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POSITIVE ACTION VIIV







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INTRODUCTION

WeKnow was a year-long virtual program for emerging leaders between ages 14-24. Throughout the year, a group of seven participants who identified as system impacted, queer or trans, and/or impacted by HIV, worked together to develop a research project for young people living with HIV (YPLWHIV). The cohort utilized an abolitionist approach to research, guided through intergenerational mentorship within the field of reproductive justice, to ask their community questions that they wish they'd been asked. This project aimed to uplift the voices that are often left out of mainstream research and use the community knowledge that already lives within all of us, because after all, WeKnow.

Studies have shown that YPLWHIV face multiple barriers to accessing and maintaining basic needs (Division of HIV Prevention, National Center for HIV, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention, 2024). Without accessible and stable basic needs, especially housing, it is difficult to build social support networks and know where community resources are and how to access them, if accessible at all. According to Call and Barman-Adhikari (2021) young adults experiencing homelessness are up to 12 times more likely to contract HIV than their peers with stable housing. People living with HIV in stable housing have been shown to have better access to HIV medical care, take their medication more consistently, see their providers more regularly, and are more likely to test for HIV (Division of HIV Prevention, et al., 2024).

Many YPLWHIV hold multiple oppressed identities that create additional "risk factors". In the report titled "HIV and Disability" (UNAIDS, 2017), disabled people, particularly women and girls, living with HIV face additional barriers to sexual and reproductive health care services. The LGBTQIA+ population also faces significant barriers when accessing health care in general, but particularly sexual health services (Bass & Nagy, 2023). In the 2022 World AIDS day report, it was found that young women aged 15-24 years old are disproportionately affected by HIV. Additionally, of the 31,800 estimated new HIV infections in the US in 2022, 71% (22,500) were among gay and bisexual men (HV Surveillance Supplemental Report, 2024). In 2022, Native American/Alaska Native people reported having the lowest rates of knowing their HIV status and Black/African American people had the highest rates of diagnosis (CDC Estimated HIV incidence and prevalence in the United States, 2024).

Empowering YPLWHIV can build self efficacy and culturally specific community, both of which have proven to improve health outcomes (Cunningham, Weiss, Nakazono, Malek, Shoptaw, & Harawa, 2018; Miller, Rutledge, & Ayala, 2021; Fee, Fuller, Guss, Woods, Cooper, Bhaumik, Graham, Burchett, Dumont, Martey, Narvaez, Haberer, Swendeman, Mulvaney, Kumar, Jackson, & Ho, 2022). In a position statement by the Society of Adolescent Health and Medicine (2023), YPLWHIV need person-centered care within and outside of clinical settings provided by not only youth friendly healthcare providers, but community members, support groups and peers. Their position also includes the need for "...economic







support, transition to adult care preparedness, elimination of legal barriers to HIV testing and treatment for minors, and elimination of discriminatory laws against individuals living with HIV, and individuals who are sexually or gender diverse." (Society of Adolescent Health and Medicine, 2023). Having a community that YPLWHIV can connect to, that understands the local landscape, and respects their values, identities, and beliefs, has the potential to improve their quality of life and overall health.







METHODS AND ANALYSIS

The *WeKnow* cohort developed an anonymous survey to identify gaps in care and access to resources among YPLWHIV. Their aim was to better understand how community impacts resources and access to care for YPLWHIV. It was hypothesized that young people who held multiple oppressed identities would have less access to community, therefore less access to HIV care. The survey was 30 questions long and took about 10-20 minutes to fill out (see Appendix A for the full survey). Survey participants were recruited by utilizing the *WeKnow* participants networks (see Appendix B for recruitment flier and outreach script). The cohort collectively gathered a list of contacts and organizations that they sent the outreach script to. Those contacts included personal and professional connections (i.e. mentors, community organizations, healthcare centers, etc.), along with values aligned organizations and networks. Survey participants had to be between the ages of 14-24 years old and living with HIV to be eligible and those who completed the survey were able to access an external link and enter their email to be randomly selected to win a \$100 Visa gift card.

Questions were sourced from a variety of reputable sources, including the National Center for Women and Information and Technology (Guide To Demographic Survey Questions, nd) and the National LGBTQIA+ Health and Education Center (A Guide For Collecting Data On Sexual Orientation And Gender Identity, 2022). *WeKnow* participants were intentional in their use of an accessibility aid (WAVE, 2024) and JotForm accessible formatting, applying a Disability Justice framework throughout the creation. They included descriptions and low barrier language to ensure comprehension as well as providing a space after each question to upload visual, verbal, or written responses. They had robust conversations about survey bias and person first language, putting together thoughtful questions that they wished had been asked of them.

