Amplifying the Voices of People Living with HIV/AIDS and Patient Advocates: Recommendations for Oral Health Advocacy

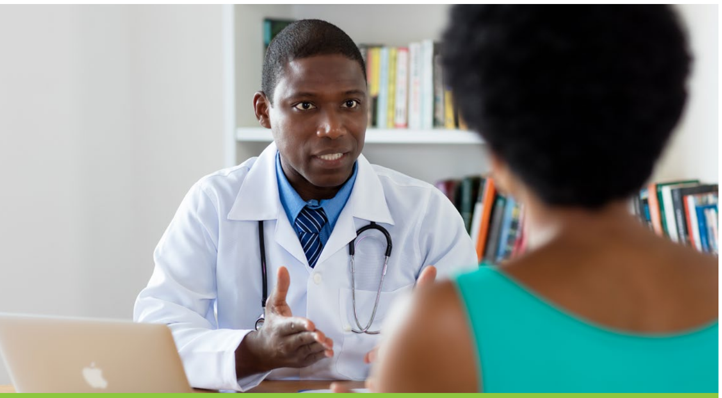
Executive Summary

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 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.[1] 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]

This brief addresses topic #3, recommendations for amplifying the vital role that patients and patient advocates play, including examples of Taskforce members' experiences advocating for the improvement of policy and programs targeting oral health 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

Since the beginning of the AIDS epidemic, people living with HIV/AIDS (PLWHA) have been at the center of advocating for treatment and care. Advocacy by patients, families, and caregivers has been at the forefront of identifying and recognizing the disease, advocating for care/treatment, and fighting stigma and discrimination. The new generations must recognize past efforts and continue expanding advocacy efforts as needs evolve.

PLWHA continue to experience stigma and discrimination and find themselves together with activists advocating for funding for research and health care programs. The 2022-2025 National HIV/AIDS Strategy for the United States mentions the importance of expanding engagement opportunities for PLWHA in the areas of research, planning, delivery, assessment, and improvement of HIV prevention, testing, and care services.

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 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.

Experiences from Taskforce Members

Taskforce members provided insight into the various ways advocacy plays a role in their lives and the impact it has on their oral health care as PLWHA. We have categorized what they shared into five categories:

1. Cultivating Advocacy Opportunities
2. Advocating for Patients
3. Fear of Funding Cuts
4. Ongoing Education and Awareness
5. The Changing Demographics of HIV/AIDS Population

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

1. Cultivating Advocacy Opportunities

Creating advocacy opportunities is important for PLWHA. This means not just advocating for their own health but for the rights and services PLWHA should have access to. Taskforce members highlighted the impact advocacy opportunities have had in their lives and work. Together with advocating it is important to fund and support opportunities where PLWHA can learn about advocacy.

Taskforce Perspectives on Cultivating Advocacy Opportunities

"I was diagnosed in 1989, and the doctor told me not to tell anyone. I didn't for many years, while I advocated for myself and my needs, I was publicly sharing my diagnosis. In 2015 I found Positive Women's Network and in Myrtle Beach was my first experience sharing about HIV. I was amazed, for all those years from 1989 to 2018 I was living in a bubble, I was afraid of people finding out. Since then it's been a wonderful experience, having the ability to give back to organizations that have helped me and others. NMAC is a wonderful organization that has helped me. A group of us developed the National HIV/AIDS advocacy network, to facilitate education and share knowledge. I have been able to attend AIDS Watch in person and (have a)great experience for education and training that have (provided) tips and ideas to meet with policymakers. I'm able to bring other people along with me. Offer many opportunities to get involved and expand education and become engaged. I was able to apply for a grant for women with HIV."

"One of the biggest positives of being an advocate is getting people to help expand services and become part of the solution. People don't know where to start, being in activism has helped other people see where they can be involved. One of the negatives, working for my last organization, people who have worked in HIV for a long time, offering an alternative, can be seen as a threat. I was treated as a threat for asking questions. Good thing was that there were other people in the organization who said maybe we should try this or that. Give people confidence to try."

"My first experience with being an advocate was with Mass. Fellowship, crash course in how to learn public policy. It was a lot of info, but thinking about how do we work with legislators to make change. I didn't know about this. I also went through another training, bringing people with lived experience and learning how to be an active member of RW council. I always think about where funds go, Boston gets all the money. Central Mass does not get a lot of funding, have to advocate to get money and think about where the needs are in my community"

2. Advocating for Patients and Services

Taskforce members shared the various ways they advocate for their clients despite issues like stigma and lack of knowledge on HIV/AIDS continuing to be barriers. At times as case workers, they are left to advocate for patients even within their own organization. They highlighted once again the important role they play as liaisons - a role that at times is underutilized but that could serve to present stakeholders, such as legislators and representatives, with a clearer understanding of the struggles PLWHA face with government funded services.

