



RYAN WHITE CLIENT SATISFACTION ROUNDTABLE DISCUSSION REPORT

CHANGE BEGINS WITH YOU AND I

PREPARED BY Kheoshi Owens



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Executive Summary

Empress Rules Equity Consulting collaborated with Multnomah County to hold roundtable discussions with Black, Indigenous, People of color living with HIV in the Ryan White Program. The findings from the roundtable discussions provide valuable insights into their experiences. Participants shared their challenges with accessing care and support services, experiencing stigma, and the need for more culturally responsive care. These findings will help inform and improve the Ryan White program to better meet the needs of people of color living with HIV. The following are the findings and recommendations from the roundtable discussions:

Findings

- **Importance of Peer Support:** Participants emphasized the importance of social and emotional support groups in managing their HIV status. They highlighted the role of peers in providing emotional strength and preventing feelings of despair. The day center was mentioned as a vital source of support.
- **Positive Experiences with Access to Talking Circles:** Participants shared positive experiences with having access to talking circles, which allowed them to discuss their problems and receive support.
- **Importance of Representation:** One participant noted that the day center they attended was predominantly attended by men, indicating a need for more representation and inclusivity for women and non-binary individuals.
- **Appreciation for the Ryan White Program:** Participants shared their positive experiences with the Ryan White program. They mentioned how the program has helped them access necessary services, including housing and dental services.
- **Need for More Transitional Housing:** Some participants noted the lack of transitional housing as a missing service in the current program. They emphasized the difficulties faced by people struggling with homelessness while waiting for permanent housing.
- **Role of Advocacy:** Some participants also highlighted the importance of advocacy and being part of discussions about program services. They mentioned how being involved in these discussions helped them feel more empowered.
- **Access to Care:** Participants identified challenges in accessing HIV management and care, including stigma and discrimination, lack of transportation, inadequate resources for non-English speakers, and limited access to mental health and substance abuse treatment.
- **Navigation of the Healthcare System:** Participants noted that navigating the healthcare system and accessing resources was often confusing and overwhelming, and that there was a lack of communication and coordination between different service providers.



- **Community Support and Advocacy:** Participants emphasized the importance of community support and advocacy in improving access to care and addressing systemic issues related to HIV management and care.
- **Education and Awareness:** Participants recommended increasing education and awareness about available resources and services, as well as addressing stigma and discrimination through education and awareness campaigns.

“And it seems like, well, at the beginning, Yeah, they would give you these little brochures like all the stuff that we can do for you. But when it comes to trying to get access to those things like housing, childcare, they have like the little camps for the kids. Then after a certain amount of time, you don't qualify for those anymore. So, they just like, okay, well, you're kind of graduated from the program, good luck in all you do, but they don't give you like a graduation or any steps on who else can you access for help.”

- **Coordination and Collaboration:** Participants recommended improving communication and coordination between service providers to promote a more comprehensive and coordinated approach to HIV management and care in the Portland area.
- **Affordable Housing and Food:** Participants also noted challenges in accessing affordable housing and food, which can have a significant impact on their overall health and well-being.
- **Mental Health and Substance Abuse Treatment:** Participants recommended increasing access to mental health and substance abuse treatment, which are critical components of HIV management and care.
- **Transportation:** Participants recommended improving transportation options for individuals living with HIV, which can be a significant barrier to accessing care.
- **Language Barriers:** Participants recommended addressing language barriers by providing translated materials in different languages.

Overall, these common themes highlight the need for greater education, awareness, support, and collaboration among service providers, community organizations, and individuals living with HIV to promote greater equity and access to care.



“We need more events like this so that we can really influence how we see BIPOC HIV data. And especially, you know, working with Ryan White and federal funds, data is pretty much our friend. And trying to figure out how to support each community. As of now, Ryan White funds force BIPOC people to work in silos.”