There were a total of 46 people who filled out the survey, with a total of 35 responses meeting the eligibility criteria (14-24 years old and living with HIV) and one duplicate, making the sample size 34 respondents. Participants were asked about their access to basic needs, social support, and community resources and how having or not having access to them within the last year impacted their lives for better, worse or not at all. Survey participants were able to self describe or provide additional information about resources they had or hadn't accessed. They were also able to provide demographic information in order to better understand the impact on specific subgroups. The demographic information requested included gender identity, sexual orientation, disability status, race, whether they were system impacted or not, and spiritual affiliation. All of the demographic questions were optional (descriptions used in the survey found Appendix A).







RESULTS

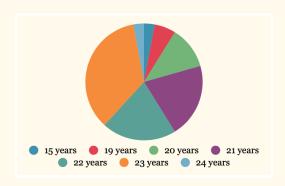
Participant Characteristics

In this section the respondent demographic data is described.

Age

This section outlines the ages of the eligible participants (ages 14-24 years old).

- The age with the highest response rate was 23 years old (N=12; 35%)
- There were no respondents 14, 16, 17, or 18 years of age
- Ages 21 and 22 years old both had the same response rate at 21% (N=7)



Gender Identity

The following describes how participants identified their gender, all gender identity questions were multiple choice.

- The majority of respondents identified as cisgender (N=29; 81%)
- A small portion identified as transgender (N=4; 11%), non-binary (N=1; 2%), and/or intersex (N=2; 6%)
- About half of the respondents identified as either a man (N=17; 47%) or woman (N=18; 53%)





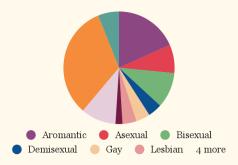




Sexual Orientation

Respondents could select multiple sexual orientation identities. For the purposes of this report the options that will fall under the LGBTQIA+ umbrella include: aromantic, asexual, bisexual, demisexual, gay, lesbian, pansexual, and questioning:

- Out of the 46 responses, 30 (65%) of those selected one or more identity under the LGBTQIA+ umbrella
- 35% (n=16) selected straight/heterosexual
- The subgroup within the LGBTQ+ responses with the highest response rate was aromantic (n=9; 30%), followed by bisexual and questioning (n=5; 17%)
- 8 (17%) people chose more than one identity



Disability Status

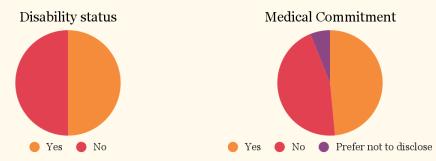
In this section, details about how respondents identified their disability status is described. Included in their disability status, is whether they have been committed to a medical facility.

- Half (N=17; 50%) of the respondents identified as someone living with a disability
- Nearly half (N=16; 47%) of the respondents identified as someone who had experienced medical commitment
- A small number of people (N=2; 6%) selected "prefer not to disclose" and one person opted to skip the question all together
- 12 participants (35%) identified as both living with a disability and being committed to a medical facility
 - o 10 of those 12 (83%) also identified as being system impacted





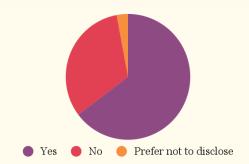




System Impacted

The following information describes whether respondents identified as being system impacted (experience with foster care, juvenile detention centers, probation or drug court, prison, or jail, and/or immigration detention centers).

- 65% (N=22) respondents identified as being system impacted
- Only one person (3%) elected not to disclose whether they identified as system impacted or not
- Out of the 22 people who identified as system impacted, over half (n=14; 64%) of them also identified as someone living with a disability

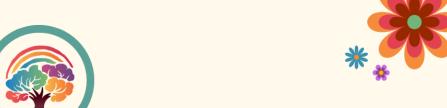


Race/Ethnicity

Respondents were given multiple choice options to best describe their racial and/or ethnic identities. They were able to select more than one identity, had the option to self describe or not answer.

- There were 38 responses within this section, the group with the highest response rate was Black/African American (n=17; 45%)
- Two (5%) responses included more than one identity
- A smaller number of participants identified as Asian (n=4; 11%), Native or Indigenous (n=4; 11%), or Hispanic/Latinx (n=3; 8%)
- No one selected Middle Eastern/North African







Spiritual or Religious Affiliation

This section represents the various spiritual and religious identities that the participants identified as. This question was multiple choice, allowing respondents to select as many that applied to them. They were also able to select the "other" option which allowed them to share an identity not listed.