Recommendations for 1 & 2:

- Extend advocacy training opportunities for PLWHA. This includes funding opportunities where PLWHA and advocates can learn about the role of Congress and policymakers in funding HIV/AIDS related research and programs and how to effectively advocate. These trainings can also increase skills to create change and help PLWHA become leaders and help others seeking to do the same.
- Policymakers and federal institutions should open spaces for HIV/AIDS advocacy, including inviting PLWHA and their advocates to board meetings, advisory/planning councils, etc. at the federal, state, and local level. These spaces should revolve around listening to PLWHA and their advocates on trends and emerging needs, with a focus on implementing their direct input and feedback. These spaces could also be an opportunity for the Ryan White HIV/AIDS Program (RWHAP) to invite open dialogue across the nation with PLWHA and their advocates. For example, by hosting national forums where they provide direct feedback on the programs.

Taskforce Perspectives on Advocating for Patients and Services

"I have had the chance to advocate for many clients and patients many times, unfortunately the sad reality is providers (do) not feel comfortable providing care for patients with HIV. Stigma, lack of knowledge"

"Being a patient navigator, but coming from the realm of advocacy within my organization I was charged with documenting client needs for folks with HIV. We should be charged with introducing their issues at board meetings, advisory/planning councils. Bringing situations to people that can actually do something about them. We can go to legislatures and people in higher power, we have to start with the situations in hand, changes can be made within the organization"

"At a local level, part of AIDS Project Worcester, they used to do advocacy day where they would go to state house and talk to legislators about how PLWHA are being treated which is really important at this time."

3. Fear of Funding Cuts

It was clear from our conversations with Taskforce members that there is a fear of what funding cuts to RWHAP could mean for their health. Specifically the House Labor, HHS appropriations Subcommittee in their proposed FY2024 spending bill proposed eliminating funding allocated to various HIV/AIDS related programs, including $74 million from the RWHAP. These proposed funding cuts will impact access to health services for all PLWHA, especially when 50% of PLWHA—about a half million people nationwide—rely on RWHAP program funds.

Recommendations:

- Include PLWHA and advocates in funding allocation efforts. Increase forums where they can share the positive impact RWHAP has on their health and outcomes in the future. When decisions are made regarding programs and funding impacting their source of health care, their voices and lived experiences should be at the center of discussions.

Taskforce Perspectives on Fear of Funding Cuts

"I was in the HIV Caucus group (meeting) this month and they were talking a lot about funding cuts. States with big cities could be getting funding cuts which affects a lot of people. [we] need more advocacy about educating people about HIV and how it isn't just a gay man's disease. It affects everyone."

4. Ongoing Education and Awareness

Although many people living with HIV can expect to live as long as their peers who do not have HIV, provided they have access to medical care and adhere to HIV treatment, it is important to continue education and awareness efforts. Taskforce members talked about the importance of having intergenerational conversations about HIV/AIDS. They also expressed the need for education and awareness about navigating RWHAP at the federal, state and local levels. Educational material that helps remove the continued stigma surrounding HIV/AIDS is still needed as voiced by our Taskforce members experiences with discrimination and stigma from both community members and health care staff.

Recommendations:

- For youth diagnosed either at birth or at a young age, educational programs are needed that emphasize the importance of advocacy for their own health and others.
- Increase education and awareness about how to navigate RWHAP and health care in general. This includes making this material accessible for all ages. It is important that those diagnosed at a young age also learn about the health care system and programs that could help address the health needs they may experience as someone with HIV.
- Continue HIV/AIDS awareness campaigns that encourage people to openly discuss HIV/AIDS. This goes hand in hand with removing the stigma the diagnosis still holds in our society.
- Create culturally sensitive education and programs related to HIV/AIDS. Revisit campaigns and programs that are tailored to minorities and make sure they are also adequately translated to other languages.

Taskforce Perspectives on Ongoing Education and Awareness

"I was diagnosed at 16, at that point I wanted to shift my narrative to help other people. Realized HIV wasn't as devastating to me as it was for my peers. At 17, I got a job at (a) children's hospital as a patient navigator helping patients younger than me. From there I got a job at another org. I work at the Youth and AIDs project, I think of my story as full circle. Took my experiences to advocate for others and teach others about advocacy. I agree that it's interesting learning all sides of the field, my focus has been patient centered but learning about program management and writing grants and learning about political advocacy. Important for people of all ages."

