

OUR OWN NORTH STARS:

SUPPORTING
THE NEXT
GENERATION
OF LEADERS

Learnings from
the Positive Action
for Youth Initiative



ViiV Healthcare's *Positive Action for Youth* initiative supports community-driven mentoring, leadership development, safe spaces, prevention and peer navigation programs. Our goal is to empower youth living with HIV to manage their diagnosis and develop healthy behaviors, as well as raise awareness and reduce gaps in HIV care for other young people across the United States and Puerto Rico.

We would like to thank everyone who generously shared their stories and experiences. We also thank our advisors and collaborators who guided the design, collected data and stories and interpreted the key findings, many of whom are named at the end of this report.

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CONTENTS

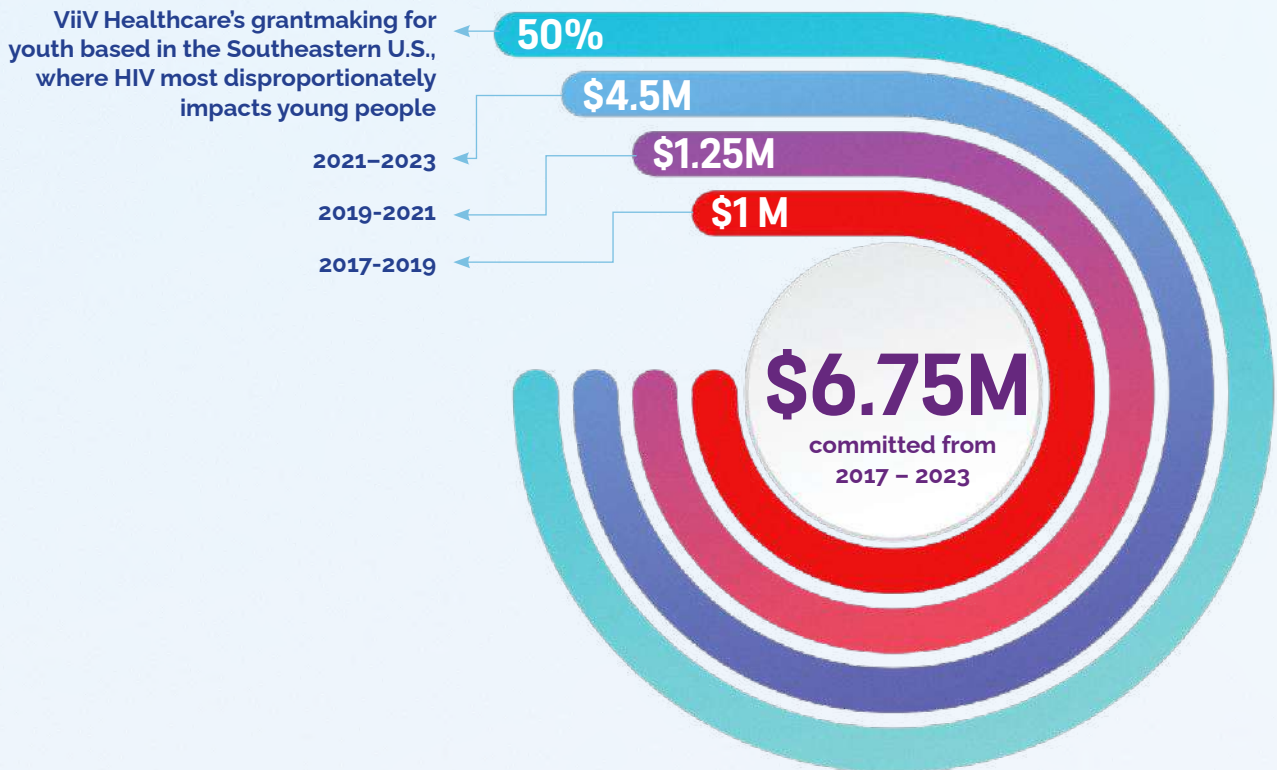
5	Executive Summary
9	FAQ
11	Background
15	Key Impacts <ul style="list-style-type: none"> Impact 1. Youth-focused funding grew programs and infrastructure for youth's unique needs. Impact 2. Thousands of young people accessed safer spaces, capacity building and HIV care and support. Impact 3. Mentorship and capacity building led to employment and leadership in the field of HIV. Impact 4. Youth voices changed ViiV Healthcare's approach to community giving and youth engagement, substantially influencing grantees' ways of working.
21	Lessons Learned <ul style="list-style-type: none"> Insight 1. Peer support models keep young people in care, but require compassionate attention to the needs and mental health of peer navigators, mentors and staff. Insight 2. Safer and braver spaces are critical to supporting youth in developing confidence, seeking independence and establishing networks of support. Insight 3. Misinformation, discrimination and deficit-framing drive HIV stigma. Insight 4. Young people need more information about HIV prevention and access to trusted resources on sexual health. Insight 5. Effective youth-centered models require organizations to address age-related power and systems, often in ways that adults overlook. Insight 6. Youth-centered initiatives depend on an openness to change our ways of working, continuously challenging assumptions. Insight 7. Funders and organizations should budget for time, space and mutual support around the realities of grassroots, youth-centered work.
27	Implications for the Field <ul style="list-style-type: none"> For Organizations For Funders
29	Conclusion
30	Acknowledgements