- There were 48 responses total, showing the overlapping spiritual and religious identities
- The identity with the highest number of respondents was Christian (n=15; 31%), followed by Buddhist (n=6; 13%)
- Jewish, Muslim, and Sikh all had the lowest number of responses, with two (4%) people selecting each
- Four (8%) respondents indicated that they did not identify with any spiritual or religious affiliation
- Two people (4%) selected "prefer not to disclose" and an additional two (4%) left the question blank



Spiritual and Religious Affiliation



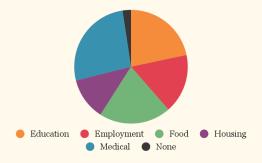




Basic Needs

WeKnow identified five basic needs (education, employment, food, housing, and medical care) that they believe are essential to a person's wellbeing. They asked respondents whether they had access to those basic needs within the last year and how that impacted them. The following section will detail the findings of the collective, along with details from subgroups within the sample.

- The basic need that respondents indicated they had the most access to was general medical care (N=22; 65%)
- Two (6%) respondents did not have access to any of the basic needs listed. Of the two people (6%) that didn't have access to any of the basic needs listed, they identified as men, cisgender, one or more LGBTQ+ identities, system impacted, living with a disability and/or had been committed to a medical facility
- Only ten (29%) of the respondents had access to housing, housing was the basic need with the lowest response rate among all subgroups



Subgroups

- One respondent selected all gender identity options (man, woman, non-binary, transgender, cisgender, and intersex)
- Out of the people who identified as women, only five (28%) had access to housing or employment
- Of those who identified as men, nearly three quarters (n=12;71%) reported that they had access to education, while only about a third (n=6; 35%) of men had access to housing
- Of the four transgender respondents (11%), 75% (n=3) reported having access to education and/or food
- Respondents could select multiple sexual orientation identities. Out of the 46 responses, 30 (65%) of those selected one or more identity under the LGBTQIA+ umbrella (aromantic, asexual, bisexual, demisexual, gay, lesbian, pansexual, and questioning) and 16 (35%) selected straight/heterosexual:
 - Only 7 (21%) of the respondents who identified with one or more LGBTQ+ identities had access to housing





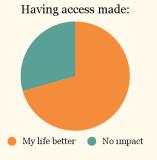


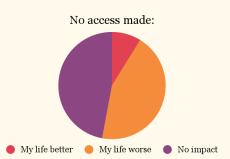
- Of the straight/heterosexual participants, only 19% (n=3) had access to housing in the last year
- System impacted respondents reported that the basic need they had the most access to was medical care (n=15; 68%) and the lowest access to was housing (n=7; 32%), followed by employment (n=8; 36%)
- Of the 17 participants who identified as living with a disability, over 50% of the participants said that they had access to education (n=11; 65%), employment (n=9; 53%), food (n=12; 71%), and medical care (n=10; 59%), while only 35% (n=6) had access to housing
- The participants who identified as Native/Indigenous did not have access to *any* of the basic needs except for medical care, which all of them reported having (n=4; 100%)

Impact of access

Participants were asked how having access, and not having access to basic needs impacted their lives. Their responses show that when they were able to obtain basic needs, they felt that their lives improved.

- Respondents had the opportunity to share any additional resources they had access to that were not listed. The following are those responses:
 - The photo provided was an additional comment:
 - o "Public advocacy and awareness"
 - "Communities soccer, health insurance, community"
- Respondents also had the opportunity to share resources they had not had access to using a written response, an image, or a voice note. They shared the following:
 - o "I currently have Virginia Medicaid until the age of 26 because I was a part of the foster care system. However, I live in DC for college, so I am limited in the services I can receive. I can't get
 - food stamps in DC or VA because I have Virginia insurance, but without Virginia insurance, I will not be able to afford my HIV medication. So, I currently have to work at least two jobs to support myself and afford my \$4000/month HIV -medication."
 - "Health care services for Special needs individuals with disabilities"







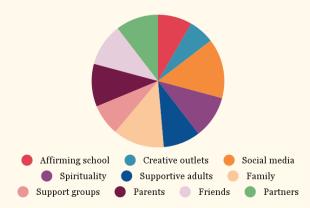




Social Supports

In this section, respondents were asked about their level of social support. *WeKnow* focused on items that included individual activities that are often connected to community, such as creative outlets and spirituality, as well as interpersonal relationships (i.e. supportive adults, family, peers, etc). Those include, affirming school environments, creative outlets, social media, spirituality, supportive adults that are not within a family, family, support groups, parents, friends, and partners.