Roundtable Discussion Participant

Introduction

Multnomah County contacted Empress Rules Equity Consulting to support in planning, recruiting for, and conducting roundtable discussions with clients who were living with HIV, as a part of Multnomah County’s biannual program/service evaluation. In 2020, the program conducted their first set of roundtable discussions in years; however, they primarily captured the voices of white men. Empress Rules Equity Consulting and Multnomah County committed to ensuring that the voices of Priority Communities, or communities whose perspectives may have been underrepresented by the program in the past (and who experience disparate health outcomes) are heard. Empress Rules was very grateful to work collaboratively with Multnomah County to learn more from these community members to help improve Ryan White programs for all participants.

About Empress Rules Equity Consulting

Empress Rules Equity Consulting is an MBE/WBE/ESB certified firm founded by Kheoshi Owens in 2017. The firm's mission is to eliminate racism and implement justice through its expertise in AREI (Anti-Racism, Racial Equity & Inclusion) centered:

1. **Strategic Planning:** Developing racial equity action plans for organizations to implement.
2. **Workshops:** Providing workshops on various topics related to anti-racism, racial equity, and
3. **inclusion.**
4. **Needs Assessment:** Conducting needs assessments to identify gaps and opportunities for growth in organizations' AREI practices.
5. **Executive Coaching:** Providing coaching services to executives to support their AREI journey.
6. **Community Engagement:** Engaging with communities to promote equity and justice.
7. **Restorative Justice:** Providing guidance and support to organizations on implementing restorative.
8. **justice practices.**



9. **Business Development:** Providing free business development services to BIPOC who are ready to pursue their dreams in entrepreneurship.

Kheoshi Owens holds an MBA and identifies as a Master Facilitator, Strategist, Philanthropist, Mother, Activist, tennis fanatic, and North Portland Native. Kheoshi is a natural born leader and teacher who enjoys supporting organizations on their AREI journey.

Empress Rules utilizes the transformational and engaging consciousness-raising technique called the "Experiential Learning Cycle" to support the embodiment of AREI practices as racism is not a cerebral experience; it must be embodied. Empress Rules provides participants with the tools that they need to be successful and prides itself on being a learning institution; a place where people are allowed to make mistakes, show up as their authentic selves, be empowered and hold each other accountable.

Empress Rules' commitment to eliminating racism and promoting justice is evident in its work. Its expertise in AREI services helps organizations to create real change and promote equity and inclusion. Empress Rules' dedication to being a learning institution and allowing people to show up as their authentic selves is commendable and aligns with the goal of promoting equity and justice for all.

Methodology

Empress Rules Equity Consulting and Multnomah County partnered to design a community engagement process that aimed to collect feedback from participants of color living with HIV in the Ryan White program. The initiative was developed with the help of an advisory group, which worked to ensure that the engagement process was intentional and inclusive. This approach emphasizes the importance of community engagement and involvement in addressing the needs of those living with HIV. Empress Rules worked with the Advisory Group and the Ryan White (RW) planning team (comprised of Aubrey Daquiz and Grace Walker-Stevenson) to develop the following:

- Participant criteria survey – Survey specific characteristics or qualities that individuals must possess to be eligible to participate in the roundtable discussions.
- Review the consent form - Document that provides information about the roundtable discussions and seeks their agreement to take part in the study or procedure.
- Round Table Discussion Guide - Set of questions or topics designed to facilitate a group discussion among participants seated around a table or “virtual table”. The guide outlines the main points of discussion and helps to keep the conversation focused and productive. The questions or topics are usually open-ended, allowing for a range of perspectives and ideas to be shared.
- Stakeholder outreach - Helps to ensure the process includes participants with lived experience.



Participant Criteria

The participation criteria for the roundtable discussions included:

- Currently living with HIV
- Living in Clackamas, Clark, Columbia, Multnomah, Washington, or Yamhill counties
- Identifying as a Black, Indigenous, Person of color
- Receiving services from Ryan White providers
- Roundtable discussion availability

We chose these criteria because we wanted to ensure that the voices of individuals from Priority communities were heard in the feedback process. Previously, most of the round table discussions and feedback that were received were not inclusive of Black, Indigenous, and people of color. By requiring that participants meet the above criteria and be available on the roundtable discussion dates and times, we aimed to create a more inclusive and diverse group of participants. It was important to us to highlight and center the voices of “Priority Populations” or individuals who were underrepresented previously in this process to ensure that their experiences and perspectives are considered when making decisions about the Ryan White program.