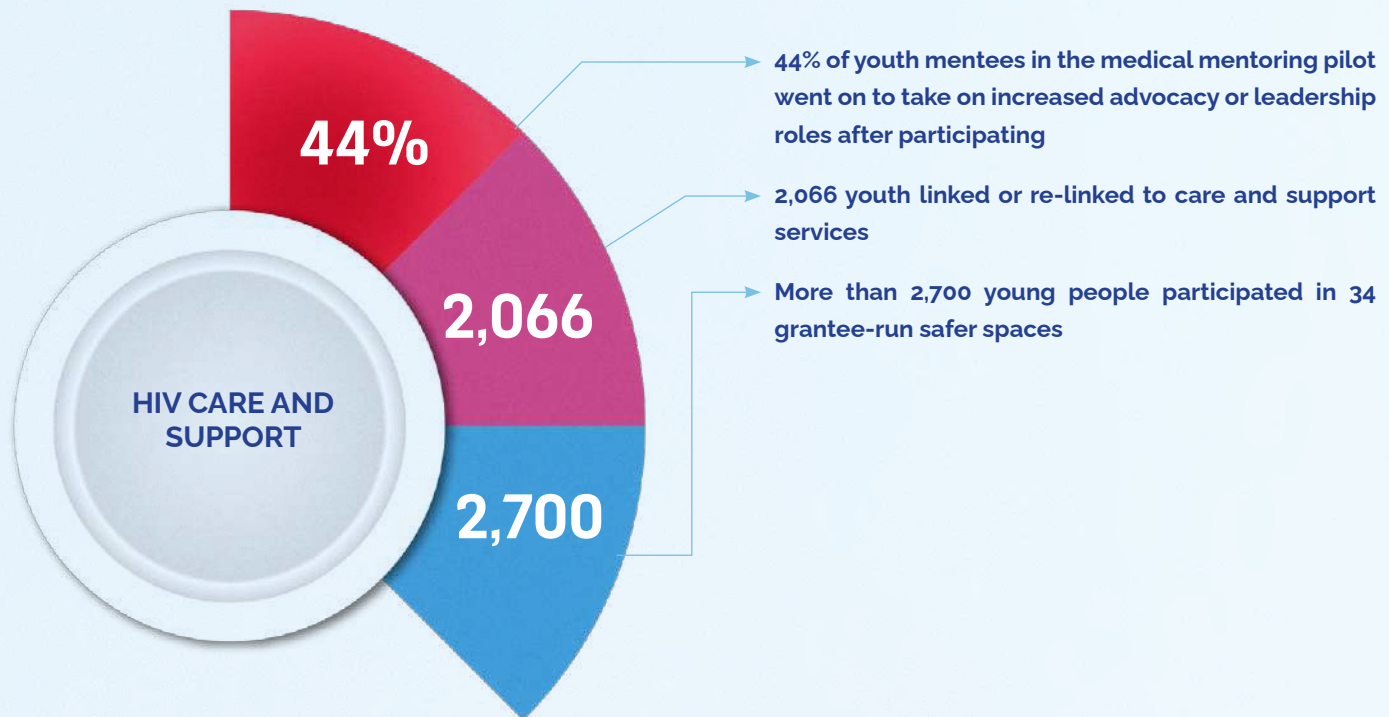


EXECUTIVE SUMMARY

Our Own North Stars reflects on the evolution, impact and learnings from ViiV Healthcare's *Positive Action for Youth* initiative as it comes of age. As allies and co-creators with youth, we synthesized five years of data and analysis to our Youth Advisory Board to "make meaning," identify key learnings and provide action-oriented implications to inspire and inform organizations and funders map new routes to our north stars.

Since the launch of *Positive Action for Youth* in 2017, ViiV Healthcare's funding support of youth-centered work more than quadrupled leading to thousands of young people accessing safer spaces, leadership development, peer-mentoring and linkage to HIV care and supportive services. ViiV Healthcare and grantee organizations have changed our ways of working to better center young people at the tables in a more meaningful way, as an ongoing practice of reflection, accountability and action.





Through this evaluation and around making meaning process, we maintained a sharp focus on uncovering insights that would help us and the field make a greater and sustained positive impact on young people's experiences, well-being and development. We learned that **peer support models work** to keep young people in care, but require compassionate attention to the needs and mental health of peer navigators, mentors and staff. **Safer and braver spaces** are crucial for fostering confidence, seeking independence and establishing networks of support, despite the stigmas surrounding HIV. At the same time, we are seeing how misinformation, discrimination and **deficit-framing¹ drive HIV stigma**. Young people still do not have access to enough information about HIV prevention and sexual health through **trusted resources**.

