

Opportunities for Addressing Social Determinants of Health and Advancing Structural Change to Decrease Oral Health Care Access and Utilization Gaps

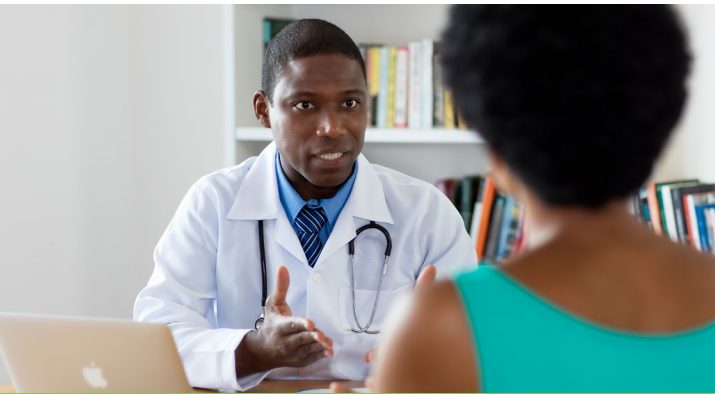
Executive Summary

The Weitzman Institute convened a Taskforce of people living with HIV/AIDS and advocates 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 (RWHAAP). 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.

This brief addresses topic #2, opportunities for addressing social determinants of health, specifically what are the social needs 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.



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.⁵ 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.⁵

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.⁶

Introduction

Research supports that the disparities in who receives oral care among PLWHA are linked to a variety of social factors including but not limited to financial hardship, lack of dental insurance, Medicaid not covering dental benefits, dental anxiety, unstable housing, and transportation limitations, among others.^{1 2} It is estimated that at least 52.4% of PLWHA report not having seen a dentist in more than two years, and 48.2% report experiencing an unmet oral need since testing positive for HIV.³

PLWHA eligible for RWHAP funding cited cumbersome administrative procedures, long waits at the dental office, and dentists' reluctance to treat people like them as added barriers.^{1 4} For PLWHA the administrative procedures associated with seeking a dentist involve the difficulty experienced in keeping track of paperwork and the extensive documentation needed to obtain a referral to a dentist.¹ PLWHA who do receive oral health care report overall positive well-being.¹ For them, having a social worker or case manager assisting them in processing dental referrals and navigating the health system and needed paperwork is key to having access to a dentist visit and in feeling positive over the process.

Although prior reports highlight the social needs PLWHA experience, with this Taskforce, the goal is to address what these reports don't tell us. How are these social needs manifested in the real world, the real consequences PLWHA faced, and highlight their and their peers' experiences at the center of the recommendations made.

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. 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, the team convened a representative Taskforce comprised of PLWHA and patient advocates working closely with PLWHA or familiar with HIV/AIDS advocacy and community work. The 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 allow Taskforce members to become comfortable speaking with one another and learning 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 from their perspectives. The last meeting 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 presents feedback and opinions of Taskforce Members related to social needs contributing to the unmet oral health needs among PLWHA.



Table 1. Demographics of Taskforce Members

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

Summary of Social Needs Presented by Taskforce Members

Taskforce members described the needs they or their clients experience as it relates to receiving oral health care while living with HIV. Using the Healthy People 2020 SDOH place-based framework we categorized the needs identified by the Taskforce members into four categories:⁶

1. Economic Stability
2. Education Access and Quality
3. Health Care Access and Quality
4. Cross-Cultural Specific Needs

Summary of these needs are presented in Table 3.

“To get a priority visit, you have to jump through hoops, have to have someone advocate for you, get the bare minimum. Confidentiality goes out the door, wanting to let people know what is going on with you so they understand, then you have to educate people and HIV is not a part of the curriculum. You have to fight so many fronts and it’s challenging.”