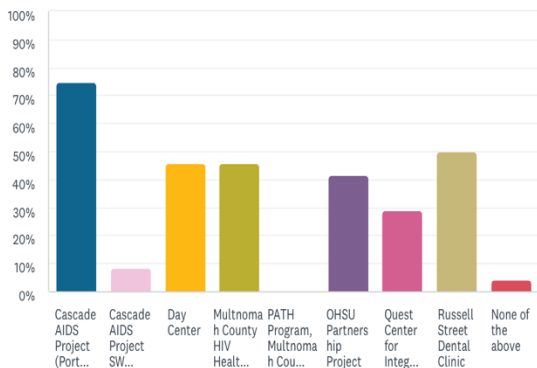
After developing the participant criteria survey, our team dispersed the surveys and focused on intentional outreach efforts. We collected 24 complete responses. Exhibit 1 below displays some of the survey applicant highlights (the survey and additional materials used in the discussion can be found in the appendices. located at the end of this report).

Exhibit 1



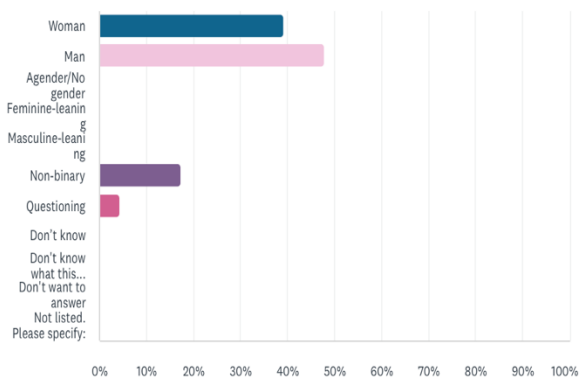
Have you received services from one of the following Ryan White Pr...

Answered: 24 Skipped: 0



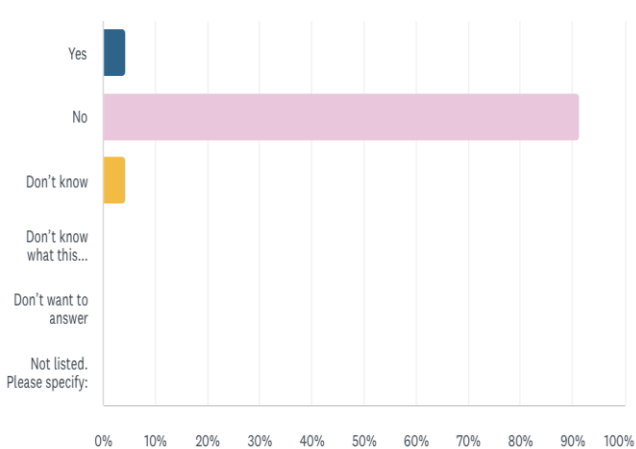
What is your gender? Please check all that apply.

Answered: 23 Skipped: 1



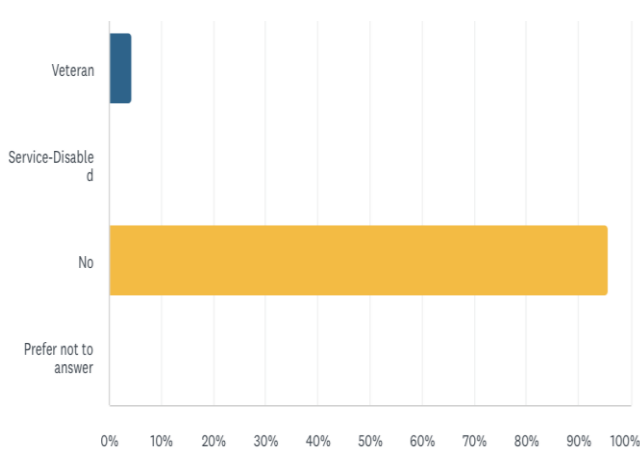
Are you transgender?