A question that drove much of the analyses was "what works for organizations that are making a great impact?" Simply put: youth-centered models. However, there is often a disconnect between adult staff perceptions of how youth-centered their model is and how youth staff and youth clients experience youth-centered work. Across these five years of learning, grantees described several key elements that are critical to their success:

- ✓ **Effective youth-centered models require organizations to address age-related power and systems, often in ways that adults overlook.**
- ✓ **Youth-centered initiatives depend on an openness to change ways of working, continuously challenging assumptions; this requires ongoing listening, reflecting and acting.**
- ✓ **Budgeting for time, space and mutual support around the realities of grassroots, youth-centered work is essential.**

¹ **"Deficit-framing"** is when a statement presents a person or community in terms of its problems first (e.g. "at-risk youth"). This negatively impacts how that person is perceived (e.g., stigma) and influences the way society responds. The opposite is **"asset-framing."** Asset-framing starts with an individual's aspirations and contributions before mentioning challenges. This is more equitable and also helps people relate to the individuals or groups being discussed by seeing them as people first, not problems. This can also help us see the root causes of problem as *situations* or *systems* so we can develop solutions that work and value young people.

IMPLICATIONS FOR ORGANIZATIONS

- / Dedicate clear and consistent resources to programs prioritizing and engaging young people living with or affected by HIV.
- / Consider non-traditional partners for deepening your work and filling your organization's gaps.
- / Use models that successfully engage young people in the public health space in a multitude of ways that respond to their needs and desires.
- / Ensure that young people being brought in as peer staff have sufficient support and resources to succeed.
- / Create opportunities to amplify and activate expanded opportunities for HIV prevention in young people, specifically those under the age of 18.
- / Reconsider and reframe language around "risk" in messaging, communications, campaigns and services for young people.
- / Seek out peer organizations that are willing to engage in network building with the explicit goal of challenging age-based assumptions, shifting power and engaging in peer learning to improve services for young people.

IMPLICATIONS FOR FUNDERS

- / Be available, be flexible and trust grantees.
- / Establish clear and transparent budgetary expectations to address operational challenges that are typically associated with implementing community-based projects.
- / Explore innovative avenues for incentivizing mental health opportunities to prevent burn-out.
- / Expand the typical definition of mentorship as a tool that improves young people's readiness for adulthood to include the transition into adult care and the ability to navigate barriers to services and resources.
- / Expand pathways to career development and for employment for youth living with or affected by HIV to be inclusive of careers outside of the healthcare or HIV space.
- / Invest in education and cultural competency for youth providers, including providers in training (e.g., nurses, medical school students, and medical residents), especially on college campuses.
- / Invest in collaboratives, cohort and shared learning opportunities that include full-service agencies that include young people and organizations that exclusively focus on young people to bridge the gap in education, outreach, and service provision.

The arc of ViiV Healthcare's youth-focused work is evolving. Young people who were NMAC Youth Scholars in the early 2010s and attended the first Youth Summit are now leading in the HIV space and elsewhere. In 2023 and beyond, ViiV Healthcare is committed to building on our collective learnings with continued resources to reduce stigma and close gaps in HIV prevention and care for young people across the US and Puerto Rico.



FAQ

The following report includes lessons learned from five years of *Positive Action for Youth* programming and strategic counsel from our advisors and partners on where we should go next.

/What is the purpose of this report?

This document is meant to inform, inspire and ignite community-centered solutions to disrupt current trends and conditions in HIV prevention, treatment and care, and improve the health and well-being of young people living with and affected by HIV.

/Why an insights report?

All too often, learnings are kept private. We believe that what we learned as an initiative can help the field grow and ultimately create better programs for young people.

/Why now?

As the *Positive Action for Youth* initiative reached its five-year milestone in 2022, ViiV Healthcare made a concentrated effort to listen and connect with youth-focused community leaders, organizations and young individuals working in and adjacent to HIV spaces to assess and possibly reimagine our goals—and to get a pulse on what's important for youth living with and affected by HIV as well as those who serve them.

/Who can use this report?

These learnings can be used by anyone who is looking to improve health outcomes for young people. This includes young people and aspiring adult allies, artists and storytellers in community-based organizations, community coalitions, funding organizations, health care organizations, educational settings and public health institutions.

/What data and methods were used to develop this report?

This report compiles a mix of evaluation and assessment data from 2017 – 2022, including qualitative data from interviews and discussions with grantees; analysis of grantee report data; grantee case studies; and Youth Listening Tour in 2022 which engaged 76 youth (ages 18 – 24) in priority regions (Chicago, Atlanta, Dallas-Fort Worth and South Florida).

/How was this report developed?

This report pulled directly from meaning-making meetings with advisory boards comprised of young people and adult allies where we discussed themes and implications from the data analysis. The report and design were also reviewed by a mix of community advisors. For a full list of the individuals and organizations that were a part of *Positive Action for Youth*, please see the acknowledgements section on [page 30](#).

/Who can I contact for more information?

Megan Falkenhan, Senior Operations Manager at megan.l.falkenhan@viivhealthcare.com. You can also visit viivhealthcare.com/us for more information about *Positive Action for Youth* or ViiV Healthcare's other *Positive Action* initiatives in the U.S. and Puerto Rico.