Table 3. Summary of Needs Identified to Oral Health Care Experienced by PLWHA

Needs Identified	Main Need 1	Main Need 2	Main Need 3
Economic Stability			
Housing	Affordability of housing, difficulties paying rent	For PLWHA and substance use disorders finding affordable housing is a problem when programs require to be off drugs to qualify. These two create additional stress with oral health the last thing on their minds.	—
Financial Hardship	Not having the funds to cover all needs (food, housing, and other expenses).	Out-of-pocket expenses. Not having money to cover medical bills related to oral health. This is one of the reasons why many forgo treatment.	—
Food Insecurity	Insufficient access to programs that support affordable, healthy food	—	—
Education Access and Quality			
Resources/ Information	State and federal websites for providers and patients are hard to navigate adding to confusion. Lack of updated information on said websites especially at the city level is also a reported challenge.	Lack of information and sharing with PLWHA, especially those recently diagnosed, on the importance of oral care.	Caseworkers, navigators, and those who serve as first contact for PLWHA at times don't know about all the resources available or don't share resources.
Health Care Access and Quality			
Transportation	The need for patients to travel long distances for appointments results in having to take a day off work resulting in other added expenses such as gas, meals, and stress.	Unreliable public transportation by companies providing the services as part of assistance programs, or PLWHA not having a way to attend an appointment.	Patients traveling across state lines for dental appointments.
Program Enrollment	Requires patients to take a day off work to visit a social worker	Case workers at times lack information on potential funding sources for PLWHA and programs. PLWHA report having to do a lot of the legwork.	—
Support Systems	Lack of social systems to help PLWHA feel supported in navigating RWHAP and health care in general.	Dental visits increase anxiety. Revisiting diagnosis, and completing paperwork take an additional toll on PLWHA.	—
Technology Barriers	For some patients, a lack of familiarity with technology results in missed appointments and opportunities for care.	During COVID, the implementation of a new system created confusion with patients as they didn't know they had to follow up using this new tool.	—
Cross Cultural Specific			
Cross-Cultural Specific Needs	Language is a challenge in every aspect, including navigating RWHAP and finding resources.	Lack of cultural competence by providers and administrators creates challenges with trust, avoidance, etc.	—

1. Economic Stability

Economic stability refers to people having the necessary resources to lead a healthy life. In the U.S., 1 in 10 people live in poverty which impacts their purchasing power to afford things like health care, housing and healthy foods. As part of this section we review areas our Taskforce highlighted that impact PLWHA economic stability.⁷

Housing

Housing is a problem for PLWHA, especially for those living in places with limited options that are affordable. Taskforce members working as case workers/managers shared how they're seeing a growing need among PLWHA for affordable housing, with many asking for enrollment to programs that could help them in this area. An option for PLWHA in Puerto Rico struggling with housing is seeking hospice care, with the care they receive extending their life for many more years. Although as shared by our Taskforce member from Puerto Rico, this scenario is far from perfect even though they report improvement in other areas of their health, oral care is an item they still struggle with.

Policy Recommendations

- Preserve and increase resources for federal affordable housing programs, improve the Low-Income Housing Tax Credit program, and reform project-based housing programs to encourage higher-quality housing.
- Embed special housing stipulations under RWHAP, focused on preventing any PLWHA enrolled with RWHAP from getting evicted.

Taskforce Perspectives on Housing

"In Puerto Rico – People in an advanced state of HIV go to hospice and recover and live there for 25 years, but they have needs, and we don't consider them and their needs. Oral care is a need in this population, missing teeth, and cavities because they have a limitation of resources."

"Housing is expensive here too, I don't know how folks are paying rent, it's a struggle on all fronts in Florida. [The] most marginalized are prioritizing keeping a roof over their head over oral care. If it's not hurting, we'll just keep working with it, when they seek care, it's an extraction."

"Housing is becoming a privilege and not a basic human right"

"For example, I've been living 30 years in section 8 and the lottery is difficult to be able to make money because you have to pay the 30%. We have advocated to see how the housing department can provide permanent housing. The house could've been mine, it's not that we don't want to pay, they don't allow you to move forward you have to decide to work or make money or keep your house. I make \$450 a month but I can't afford [it], I want to pay a fair amount."

Financial Hardship

Financial hardship impacts many social needs highlighted in this brief, but they also directly impact the ability to pay for needed oral care services. As mentioned by taskforce members, delaying oral care and procedures occurs because they don't have the ability to pay for out-of-pocket services. Many depend on RWHAP funds for this purpose, but these are also limited. Unfortunately, Taskforce members shared how at times by the time they see a dentist and are given a list of procedures they need done and RWHAP funds for that funding year have been spent, resulting in them having to delay care to the following year when new program funds are available.



Policy Recommendations

- Expand RWHAP Part F funding to cover patient needs.
- Expand the number of oral health providers accepting RWHAP patients. Increasing the number will help address other social needs such as transportation.

Taskforce Perspectives on Financial Hardship

"As far as affordability, there are caps on services where it is a choice, where you go to work and risk losing benefits, or stay where you are. Services are wonderful and helpful, but they end up being handcuffs and hold you back from growth and advancement. If I go to work, what does that look like, do I lose my benefits? More information needed, what happens if you do lose benefits, relieve some fears. I've been over \$10 or \$100, still don't have enough to pay out of pocket."

"There are very few things that are good for dentures, products aren't expensive but can be for folks who can't afford it. It's all over the place, no regulation or education. Go to the dentist and they won't tell you. How do I know what is good for me, it becomes to the point where people neglect what is good for them and go with what's cheaper. Have to go to an expensive store to get better quality."