Answered: 23 Skipped: 1



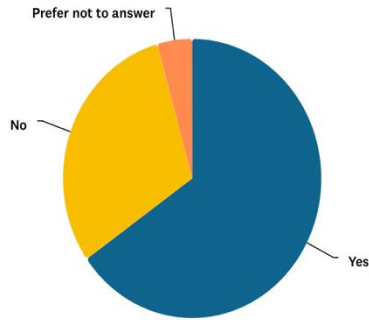
Are you a veteran of the armed forces? * Required

Answered: 23 Skipped: 1



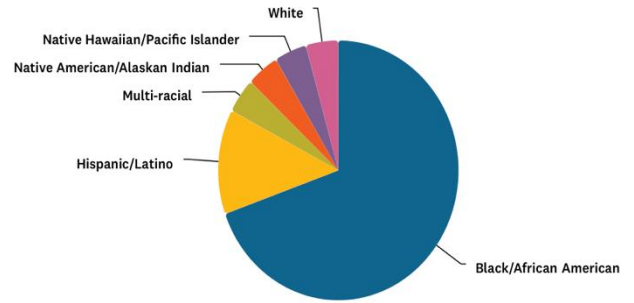
Are you impacted by a disability?

Answered: 23 Skipped: 1



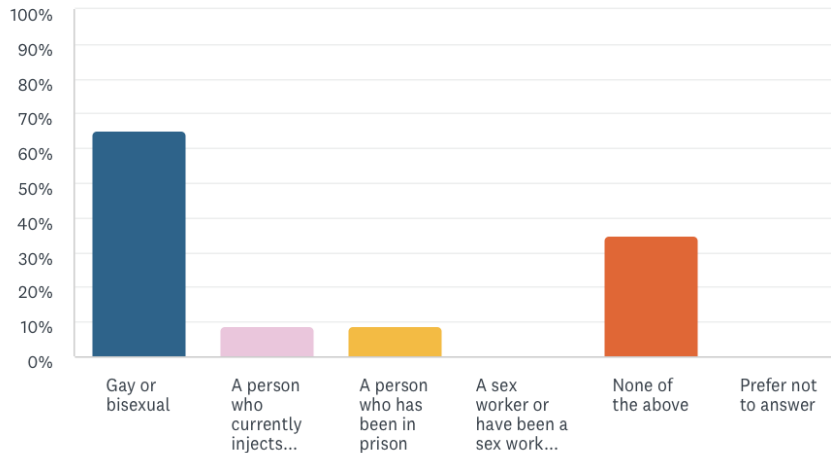
Which of the following most closely describes your Race/Ethnicity?

Answered: 23 Skipped: 1



I am (check all that apply):

Answered: 23 Skipped: 1



After receiving responses to the survey, we contacted applicants who expressed their interest in participating in the roundtable discussions via phone, email, and text. Two discussions were held on February 13, 2024, from 5:30PM to 7:30 PM and February 15, 2024, from 5:30PM to 7:30 PM, respectively. 7 participants attended the first roundtable discussion online, and 8 participants attended the second roundtable discussion. The second roundtable discussion was offered as a hybrid option, although all participants attended online.

The discussions were productive and provided valuable insights into the experiences of people of color living with HIV in the Ryan White program. Participants shared their experiences with stigma, challenges accessing care and support services, and the need for more culturally competent care. Based on the findings



and recommendations provided by the participants, we were able to develop actionable steps to improve the Ryan White program for people of color living with HIV.

After conducting the roundtable discussions, participants were offered a stipend or gift card. Our team analyzed the data from the roundtable discussions in this report as a qualitative analysis of a recorded Zoom call. The call was recorded and transcribed for analysis. The data was analyzed through thematic coding to identify common themes and patterns in the participants' experiences and recommendations. The report presents the findings of this analysis and provides recommendations for improving HIV management and access to care in the Portland Transitional Grant Area (TGA).

The limitations of this methodology include the small sample size of the roundtable discussion and the potential for bias in the selection of participants. Additionally, the findings may not be generalizable to other geographic areas or populations. However, the use of a roundtable discussion allowed for in-depth exploration of the participants' experiences and perspectives, providing valuable insights for improving HIV management and care in the Portland TGA. Overall, this methodology was effective in gathering qualitative data on the experiences and recommendations of BIPOC individuals in the program.