BACKGROUND

"Each young person is so radically different – they each have their north star. And our programs have to reflect that." – Adult Lead, Grantee Project

Coming of age is a time of seismic shifts in identity and sexuality. HIV does not exist in a bubble and young people affected by HIV are also face-to-face with a new phase of racial reckoning in our country, an upswing of homophobic and transphobic policies and sentiment and the new realities of the COVID pandemic.¹ Young people¹ continue to witness, form and lead movements to reshape our society for more equity, while at the same time treading water through mental health challenges, record increases in STIs, homelessness and evolving opioid and crystal meth crises.^{ii,iii,iv,vvi}

The story of *Positive Action for Youth* is a story of finding our north stars. *Positive Action for Youth* launched in 2017 at a time when breakthrough scientific advances around treatment as prevention and pre-exposure prophylaxis (PrEP)² were being rolled out across the country. These advances alongside the bold work of community organizations and advocates had helped lessen the number of new HIV diagnoses substantially and improved the well-being of adults living with HIV.

Despite this progress overall, HIV diagnoses among youth (13-24 years) increased by 6% between 2012 and 2016, with Black and Latinx³ gay and bisexual young people most affected.^{vii,viii,ix} At this time, young people were experiencing the lowest rate of viral suppression⁴ compared to all other ages—only 1 in 2 young people diagnosed with HIV had viral suppression in 2015.^x

"I wish I knew how difficult it would be for young people to navigate the care system - just offering it for free doesn't guarantee they'll stay engaged." – Adult Lead, Grantee Project

1 "Youth" and "young people" are used interchangeably in this report and refer to people 13-24 years unless otherwise noted.

2 PrEP is a medication that can prevent HIV. For more information go to: Ready, Set, PrEP. <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/prep-program/>

3 Throughout this report, we use the term Latinx unless we are citing a data source, in which case we use the term from the original source. Latinx is a gender neutral descriptor of the diverse community of people of Latin American cultural or ethnic identity, including people who identify as Latino, Latina, Hispanic, Chicax, Xicanx, Latin@, Latine, or specific nationalities and indigenous groups that have called Latin America home in past or current generations. The term was first coined by Latinx LGBTQ communities.

4 Viral suppression is a measure of the amount of HIV in the body and an indicator of adequate HIV treatment and prevention.

RESPONDING TO YOUTH DEMAND: POSITIVE ACTION FOR YOUTH

From its inception, ViiV Healthcare has shown its commitment to young people by supporting programs co-created with and for youth. In 2014, young people attending ViiV Healthcare's annual **Youth Summit** and participating in **National Minority AIDS Council's (NMAC) Youth Scholars Initiative** published a youth manifesto, calling for more HIV-focused resources that put youth first.

Responding to the call, ViiV Healthcare conducted listening activities in 2016-2017 to shape the focus and structure of a new *Positive Action for Youth* initiative. This included key informant interviews with critical stakeholders, both youth and adult allies, and a review of the epidemiological data.

In 2017, we launched the *Positive Action for Youth* initiative to empower youth living with HIV to manage their diagnosis and develop healthy behaviors, reduce stigma and close gaps in HIV prevention and care for young people across the country.

At that time, ***Positive Action for Youth*** was specifically focused on funding youth-led and youth-serving organizations to implement **medical mentorship programs** as a tool to reduce stigma and help youth living with HIV stay engaged in care and, as a result, live healthy lives with access to role models and a suite of supportive services. Advocates for Youth was

funded to collaborate with the *Positive Action for Youth* cohort to document the voices and expertise of community on best practices, learnings and recommendations in a **[new Medical Mentorship for Young People Living with HIV](#)** toolkit.

After several years of laser focus on mentoring projects and this ground-breaking medical mentorship toolkit, we began hearing more and more calls from grantees and advisors to widen our lens, which were echoed in epidemiological data reasserting the disproportionate impact of HIV on youth. Grantees and advisors advocated for including leadership development and advocacy to close gaps in care and bolster young people's income, stability, empowerment and health.

FOSTERING YOUTH LEADERSHIP

The following activities pre-date *Positive Action for Youth* initiative but provided critical insights and momentum for establishing a full-fledged initiative focused on the needs of young people in the HIV space in 2017.

- ✓ **ViiV Healthcare's Youth Summit** – Started in 2012, the annual Youth Summit is designed with and for youth aged 18-30 to inspire discussions, increase leadership opportunities for the next generation of leaders in the HIV workforce and identify new ideas and solutions to the issues faced by young people living with and affected by HIV. In a time where HIV continues to disproportionately impact young people, it is critical to equip leaders to disrupt disparities with the resources to effectively reach the communities most affected.
- ✓ **NMAC's Youth Initiative** – Created in 2010, the Youth Initiative aims to assist young leaders in the fight to end the HIV epidemic in becoming more effective and informed health advocates. Each year, the program selects 30 qualified young people aged 18-25, both living with HIV and HIV negative allies, to build their capacity to partner with a local community agency. This partnership builds the skills and networks to influence HIV prevention and service delivery in their communities. Youth Scholars take part in various activities through their tenure, including webinars and conferences, to prepare them to lead efforts to end the HIV epidemic in their communities and across the country.

In response to these recommendations, in 2021 *Positive Action for Youth* expanded its aims to advance:

- / Linkage and Engagement, with a focus on mentorship and peer navigation;
- / Advocacy, with a focus on leadership development;
- / Advocacy, with a focus on arts and culture to raise awareness, reduce stigma and build or deepen respect around youth living with HIV;
- / Networks of Support and Safer Spaces, with a focus on supporting youth to achieve independence.