"Transportation involves gas and time. Even if the visit is covered, there is a minimum of \$30 in gas and over an hour for travel. Lunch is also involved. Frequently there is a copay or a deductible, especially if a case manager or provider did not send a referral. Have to cancel appointment, get in touch with a case manager. If they did not send it in a timely manner, I would have to wait"

Food Insecurity

Another concern expressed by Taskforce members was the struggle to find affordable food. This is also related to the financial hardship reported in the next section.



Policy Recommendations

- Extend navigation to food assistance programs for all PLWHA under RWHAP. Improve mechanisms to enroll PLWHA or any RWHAP patient in assistance programs addressing social needs such as food assistance. Improving such mechanisms will involve making enrollment less cumbersome.
- Provide vouchers and stipends for RWHAP patients to use/spend on days they have to travel for an appointment. Considering that appointments often require added costs including meals/lunch, these vouchers/stipends can help with addressing food insecurity for those specific occasions.

Taskforce Perspectives on Food Insecurity

“Education is so important, I work with all adults and am taken aback about the little information folks have about oral care. People don’t realize how important it is, education can help. What foods you’re eating and how that impacts oral health. They can’t just go buy it because it’s so expensive.”

“We have clients coming in all the time, now they are asking for help filling out applications for food stamps, housing, [and] transportation.”

2. Education Access and Quality

Access to education enhances quality of life resulting in people living healthier and longer. As part of this section we review areas our Taskforce highlighted that impact PLWHA education access and quality.

Resources/Information

Taskforce members cited the importance of access to resources and information. The internet has made it easier to find information, but to ensure accuracy and timeliness, it is important that information on government websites be updated frequently and consistently. For many patients, searching online is one of the first things they do when trying to find both resources and information. This includes updating providers that are in fact accepting RWHAP funding or in network. Taskforce members highlighted also the wealth of information that is available regarding funding and programs that could essentially help PLWHA with a variety of needs. The issue is that in many cases, taskforce members who are case workers find out about these programs and funds through peers and other contacts, and not necessarily through an official channel. All taskforce members shared how they individually keep personal databases, where such information is stored and they can refer to it as needs arise. Taskforce members who work as case managers have come to develop their own internal databases to use at work.

Policy Recommendations

- Create a repository database to include important resources for PLWHA. This includes storing information on quality providers, funding streams, and advice on navigating systems. Support from RWHAP and other federal entities could be useful in maintaining this database. The database should include a space dedicated to oral health services. Participants suggested having such resources supported by a dedicated group of advocates, such as this Taskforce of PLWHA, could help timeliness and accuracy amid the changing needs of PLWHA and changes to federal programs.

Taskforce Perspectives on Resources/Information

"They don't give you a list of services available to you unless you ask. There is so much information."

"Creating these "guidebooks" and having them updated all the time would be really helpful, but it seems that it is not in the state's capacity to get that done."

"State government websites [...] use websites for providers and clients and it's hard to navigate which website (you're) supposed to be going to because there is so much information and it is not well organized. Can be confusing at times."

"Most plans do not have a reliable database for providers under the plan who are actually in the plan, still in business, or have the right contact information."

"I'm the resource guru in my agency. I google a lot. But the capacity of these agencies is super low."

"When a person is seeking other services, including housing or domestic violence [supports], there should be outreach for dental care and other organizations to make sure clients/patients are aware of the importance of oral care. One way to do that is through community health workers or community support."

2. Health Care Access and Quality

Health care access and quality is defined as a person's ability to have equitable and affordable access to health care services when needed. This includes both physical access and availability. As part of this section we review areas our Taskforce highlighted that impact PLWHA health care access and quality.

Transportation

Medicaid offers non-emergency transportation but unfortunately for many the services can be unreliable. This is manifested in cancellations on the day of appointments, arriving late for pick up, and 'no shows' where no ride arrives as scheduled. As taskforce members expressed, these service providers must understand the importance of arriving on time to appointments. If a health care provider refuses to see a patient who arrives late or does not show up, getting a new appointment can take six months to a year.

Policy Recommendations

- Increase oversight of companies receiving funding to provide transportation services for medical appointments. This includes a mechanism so complaints can be processed, and when patients are left on their own, they are able to report back swiftly.
- Provide another appointment within the next month for patients experiencing difficulties with transportation and making it to appointments and in the event they show up late because of an issue with assigned transportation. This requires RWHAP to work with oral health providers in adding these stipulations in contracts.

Taskforce Perspectives on Transportation

"I just got into the RWHAP program and didn't see a difference between this and Medicaid. [I] have to travel 45 min to another state to see the only dentist that provides such services."

"Lack of providers that are available. Traveling is 1 hour and 45 minutes and you're there for 4 hours. [And you] have to pay to park and gas."