"I want to share my experience in navigating HIV, here in Puerto Rico it's been very hard. It's a health condition that has so much stigma and it's been hard getting help from the community. They think that to help with gatherings they are going to mingle with folks with HIV. I believe that my best way of advocating is showing my face and saying things as they are. I'm validating myself and my peers. It's always a steep hill, it's been 31 years since I've been diagnosed and I'm still learning about HIV. If I have my college degree, it doesn't matter, they still stigmatize me. We are the only ones that have to do things for free, but everyone else gets paid. We are the experts, we have knowledge and the experience, it's a big challenge. People try to intimidate me. How can we empower other people with HIV? I'm a 55 year old activist and I want to let other Puerto Ricans know that they can advocate. You lose the battle when you don't fight for the services we have now, I feel privileged to be here. We can't lose what we already have, we have to unify. We are looking for equality."

5. The Changing Demographics of our HIV/AIDS Population

A topic that resonated with Taskforce members was imagining what the future held for an aging HIV/AIDS population. Many of the participants were told when first diagnosed they wouldn't be able to live long, and yet they continue to live productive lives.

Recommendations:

- Need to prioritize older populations in HIV/AIDS advocacy by including older populations in discussions about the type of assistance they will need in relation to their HIV status as they age. Our aging HIV/AIDS are subject-matter experts that should be at the center of providing guidance in these matters.
- Need consensus guidelines for the dental treatment for PLWHA that include recommendations of a specialized oral health protocol for children and youth that are HIV Positive.

Taskforce Perspectives on the Changing Demographics

"When I was diagnosed there was no medication, little hope. Then I came into support groups, laying out the path for those who will come behind me. I am concerned about aging, I thought I was not going to be able to retire. I don't know what the future will look like for me, but eventually age will take its course and I will need a lot of assistance. Grateful to be able to be here and participate in things that were not available to us."

Conclusion

The current brief makes recommendations for amplifying the vital role that patients and patient advocates play, including examples of Taskforce members' experiences advocating for the improvement of policy and programs targeting oral health among PLWHA. As stated in our policy brief, PLWHA and their families since the first case was observed have been at the center of advocating for improved access to care and discussions to remove stigma and discrimination associated with HIV/AIDS. Oral care is important for PLWHA as they experience more oral health problems compared to their non-infected counterparts, and yet they have greater difficulties accessing and using oral health services. Specifically for PLWHA federal programs such as the RWHAP have been instrumental in increasing access to dental services. Yet much work remains to be done to improve access to RWHAP and address social and political factors impacting general access to oral care services. Recent threats to funding cuts associated to RHWAP and other HIV/AIDS-related research programs instill fear among PLWHA as to what access to oral care may look like in the future.

PLWHA are already doing everything they can to advocate for themselves. It is about recognizing the voice and experience they bring to discussions and valuing them as the subject matter experts they are. It is not just about having an outlet, it is about their voices, experiences and input being used directly influencing policy and programs that impact their health. They should be at the center of providing feedback to how programs that work well on paper are actually reflected in reality. If we intend to end the HIV epidemic by 2030 as outlined in the National HIV/AIDS Strategy for the United States (2022–2025), they must be included in conversations that expand programs, including prevention and implementation, and in funding allocation, and continued feedback on programs at every level (city, state, federal) so we can improve on.

> *"I think that, specifically in my current position in program management and development. I try to reach out to all the providers and folks in the clinic who can be an ally. Measuring the level of comfort of folks with HIV to provide training and competencies. From the program development aspect, bringing my own resources and creating a team that can help support in grant management and advocate for the program. Not only for people with HIV but everyone that can be tested. Sending a survey, and asking people what do you know about HIV, what is your comfort level in talking about HIV. It's ongoing and ever evolving. We are doing a series of training sessions in the fall and the winter, including prevention, PrEP, cultural competency, and treatment."*

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Endnotes

1. Oral Health and HIV, The Ryan White HIV/AIDS Program. https://www.hrsa.gov/sites/default/files/publichealth/clinical/oralhealth/hivfactsheet.pdf.

2. Parish C, Siegel K, Pereyra M, Liguori T, Metsch L. Barriers and facilitators to dental care among HIV-Infected adults. Spec Care Dentist. 2015 Nov-Dec;35(6):294-302. doi: 10.1111/scd.12132.

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