We do this by supporting community-driven mentorship programs for youth ages 18 – 24; fueling leadership development initiatives to amplify youth voices to increase visibility and reduce HIV stigma; fostering safer spaces where young people can connect and find support with peers and allies; and in championing peer navigation as a vital piece of all youth linkage to care and prevention work.

Positive Action for Youth activities include:

- / Grantmaking efforts began as a \$1 million commitment to 5 grantees, and has expanded to more than \$4.25M to 13 grantees.
- / Learning Communities provide sustainability and capacity building that engage, inspire and energize community-based work through collaborative learning.
- / Continuous listening efforts keep youth and communities at the center of initiative evolution, including regular youth advisory board meetings, bi-annual connection calls with grantees, ongoing guidance of leadership development programming by Youth Ambassadors and more.
- / Amplification of projects at conferences and on social media elevate youth voices and place the concerns, successes, accomplishments and innovations of young people front and center in the conversation.
- / Learning and evaluation help us refine, sustain and scale our efforts and grantee work through iterative learning.

Like all ViiV Healthcare initiatives, *Positive Action for Youth* is grounded in our community-centered framework— to continuously **listen**, boldly **activate** new and promising work, **amplify** bright spots, and **sustain** momentum through applying field learnings to impact change.

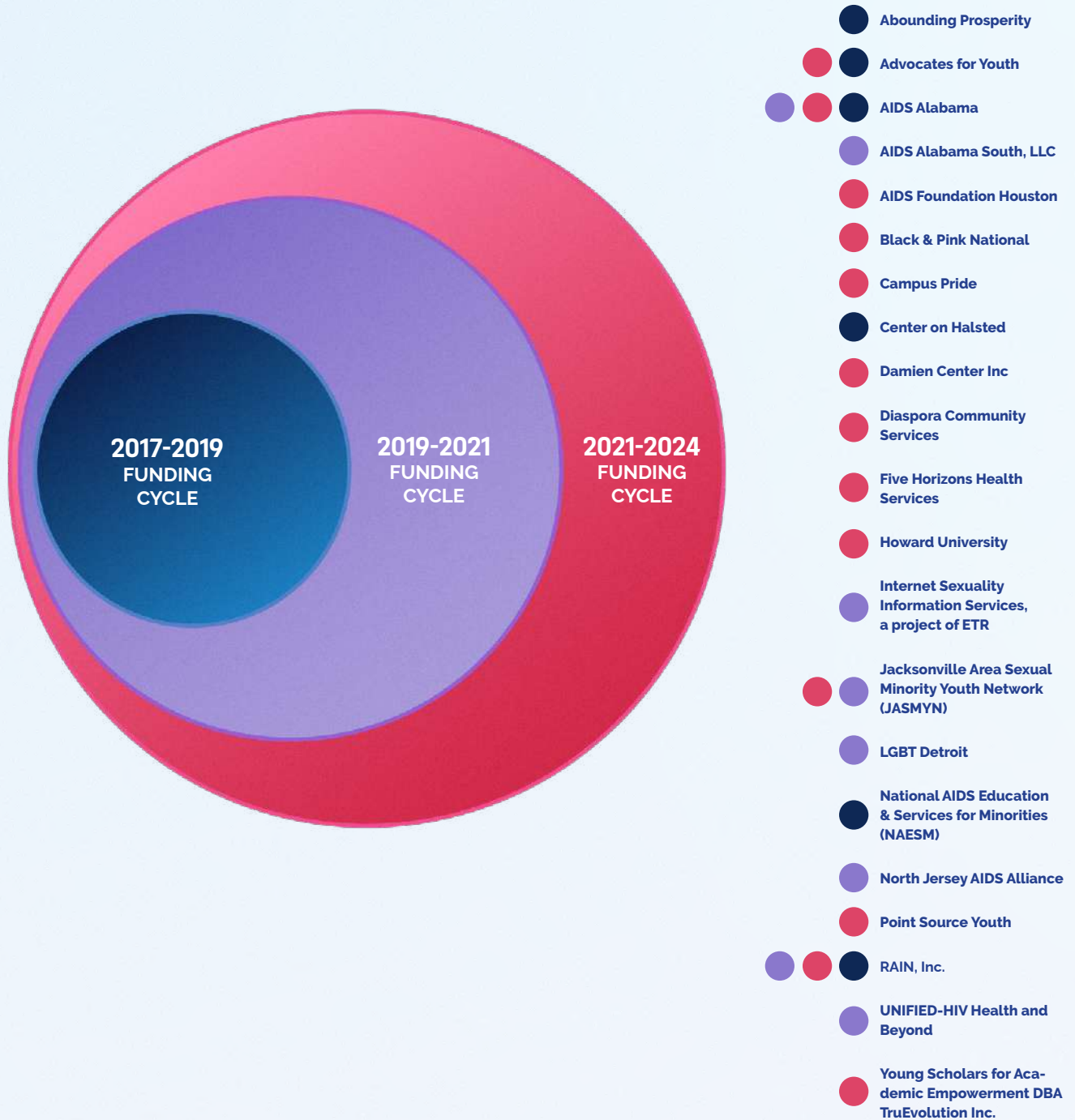
Today, there is still a steep climb to change the curve and reduce the negative impact of HIV on young people. In the most recent national data (2020), one in five new HIV diagnoses in the US are among young people, with Black and Latinx queer youth experiencing the greatest number of new diagnoses.^{xi} Young people are the least likely of all age groups to know their HIV status – only about half of young people know their status, and knowing one’s status^{xii} is the entry point to HIV care. When young people are diagnosed, they are the least likely to be linked to HIV care in a timely way.^{xiii} Across all areas of life, youth report experiencing the most HIV-related stigma⁵ in the past year compared to other age groups.^{xiv} Stigma is the culprit