"Transportation is also a big concern in South Florida, [the] bus system is not the most effective, folks are waiting up to two hours just to get to an appointment, waiting a long time at the doctor's office due to a line of other patients, it's a whole day situation, relying on Medicaid and have to take off from work, taking off too often can result in them losing their job, they don't have that flexibility, may have to sacrifice a few appointments, sacrificing services, have to choose between medical or dental appointment, forgo dental and now have oral [health] issues."

"Two in-one system [Florida] has received a grant for transportation, which we advocated for, but when people get to the clinics, it creates bottlenecks, [the] cycle continues."

"[Transportation services] arrive late and then don't pick you up when you're done. I have had clients waiting for transportation until after dark."

Program Enrollment & Support Systems

Having a support system is considered essential for PLWHA in need of dental care. This support group is important in helping them keep up to date with appointments, seek information, and navigate the health care system. For PLWHA social workers/case workers play a crucial role in facilitating access to oral care. As described by many, social and case workers play a key role in advocating for patients when they are in need of emergency services. Navigating RWHAP can be cumbersome, yet having a good social worker is imperative to doing so in a successful way.



Policy Recommendations:

- Offer continuing training to case managers/social workers so they stay up to date with changes to RWHAP, new funding sources, and most importantly the struggles PLWHA face in seeking services.
- Increase sensitivity training for case managers/social workers to remove stigma and discrimination towards PLWHA.
- Ensure that social services offices, that help individuals enroll in various programs, are more inclusive towards the people they serve. This may involve adjusting work hours so people can visit them after work or during the weekends. PLWHA in need of enrollment can't afford to take a day off work and lose that income.

Taskforce Perspectives on Program Enrollment & Support Systems

"You have to fight so many fronts and it's challenging. We have clients coming in all the time, and now they are asking for help filling out applications for food stamps, housing, and transportation. We ask about HIV status, and find them (related) programs. (We) collaborate with multiple organizations to help (them), they are showing up in crisis. But by the time we get done helping them, we haven't talked about dental care."

"Had a young lady who had a 3-day [eviction] notice, with HIV, kids with disabilities, and [we] stayed late to find resources for her, [we] have to keep addressing these issues to keep clients stable."

"You have to do all the legwork to call and see if the provider is still in service, what they provide, etc. – [it] begs the question: "Why do I have a case manager for?"

"Many people feel too ashamed to talk to their case manager about the resources they need– there is the 988 text line for mental health, but there is none for PLWHA specifically and there should be!"

3. Cross-Cultural Specific Needs

For this project, cross-cultural specific needs are those observed that impact racial and ethnic disparities in health issues. Language barriers and health care provider and staff ability to comprehend and identify needs of people from a variety of cultures are two examples Taskforce members highlighted.

Language Barriers & Culturally Sensitive Trainings

Taskforce members discussed cross cultural specific needs, in particular those created by language barriers. For taskforce members working with minority populations, having resources to share in other languages and providers providing culturally sensitive health services are important.

Policy Recommendations

- Provide cultural sensitivity training to providers and staff.
- Increase the number of resources available in other languages.
- Conduct a needs assessment to better understand the needs of PLWHA that come from minority populations and that experience language barriers in receiving health care services, including oral care. The results could inform allocation of funding, what gaps must be addressed, and how to meet them to make care more accessible to this population.

Taskforce Perspectives on Language Barriers

“Most clients are new to the country, don’t know of services, and language is a barrier.”

“[Case workers] Must try to find providers that the patient prefers, speaks their language, and would take their insurance.”

“Language is a barrier and the lack of cultural humility to provide services for diverse communities.”

Conclusion

The current brief brings attention to the social needs PLWHA experience and how this impacts their availability to access oral care. As stated in our policy brief, oral care is important for PLWHA as they experience more oral health problems compared to their non-infected counterparts, have greater difficulty accessing and using oral health care services, and thus, experience greater unmet oral health needs than the general population. The 2023-2025 National HIV/AIDS Strategy for the United States makes emphasis on the need to address the social determinants of health influencing an individual's HIV outcomes. Our Taskforce identified important social needs experienced by PLWHA that include housing, transportation, financial hardship, food insecurity, and the need for resources and information. They also identified the key role program enrollment, when done effectively, has on patients' access to programs that can help them meet their social needs. Case workers play a key role in helping PLWHA address many of the social needs they experience by finding programs and services that can help them meet these needs. As recommended in our brief, case workers and patients should be included in funding allocation discussions as they can provide a better perspective on how actual needs are manifested across patients. Case workers' perspectives can provide a holistic view of what patients experience specific to social needs and the barriers to obtaining assistance to social programs, which can potentially target social determinants of health. They can provide an in-depth understanding of the interconnections across various social needs and the impact these have in the lives of PLWHA.

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Endnotes

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