Recommendations

The round table discussions were very insightful as participants shared their experiences with the Ryan White program and highlighted several challenges they faced. Based on the recommendations provided by the participants, we have developed a set of actionable steps to address these challenges and create a more inclusive and accessible environment for people living with HIV. These steps aim to improve the overall quality of care provided by the Ryan White program. To address these challenges, we've developed a set of recommendations identified by participants that aim to create a more inclusive and accessible environment for people living with HIV and to improve the overall quality of care provided by the Ryan White program.

Access to Services

- **Create more options for accessing Ryan White funds:** Participants expressed discomfort with the monopolization of accessing Ryan White funds by certain organizations, highlighting difficulties in accessing housing, substance use, and eviction prevention funds. To address this challenge, there needs to be more transparency and accessibility in the distribution of funds. One way to achieve this is by diversifying the providers and creating more options for accessing funds.



“I think one of my concerns with Ryan White funds and Ryan White access is the monopolization of accessing such funds. There's one organization that holds all the cards, and that's the Cascade AIDS Project. Like everyone has said, we all have had very difficult experiences with accessing Ryan White funds, especially housing funds, substance use funds, and eviction prevention funds. Those are imperative for a person living with HIV to live a healthy HIV life, especially housing.”

- **Create more options for healthcare providers:** Participants shared challenges in accessing healthcare and HIV treatment, including concerns about clinic locations, continuity of care, pharmacy costs, and the lack of broader services such as massage therapy for neuropathy. To address this challenge, there needs to be more options for healthcare providers and ensure continuity of care for individuals living with HIV.
- **Create more options for complementary and alternative therapies:** Participants expressed challenges in accessing broader services such as massage therapy. To address this challenge, providers can work to create more options for complementary and alternative therapies. This can include partnering with community organizations and healthcare providers to provide these services.
- **Create more options for gender-diverse individuals:** Participants highlighted the lack of gender diversity in service facilities. To address this challenge, providers can work to create more options for gender-diverse individuals. This can include creating more gender-inclusive spaces and services and providing education and training for healthcare providers on working with gender-diverse individuals.

When discussing discrimination, one participant shared:

“I got mine (HIV) from [non-sexual exposure], So I remember one time I was in a CAP group. It was only gay men and me. And they were talking about how you got it or whatever. And then they told me that I didn't get it through sex. And so, I don't understand how it is to have HIV. [...] I think that was the only time I was really told like, you didn't get it how we got it, so, we don't wanna hear your opinion.”

- **Create more options for older individuals living with HIV:** Participants highlighted the need for more education and support in advocating for healthcare and addressing discrimination and access to services for older individuals. To address this challenge, providers can work to create more options for this population. This can include creating more services and resources specifically for older individuals living with HIV and providing education and training for service providers working with this population.
- **Create more accessible services and resources for individuals with disabilities:** Participants shared challenges in accessing services for individuals with disabilities. Providers can



work to create more accessible services and resources, including creating more accessible physical spaces, as well as providing education and training for providers on working with individuals with disabilities.

- **Create more culturally competent services for individuals from Priority Communities:** Participants highlighted the need for more education and support in advocating for healthcare and addressing discrimination and access to services for marginalized groups. Providers can work to create more inclusive and culturally competent services including hiring culturally responsive staff in all positions, not just outward facing; providing education and training for providers on working with individuals from different cultural backgrounds and partnering with community organizations to provide more culturally responsive services.

“Changing our guidance language so that the grantees of Ryan White funds are hiring people with lived experience. That is very imperative. What I learned was [...] using our BIPOC voice to change the system.”

- **Increase outreach efforts:** Providers can increase outreach efforts to inform individuals living with HIV about available services and resources, and to ensure that they are aware of how to access them.
- **Provide case management services:** Providers can offer case management services to help individuals living with HIV navigate the healthcare system, access resources, and coordinate care.
- **Offer mobile healthcare services:** Providers can offer mobile healthcare services to increase access to healthcare and HIV treatment for individuals who may have difficulty accessing traditional healthcare settings.