- Social media was shown to have the highest response rate from participants, with 62% (N=21) of them saying they found support there, followed by family (N=18; 53%)
- Nearly three quarters (N=25; 74%) did *not* have access to creative outlets, followed by support groups (N=23; 68%)
- Less than 40% of participants had access to affirming school environments (N=12; 35%) and supportive adults who were not in their family (N=13; 38%)
- 45% (N=15) of respondents indicated that they had access to spiritual outlets, supportive parents, peers, and partners
- None of the respondents indicated that they did not have access to at least one of the social supports listed



Subgroups

- Native/Indigenous people, those who selected questioning, and pansexual indicated that they did not have an affirming school environment.
 - Respondents who were system impacted (n=6; 27%), women (n=5; 28%), and selected Buddhist (n=1; 17%) had less than a 30% response rate for access to affirming school environments
- Women had the highest response rates for supportive social media (n=14; 78%) out of all subgroup, and the lowest response rates for having access to creative outlets at only 17% (n=3), followed by bisexual and questioning people (n=1; 20%)
- Men had the lowest response rates for access for both supportive adults outside of their family (n=6; 35%) and supportive partners (n=6; 35%)





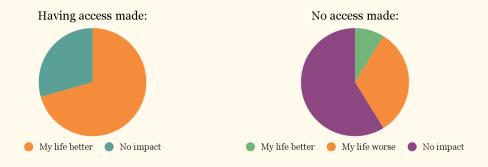


- Of the four transgender respondents, spiritual, family, and parental support only had one (25%) respondent stating that they had access to those support systems. Whereas cisgender respondents had some of the highest response rates for those items: cisgender spiritual and parental support (n=15; 52%); family support (n=17; 59%)
- When looking at spiritual and religious affiliation, agnostic participants (n=1; 25%), people who are not religious (n=1; 25%), and spiritual people (n=1; 25%) had the lowest response rates for accessing supportive spiritual spaces with Christians having the highest rates at 60% (n=9)
- Respondents who selected pansexual and not religious indicated that they had no access to supportive partners

Impact of access

Participants were asked how having access, and not having access to basic needs impacted their lives. Having access to social support made their life better, but the lack of access only impacted about a third of participants' lives.

• One respondent suggested sexual health education as a social support





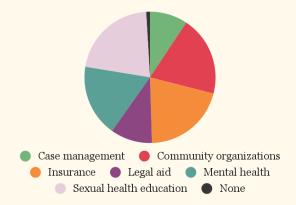




Community Resources

This section details the access respondents had to community resources. Community resources were items that *WeKnow* found to be high level supportive institutions that they found to be essential to the wellbeing of YPLWHIV. This section asks respondents what their access to case management, community organizations, insurance, legal aid, mental health resources, sexual health education, or none of the above. They also had the option to share additional resources and information via writing, images, or voice notes.

- Participants had the most access to sexual health education (N=23; 68%), followed closely by insurance (N=22; 65%) and community organizations (N=21; 62%)
- Case management (N=10; 29%) and legal aid (N=11; 32%) had the lowest response rates
- One participant said they didn't have access to any of the community resources listed, they
 identified as system impacted, a cisgender man, aromantic, disabled, previously committed to a
 medical institution, and Black



Subgroups

- System impacted participants had the lowest response rate for access to case management (n=8; 36%) and legal aid (n=9; 41%), but almost 70% (n=15; 68%) had access to community organizations
- Of the four transgender respondents, only one person (25%) in had access to sexual health education, whereas their cisgender counterparts had a 76% (n=22) response rate
- Respondents who identified as men (n=7; 41%) and those who selected questioning (n=2; 40%) had a response rate of 40% or below for access to mental health resources
- Native/Indigenous participants reported that all of them had access to insurance, mental health
 resources, and sexual health education. However, they reported that *none* of them had access to
 community organizations or legal aid

Impact of access

Of the 34 participants, nearly three quarters (71%) said that having access to community resources in the last year made their lives better. About a third (35%) said that not having access made their lives worse,



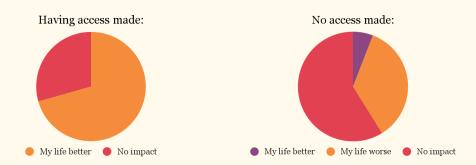




and two participants said not having access actually made their lives better. However, no one indicated that *having access* made their lives worse.

