to repeatedly explain the circumstances behind the current state of their oral health is overwhelming, contributes to stigma and negative experiences while navigating the health care system, and humiliation. Taskforce members shared a number of helpful examples of the connection between substance use disorder stigmas and oral health.

### Policy Recommendations:

- Establish dental programs to utilize a harm reduction approach for PLWHA and co-occurring substance use disorder. This would help bring services to people who wouldn't otherwise use them.
- Provide oral health, HIV, and substance use training to dental providers and dental students to reduce negative experiences and stigma for PLWHA and co-occurring substance use disorder. A 2011 study found that substance use other than alcohol, tobacco, and prescription drugs were discussed less frequently in dental schools.<sup>7</sup> Dental school curricula should not only include all substance use as it relates to oral health, but also include the intersection of substance use, HIV/AIDS, and oral health, as well as how to implement harm reduction in dental care practices.

## Taskforce Perspectives on Substance Use

*"There are so many folks that have co-occurring disorders like HIV and substance use. Those folks have been beaten down by stigma and shame. I appreciated the Drug Policy Alliance for talking about the "meth mouth" stigma.*

*"I think about the intersection of people living with HIV and substance use disorders. Massaging around meth mouth and stigma, has been ingrained. [It] doesn't come from a place of empowerment. Trying to get to my dentists, I think about that, has negatively framed my experience. Stigma is hard, is there a way to teach how to be conscious of that stigma and be aware of your experience and not make assumptions?"*

*"Former drug user, having to explain why I grind my teeth to a dentist, it's humiliating, they treat me differently when I tell them why, and I put off going to the dentist because of those experiences."*

## Immigrants

Barriers immigrants experience in the health care system as it relates to oral health include difficulty navigating services, language barriers, and a lack of information. Taskforce members who are immigrants shared their experiences trying to navigate the health care system.



## Taskforce Perspectives on Immigrants

*“Dental care is not considered important. As an immigrant, I felt myself lost in accessing services, and barely knew I could access primary care. In the Latino community, there is a need to understand that it is important to access these services.”*

*“As an immigrant, when I was in the clinic, they didn’t offer it and I didn’t know about the importance of oral health. They only disclosed availability of oral health insurance until you had oral issues. There is a lack of information, especially for immigrants.”*

## Policy Recommendations:

- Provide oral health education to immigrants and assign patient navigators to immigrant patients who are navigating a health care system that is likely different from the one in their home countries
- Ensure availability of interpretation and translation services for immigrant populations to reduce language barriers and ensure health literacy
- Utilize community health workers or promotores de salud to assist immigrant populations in navigating the health care system and provide oral health education. Utilizing this health care workforce can also ensure culturally competent care

## Puerto Rico

Our Taskforce member from Puerto Rico gave meaningful insight about the oral health issues PLWHA experience in Puerto Rico. As a commonwealth of the U.S., Puerto Rico is able to receive Ryan White funds to financially assist Puerto Ricans living with HIV.<sup>8</sup> Challenges regarding oral health care for PLWHA in Puerto Rico included difficulty accessing the Ryan White program, funding issues regarding dental clinics for HIV, HIV medication, and the Ryan White program, experiencing stigma/discrimination, having to rely on dental students, and difficulty accessing oral care due to limited availability from providers and having to travel long distances.

See the blue side bar for what a Taskforce member had to say about some of the issues Puerto Rico is experiencing regarding oral health and HIV care.

## Policy Recommendations:

- Encourage an assessment of how PLWHA experience access to oral care in Puerto Rico, including a closer look at gaps and barriers to service. This could help bring more light to the specific issues experienced in this region and help provide recommendations to federal and state institutions so improvements can be made.
- Include PLWHA from Puerto Rico in funding decisions and national forums looking at HIV/AIDS awareness and advocacy efforts. It's clear from the discussion that many in the rest of the United States did not understand the issues experienced by PLWHA in Puerto Rico and including them in conversations at the national level could help bring forthcoming solutions and attention to key stakeholders from government entities.

## Taskforce Perspectives on Puerto Rico

*"Oral health [is] important for all people. People with HIV are educated about the importance of oral health...but access to oral health services we need is complicated. Even though Ryan White funds include oral health services as a category, access and availability of this service remains difficult. Oral health is much more than a dental cleaning, there is a need for specialized oral health services."*

*"In Puerto Rico, the main providers are part of the government medical plans, if Ryan White covers, it's not enough for the necessity of the care, especially oral care. In Puerto Rico, for example, [at the] University of Puerto Rico, residents are there and doing specialties in different areas, they have affordable prices and the government covers payment plans for those who can't afford. In metro areas, any patient can come from all over the island but it is far. They [providers] work during university times in the summer, and then go on vacation. They [PLWHA] don't have access, oral care [in the] emergency room is a barrier, it is not enough to meet the demand. Oral care clinics could have emergency rooms to meet the demands on the weekends, at night. [The] Pain is strong, but you have to wait to see if someone can provide the service."*

## Conclusion

This brief brings attention to the present-day challenges PLWHA experience accessing oral care. The Taskforce highlighted important challenges experienced by PLWHA which include ongoing stigma/discrimination by health care providers and staff, need for increased training to medical providers and health care staff to counter the stigma/discrimination. From a program perspective, there are not enough dental providers available to meet the growing oral health needs of this population, thus creating added issues with limited appointments available, long waiting lists and long travel distances to see a provider. The Taskforce also identified specific needs from populations such as immigrants and those experiencing or that previously experienced substance use disorder and the specific barriers they experience with accessing oral care.

Because the RWHAP is a key program serving this population, additional investment and support would help improve access to health care in general and improve the capacity of case workers in providing PLWHA with adequate information on enrollment. Our recommendations address the challenges identified, and highlight the importance of centering patients' voices and experiences to solutions, including leveraging their experience to inform programs and funding allocation.

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## Endnotes

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