5 CDC’s Medical Monitoring Project (2019) used a 10-point scale measuring personalized stigma, disclosure concerns, negative self-image and perceived public attitudes about people with HIV.

that perpetuates the many challenges experienced by young people living with HIV and those with reasons to know about and practice HIV and other STI prevention.

This report reflects on the evolution, learnings and impact of ViiV Healthcare's *Positive Action for Youth* initiative as it comes of age. As allies and co-creators with youth, we synthesized five years of data and analysis to our Youth Advisory Board to "make meaning," identify key learnings and provide action-oriented implications to inspire and inform organizations and funders map new routes to our north stars.

Positive Action for Youth Grantees 2017-2024



KEY IMPACTS

Impact 1

Youth-focused funding grew programs and infrastructure for youth's unique needs.

Communities have made it clear – one of the most important things a funder can do to increase impact is expand resources for *community-led* work focused on the unique needs of young people. Since launching, *Positive Action for Youth* **more than quadrupled funding** to youth-centered work. Grantees who had piloted youth-serving projects were able to exponentially expand their programming, reaching more young people in new places. Grantees also reported that by having this type of funding, they were able to create full positions that begin to integrate youth into the broader organizational procedures, helping to create initial structures to make sure youth aren't an afterthought of adult programming.

✓ Grantees credited their *Positive Action for Youth* grant with helping them solicit additional funding for their youth work: more than \$500K in 2021 alone.

\$6.75M committed by *Positive Action for Youth* 2017 – 2023

• 2017-2019: \$1M

• 2019-2021: \$1.25M

• 2021 – 2023: \$4.5M

• 50% of ViiV Healthcare's grantmaking for youth is based in the Southeastern U.S., where HIV most disproportionately impacts young people

"One thing we learned was that sometimes in the past we try to create a youth space, but it's really an older person's space with young people in it."

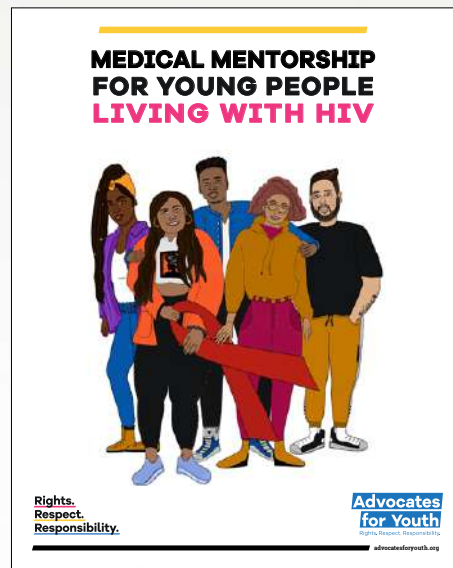
- Adult Lead, Grantee Project

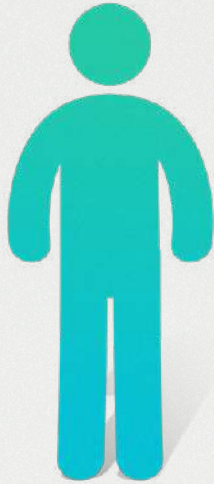
Impact 2

Thousands of young people accessed safer spaces, capacity building and HIV care and support.

Safer spaces are critical for building trust with young people—including young people who are program staff, mentors, mentees and clients—in order to provide social supports and promote engagement in care. Safer spaces must be more than a physical space. Our evaluation showed that effective safer spaces prioritized:

- / a working and training environment for youth workers considering pay, the realities of young people's unique circumstances, and flexibility;
- / an official process and encouragement for program alumni to be mentors;
- / culturally responsive adult allies as colleagues and providers;
- / ongoing reflection to cultivate stigma-free culture where young people are valued and listened to, and
- / youth-focused capacity building and medical mentoring and navigation that promote self-care, self-advocacy and holistic well-being.





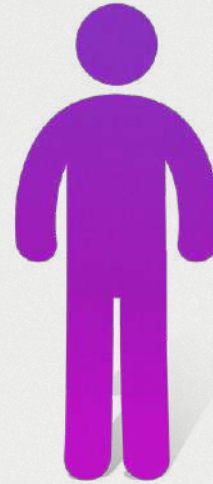
3,000+

people accessed Advocate for Youth's Medical Mentorship toolkit



2,700+

young people participated in 34 grantee-run safer spaces



2,066

youth linked or re-linked to care and support services and 26 peer navigators engaged to facilitate linkages

"We need to understand that everything isn't for every young adult. Some might want to participate in Pride, some might want to create a group for the AIDS Walk, and some just weren't comfortable with that. Leadership doesn't have to be upfront and plastered all over the place. There's so many different ways to engage youth, and it doesn't have to be at the 'forefront.'" – Adult Lead, Grantee Project

Impact 3

Mentorship and capacity building led to employment and leadership in the field of HIV.