- Multiple respondents provided written and visual responses about resources they did not have access to. The following are their replies:
 - "I didn't use community resources because I was afraid that I would influence others and bring trouble to others."
 - o "Soccer competition, health care provider"
 - o The photo provided was an additional comment











SUMMARY OF RESULTS

Out of the sections (basic needs, social support, and community resources) the area that negatively impacted respondents the most was basic needs, 44% said it made their lives worse because they did not have access. Housing was found to be the basic need that participants had the least access to, with 71% (N=25) of them not having access within the last year. Regardless of gender identity or sexual orientation, respondents' access to housing within those categories were all below 35%. Only 35% (n=6) of YPLWHIV who identified as living with a disability (N=17) reported that they had access to housing. Out of the four respondents who identified as Native American or Indigenous, none of them had access to housing. Both respondents (N=2; 6%) who reported that they didn't have access to *any* of the basic needs held multiple marginalized identities, including (but not limited to) one or more LGBTQ+ identities, being system impacted, living with a disability and/or had been committed to a medical facility.

Within the social support section, creative outlets were found to have the lowest response rate. Only 26% (N=10) had access to creative outlets followed by support groups, with only about a third (N=12; 32%) reporting that they had access. Creative outlets have been perceived as non-essential services for many communities but it has been shown to be important to the wellbeing of individuals, particularly in oppressed populations, which includes those living with HIV and young people (Ducel, 2024; Butler & Hahn, 2021). Nearly 75% of respondents did not have access to creative outlets as mentioned in the social support section. One study showed that creative arts programming for YPLWHIV had beneficial effects in community building, confidence, and the potential to enhance medical treatment (Ness, Agrawal, Guffey, D. et al., 2021). Another study found that even participating in creativity virtually, young adults found it helpful to their creative expression, inspiration, and growth to meet their personal needs (Zaeske, Harris, Williams, Long, Kerr, & Birdnow, 2022). The data also shows that the subgroup with the lowest rate of access to creative outlets were women (n=3; 17%), followed by bisexual (n=1; 20%) and questioning (n=1; 20%) participants.

The findings detailed in the community resource section show that case management had the lowest response rate. This was followed by legal aid (N=11; 32%), resources of which could be navigated with the support of case management in some situations. Only 29% (N=10) of YPLWHIV surveyed had access to case management, many of the identities who reported lower access to case management were people who would be considered "hard to reach populations". For YPLWHIV, case management can be crucial to finding resources and support within their community. Studies have shown that having access to case management supports people living with HIV by increasing their self-efficacy (Fee, et al., 2022), status disclosure, maintaining a medication regimen (Tegegne & Zeru, 2022), and their overall health outcomes (Zinck, Minichiello, Fick, Sawry, & Fonner, 2024). The identities that fell below a 40% response rate included: system impacted (36%), man (35%), woman (28%), cisgender (31%), bisexual (20%),







pansexual (0%), questioning (20%), straight (31%), disabled (35%), Black (35%), Asian (25%), Hispanic/Latinx (33%), and Native/Indigenous (25%).

Following the completion of all the specific sections, survey takers were asked why they thought that any of the services/resources were not available to them. Their responses varied:

- It's not very useful (translated from Chinese using Google translate)
- Not well taken care of (translated from Chinese using Google translate)
- It didn't make me very good (translated from Chinese using Google translate)
- HIV support services have been limited or inaccessible in my society due to a combination of factors, including stigma, funding shortfalls, healthcare disparities, and systemic barriers, disproportionately affecting marginalized communities
- Racism







RECOMMENDATIONS AND CONCLUSIONS

The findings of this survey provide information that has the potential to shift the way community and healthcare organizations provide care to YPLWHIV. From this data, it is clear that there is no "one-size-fits-all" approach to supporting YPLWHIV. Identities, and especially oppressed identities, impact the availability and accessibility of resources and services. They face complicated government systems, inability to qualify for services, or barriers like transportation, cost, confusing paperwork, etc... For example, the respondent quoted in the basic needs section:

"I currently have Virginia Medicaid until the age of 26 because I was a part of the foster care system. However, I live in DC for college, so I am limited in the services I can receive. I can't get food stamps in DC or VA because I have Virginia insurance, but without Virginia insurance, I will not be able to afford my HIV medication. So, I currently have to work at least two jobs to support myself and afford my \$4000/month HIV medication."