“I just don't like where it's located. Because I have to have an appointment where I'm at least leaving out of there by two o'clock. Because there's just so much homeless and the drugs. I just get nervous. I just don't like the location. I love the clinic, the HIV clinic. I just don't like where it's located.”

- **Expand telehealth services:** Providers can expand telehealth services to increase access to healthcare and HIV treatment.

Psychosocial Support

- **More resources and support for individuals living with HIV:** Participants expressed challenges in accessing psychosocial support. Providers can work to provide more resources like peer support services, counseling services, and access to more, better, and timely mental health resources.



- **Provide more mental health and peer support services:** Participants emphasized the importance of peer support services in providing a supportive environment for individuals living with HIV. To address this challenge, providers can work to provide more peer support services, access to counseling services, and mental health providers.

“When I was diagnosed, I didn't know about peer support until I came here. And I think that is something that is very important. Me coming here and getting introduced to peer support. It's like somebody holding your hand when you're falling, like giving you a shoulder or holding you up, you know?”

- **Offer mindfulness-based interventions:** Providers can offer mindfulness-based interventions, such as meditation and yoga, to help individuals living with HIV manage stress and improve their mental health.
- **Create safe and supportive environments for individuals of color living with HIV:** To create safe and supportive environments for individuals of color living with HIV, it is crucial to address systemic racism and dismantle barriers to healthcare access and outcomes. Providing culturally responsive care, increasing access to healthcare through free or low-cost services and outreach to underserved communities, promoting community engagement through support groups and peer mentoring, and addressing social determinants of health such as poverty, housing insecurity, and food insecurity are all essential components of a comprehensive approach to supporting individuals of color living with HIV.
- **Offer group therapy:** Providers can offer group therapy sessions to provide a supportive environment for individuals living with HIV to share their experiences and build connections.
- **Provide access to self-help resources:** Providers can provide access to self-help resources, such as books, videos, and online support groups, to help individuals living with HIV manage their condition and improve their mental health.
- **Offer trauma-informed care:** Providers can offer trauma-informed care to address the trauma that some individuals living with HIV may have experienced, and to provide a safe and supportive environment for healing.
- **Offer art therapy:** Providers can offer art therapy to help individuals living with HIV express themselves and process their experiences in a creative and therapeutic way.
- **Provide access to support animals:** Providers can provide access to support animals, such as therapy dogs, to help individuals living with HIV manage stress and improve their mental health.

Housing and Transportation

- **Create more affordable and safe housing options:** Participants shared challenges in accessing housing. To address this challenge, providers can work to create more affordable and safe housing options. This can include partnering with community organizations and government agencies to create more affordable housing options for individuals living with HIV.
- **Create more accessible transportation options:** Participants shared challenges in accessing transportation.
- **Partner with transportation providers:** Providers can partner with transportation providers to create more accessible transportation.
- **Offer transportation vouchers:** Providers can offer transportation vouchers to help access healthcare, services, and resources.
- **Provide rental assistance:** Providers can offer rental assistance to help individuals access safe and affordable housing.

“It's very hard to get rental assistance...and when a person is evicted, it's really hard to get those services back without being scrutinized. [...] Is very demoralizing when one agency is gatekeeping how a person access funds.”

I'd have to ditto on the help as far as rental assistance and the hoops that you have to go through. And one could end up homeless waiting to get said assistance in trying to get into a place with the hoops that you have to jump through.

Medication

- **Provide more affordable medication options:** Participants shared challenges in accessing medication. To address this challenge, providers can work to provide more affordable medication options for individuals living with HIV.

“In my case, there is a pharmacy that I still go to, and I don't have to pay anything because I'm on Medicare. The pharmacy is further away, but I don't have any copayments. But guess what? The pharmacy that is close to me has a \$40 copayment, and I don't understand why one pharmacy can do that (zero copay) and the other one cannot. I mean, it's weird. So, I was hoping that Ryan White can look at it and say, hey, people who are on fixed income, low income, disabled, they need some help with the medication, and they are expensive. “



- **Ensure that individuals have access to necessary medication:** The program can work with healthcare providers to identify and address barriers to medication access, such as transportation and language barriers. Additionally, the program can support education and outreach efforts to ensure that individuals are aware of the resources available to them and how to access them.
- **Advocate for lower drug prices:** Providers can advocate for lower drug prices to make medication more affordable for individuals living with HIV.
- **Offer medication adherence support:** Providers can offer medication adherence support, such as reminder systems and counseling services, to help individuals living with HIV adhere to their medication regimens.