Youth received professional development and support, earning paid positions at grantee organizations and with ViiV Healthcare as peer educators, coordinators and navigators, mentors and advisors. Young people led discussions and efforts to reform and reconsider how organizations engage with youth across staffing and programs, making key contributions to bettering the field. These efforts together created an informal pipeline of the next generation of leaders, giving them opportunities to exercise their leadership.

Collaborations and partnerships among and between grantees provided a point of entry into the leadership development pipeline and networks nationally.

For instance, one grantee described how a young person “who gained organizing skills through Advocate’s for Youth’s ECHO activist cohort went to the White House to talk about their work and advocate for better services. And it wouldn’t have happened if we weren’t connected to RAIN and their Empowering Positive Youth program.”

520 mentees and other youth engaged in leadership development and skills building

44% of youth mentees in the medical mentoring pilot went on to take on increased advocacy or leadership roles after participating

46% of organizations hired young people with *Positive Action for Youth* funds

25 young people have served as paid advisors on ViiV Healthcare’s *Positive Action for Youth’s* Advisory Boards and External Grants Review Committees strengthening connections, building camaraderie and leveraging talents and shared interests

Impact 4

Youth voices changed ViiV Healthcare's approach to community giving and youth engagement, substantially influencing grantees' ways of working.

Positive Action for Youth challenged how ViiV Healthcare and grantees engage with young people. The initiative created space for collective reflection, learning and skill-sharing that shifted organizational procedures to have young people at the tables in a more meaningful way.

- / Positive Action Boards and External Grants Review Committees—including *Positive Action for Women*, *accelerate*, and *Positive Action for Latinx Men*—hire young people in these roles to help guide program strategy and funding and strengthen young people's skills around grant-making processes.
- / In 2023, 82 grantee projects across all programs are advancing projects focused on young people, including Black and Latinx gay, bi and trans men, cis and trans women and Southerners.
- / ViiV Healthcare's **AMP Grant** piloted a micro-granting method to fund young leaders with innovative projects in the HIV space who would not typically be able to access philanthropic funds. This innovative model grew to include \$2.5M for programs centering young people, and an additional \$5M for elevating emerging leaders and initiatives of all ages.

Since launching *Positive Action for Youth*, we have seen meaningful impact in the lives of young people, including real improvement in viral suppression among young people nationally – about 2 in 3 young people diagnosed with HIV were virally suppressed in 2020.^{xv} While we cannot say that our programming impacted national epidemiology (given our methodology), it is clear that safer spaces and peer mentorship are part of the solution, especially when programs are given the flexibility, mutual support and resources to redesign and recenter youth.





LESSONS LEARNED

When analyzing and integrating the findings across the methodologies, the biggest challenge was that the experiences of young people defy categorization, or that society's categories are not specific enough. Every project, every demographic, every region touched by the *Positive Action for Youth* initiative is different—making flexibility and adaptability core components of any successful initiative. *Positive Action for Youth* may have initially piloted mentorship programs as a framework for engaging young people, but we've since learned that a young person needs to feel safe and cared for first. We must meet young people where they are and encourage them to believe in the possibility of getting to where they want to be.

Lessons learned and implications for the field are organized across seven core areas impacting young people's experiences, well-being and development.

Insight 1

Peer support models keep young people in care, but require compassionate attention to the needs and mental health of peer navigators, mentors and staff.

Grantees have reported again and again that peer support models are highly effective for navigating and engaging young clients in care. Evidence shows that the peer mentorship models also play an important role in stigma reduction, boosting trust in care and addressing social determinants of health—particularly when it comes to mental health.^{xvi} Former clients are often eager to support the young people in their sphere of influence, solidifying bonds that build formal and informal networks of referrals, support and advocacy.

“Having staff that's positive who are going through the same stuff as me, that's the biggest thing. I feel like that understanding really helps when you're first coming into the program. I probably wouldn't have come into the program if it wasn't for the staff members that are HIV positive.” – Youth Participant, Grantee Project

However, the demanding nature of this work can prompt exhaustion, burnout, and high turnover if peer supporters are not given proper training, ongoing support, appropriate pay and time and resources for self-care. This is particularly important when peer navigators serve communities so close to their experience, including individuals from their own social and personal networks. Modeling good boundaries is crucial when bringing on new peer staff. Workplace training and professional development in self-awareness, boundary-setting, and trauma-informed communication—paired with compassionate supervision—helped peer navigators, mentors and staff sustain healthy engagement in the HIV workforce.

“A lot of youth really start to feel lonely doing the work we’re doing. We talk about the dichotomy of serving the community you are a part of, which can create some identity issues. It was empowering to talk to youth across the nation. We all accomplished and achieved so much. There were a lot of tears at that one, it was great. I felt really empowered after that. I went back to work and asked for a raise. And it worked.” – NMAC Youth Scholars Participant

Insight 2

Safer and braver spaces are critical to supporting youth in developing confidence, seeking independence and establishing networks of support.