However, there are specific things that almost all of the YPLWHIV surveyed reported. The items that they reported having the least amount of access were housing, creative outlets, and case management. Items with the highest rates of access from each section were general medical care, supportive social media, and sexual health education.

It is not lost on the researchers that at one time, the services YPLWHIV reported having access to were dismal. There has been a significant effort over the years to increase those resources. This information should be seen as a victory for those doing work within those areas. This is an opportunity to move to the next step in collective care. Organizations who support YPLWHIV with medical care, supportive online space, and sexual health education, but not low barrier housing, creative outlets, and case management should consider the impact that may have. This data reflects a shift in the needs of YPLWHIV, and if organizations intentions are to serve that population, then it is important that they consider shifting their funding and approach to meet their needs.

Studies have found that when YPLWHIV utilized online social networks to learn and build community around their diagnosis, they have better health outcomes (Bazrafshani, Panahi, Sharifi, & Merghati-Khoei, 2022; Hightow-Weidman, Muessig, Bauermeister, Zhang, & LeGrand, 2015; Taggart, Grewe, Conserve, Gliwa, & Roman Isler, 2015). Homeless YPLWHIV benefit especially from online social networks where they can gain knowledge about HIV and increase the likelihood of them being tested for HIV (Young & Rice, 2011; Zanoni, Elliott, Neilan, & Haberer, 2018). LGBTQIA+ youth are disproportionately at risk for







homelessness. The Trevor Project (2021) found that 28% of LGBTQIA+ youth experienced homelessness or housing insecurity at some point in their lives. Half (n=17) of the respondents identified as living with a disability, making online social networks even more important. Having an online space could eliminate common barriers like transportation, accessibility, inconvenient scheduling, etc..

Moving toward virtual case management has been proven to be an effective technique and is a WHO (World Health Organization) recommendation for digital healthcare (WHO guideline: recommendations on digital interventions for health system strengthening, 2019). Together, WHO and UNAIDS collaborated to outline innovative ways to implement virtual case management in the report, "Virtual interventions in response to HIV, sexually transmitted infections and viral hepatitis (2022)." This can be an effective tool for organizations wanting to adapt their case management practices. Peer and community based case management and linkage to care approaches have also been proven to be effective for oppressed populations, such as formerly incarcerated men and transgender women (Cunningham, et al., 2018; Miller, et al., 2021), and Black gay and bisexual men (Miller, et al., 2021; Kisler, Fletcher, & Reback, 2022). All of which were represented in the survey sample. One study found that utilizing a health app that provides results, information, support, and appointment reminders showed a significant increase (20%) in linkage to care for people under 30 (Venter, Fischer, Lalla-Edward, Coleman, Lau Chan, Shubber, Phatsoane, Gorgens, Stewart-Isherwood, Carmona, & Fraser-Hurt, 2019).

Using traditional methods to HIV prevention, stigma reduction, and viral suppression are proving to be out of date and out of touch for YPLWHIV. Many organizations and funders refer to YPLWHIV as a "difficult to reach" population, when minimal efforts are made to find out where they are and how they are engaging with others. Cohort members stated the following about the perceptions adults may hold toward them in HIV care:

"Traditional methods of HIV prevention, stigma reduction, and viral suppression are increasingly outdated for Young People Living With HIV. Labeling us as a 'difficult to reach' group overlooks the reality that barely serious efforts are made to understand their unique experiences and how we engage with our communities." - T (he/him)

"Community care is the path to creating a more just world and that means caring for all of us."- E (they/them)

"Describing young people living with HIV as 'difficult to reach' ignores the reality that traditional methods fail to connect with us. True progress lies in finding where we are, understanding how we engage, and creating strategies that reflect our needs and realities." - C (she/her)







Public health professionals frequently discuss meeting people where they are and YPLWHIV are online. To push back against moving care online is not only ageist, but ableist and capitalist. YPLWHIV need community and joy, all of which can be facilitated online. Engaging in virtual community based outlets may have the power to dismantle HIV stigma not only individually, but collectively. This data shows that it is time to invest in platforms that are easy to use and connected to creativity and additional social networks. Not just HIV care, but holistic in nature.







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APPENDIX

Appendix A

WeKnow Survey.pdf

Appendix B

Q3 W7 Outreach Script



Appendix C

▼ WK Survey Results.xlsx