Education and Training

- **Provide education and training for providers on working with individuals from different cultural backgrounds:** Participants emphasized the need for education and training for healthcare providers on working with individuals from different cultural backgrounds. To address this challenge, providers can work to provide education and training for healthcare providers on cultural competency.
- **Provide education and training for providers on working with gender-diverse individuals:** Participants emphasized the need for education and training for healthcare providers on working with gender-diverse individuals. To address this challenge, providers can work to provide education and training for healthcare providers on working with gender-diverse individuals.
- **Provide education and training for providers on working with individuals with disabilities:** Participants emphasized the need for education and training for healthcare providers on working with individuals with disabilities. To address this challenge, providers can work to provide education and training for healthcare providers on working with individuals with disabilities.
- **Provide education and training for family members and caregivers:** Providers can provide education and training for family members and caregivers of individuals living with HIV to help them better understand the condition and how to provide effective support.

“My sister was the only family member I told, and she was my test subject, put it that way, and we didn't speak for about a year and a half. Then she started talking, but still sometimes she's a bit distant. And I think it's the point of having people be educated. And she is super smart, got her master's and all that. But it's just, you don't have to be uneducated because there are people who are really educated, who know about things and just freak out when you say, I'm living with HIV.”



- **Offer training for peer educators:** Providers can offer training for peer educators to help them provide accurate and effective information about HIV prevention and treatment to their communities.
- **Provide education and training on harm reduction:** Providers can provide education and training on harm reduction strategies, such as safer drug use practices and needle exchange programs, to help individuals living with HIV reduce their risk of infection and improve their overall health.

Feedback and Monitoring

- **Gather feedback from participants:** Participants emphasized the importance of gathering feedback to ensure that the program meets the community's needs. To address this challenge, providers can work to gather feedback from participants regularly, ensuring that they are offering participants compensation for their time.
- **Monitor services regularly to ensure they are meeting the community's needs:** Participants emphasized the importance of monitoring services to ensure they are meeting the community's needs. To address this challenge, providers can work to monitor services regularly to ensure that they are meeting the needs of the community.

Overall, these recommendations highlight the need for providers to work collaboratively with community organizations and government agencies to create more accessible and inclusive services for individuals living with HIV.

Conclusion

In conclusion, participants were grateful for the assistance received, particularly in areas like housing, transportation, and obtaining necessary identification documents. However, they also highlighted several areas of concern, including the need for improved accessibility, more personalized resources, and better methods of conveying information about services. The participants also shared their experiences with the struggles of job searching, the impact of stress on their health, and the importance of self-advocacy. The participants' experiences underscore the importance of individualized support and the need for better communication and information about available services. They also highlight the need for services to be more accessible and inclusive, with the aim of reaching a broader range of individuals. The participants' feedback provides a crucial perspective that can guide the organizations in addressing these concerns and improving their services.



On behalf of the Empress Rules team and Multnomah County, we want to thank all participants who engaged in this process to provide feedback on the Ryan White program. Your voices are critical in shaping the future of this program, and we are grateful for your willingness to share your stories and experiences. We are committed to ensuring that the Ryan White program remains a vital resource for years to come, and we recognize and appreciate all the wonderful things that it does for our community members. We want to encourage Multnomah County to continue to prioritize these paid discussions with community members to ensure that everyone has access to the services they need. It is crucial that service providers take this feedback and work collaboratively with participants to ensure that services are built around their needs, rather than the other way around. We hope to continue working together to make the Ryan White program the best it can be. Once again, we are grateful to all the participants for sharing their feedback, and we hope to continue collaborating with you to improve the program. Thank you for your participation and take care.