Safer and braver spaces are crucial to foster confidence and advocate for affirming care, despite the stigmas surrounding HIV. These spaces can be “programmed” to provide activity or linkage to services, but grantees noted the empowering nature of an “unprogrammed” space for young people to utilize the space in whatever way they most see fit. More of these types of confidential spaces are needed for young people to thrive, particularly for trans and gender non-conforming youth, with access to resources, like-minded peers and trauma-informed services at traditional and non-traditional hours.

WHAT MAKES A SPACE SAFER?

“This is the only space that I feel comfortable coming to. I know my confidentiality will be okay, I know that staff will follow up with me... And then I have friends that are in the same position as me, feeling like we don’t have an outlet. And being here we can express that stuff, and not worry about being put down.”

— Youth Participant, Grantee Project

“Now I feel like I’m living, before I was just there.”

— Youth Participant, Grantee Project

Grantees have found a multitude of innovative ways to expand access to their spaces: Leveraging cross-sector partnerships to enhance service delivery; engaging young people's chosen families in prevention and education (including the house and Ballroom communities); and partnering with grassroots community networks to enhance service delivery. While brick-and-mortar spaces and in-person activities are critical to building rapport and connecting to critical resources such as medication and food pantries, trusted virtual spaces can be easier to access when a young person is concerned with confidentiality or the cultural competency of their local providers.

Insight 3

Misinformation, discrimination and deficit-framing drive HIV stigma.

Stigma from family, peers and adults rooted in harmful misinformation and racism continues to be a barrier to care for young people. Latinx and Black youth in particular face wide-spread discrimination, resulting in a lack of support for engagement and retention in care. Unhoused and recently incarcerated young people often find themselves experiencing compounded disparities, especially when the young person identifies as LGBTQ or BIPOC. Across the country, and especially in Southern states where youth already face environments with abstinence only education, youth are bearing the brunt of an increasing number of anti-LGBTQ policies that weaponize culture, politics and disinformation at the state and local levels, leaving youth-serving organizations struggling to navigate the shifting socio-political landscape.

When it comes to adolescent and young adults' sexual health, adults (providers in particular) often talk about HIV prevention, treatment and care from a fear-based perspective that does not motivate young people to take charge of their sexual health. They are approached with attention to their deficits, not the social determinants of health that have impacted their care journey or the perspective they bring to the work. As such, a lot of young people do not trust the medical system and don't develop critical skills in advocating for or navigating their healthcare needs.

Evidence shows that arts and culture programming can and should play a role in countering stigma, and that storytelling can be leveraged in innovative ways to change harmful narratives, connect communities and foster dialogue on sensitive topics.^{xvii} Creating space for youth to work outside public health is a way to reduce stigma, as well as foster leadership and employment pathways.

Insight 4

Young people need more information about HIV prevention and access to trusted resources on sexual health.

Today, there are more HIV prevention options for individuals than ever before. In 2022, ViiV Healthcare conducted a community survey and series of youth¹ listening sessions in four areas to learn more about young people's experiences, attitudes, and environments that impact HIV prevention (Atlanta, Chicago, Dallas-Fort Worth and South Florida). The findings: not only are youth less knowledgeable and less comfortable discussing PrEP than adults, young people also believe they have a lower likelihood of getting HIV based on their per-sonal activities, actions and where they live.

When it comes to identifying trustworthy sources of information regarding sexual health, youth report less trust than people of other ages. While young people say that doctors are the most trustworthy of all suggested sources of information and care, they often don't have access to providers consistently. A robust prevention strategy would recognize the unique networks that exist in well-resourced major metro areas and also account for the unique ecosystems that exist in more rural communities.

Insight 5

Effective youth-centered models require organizations to address age-related power and systems, often in ways that adults overlook.

There is often a disconnect between adult staff perceptions of how youth-centered their model is and how adolescent and young adult staff and clients experience youth-centered work. Often, adults overestimate the level of youth-centeredness in their programming. Having mechanisms for clear, transparent, and non-punitive feedback are extremely important for ensuring greater commitment to a youth-centered approach.

"Seeing people kicking ass in the world, it is so powerful to let them know that 'you deserve to have a seat at the table, you are able to contribute to this environment and you belong here.'" – Adult Lead, Grantee Project

¹ "Youth" was defined as 18-24 years old in the survey and listening sessions.

A good indicator of a commitment to being youth-led is when young people (staff and clients) feel empowered enough to ask for what they want in programming and roles. Providing tangible youth ownership of activities or spaces is a good way to build leadership muscles for the youth as well as strengthen trust and commitment.

"Having the relationship [with young staff] where you can see 'you're giving me that energy today,' I can really work with that. We [adults] are not far removed from being chastised - respectfully, pull us aside if you need to. I don't take anything wrong with it - sometimes I tell them we'll revisit things tomorrow - but I understand them getting frustrated or being passionate about things in this group, I love to be able to receive it as that and expect nothing less." – Adult Lead, Grantee Project

Insight 6

Youth-centered initiatives depend on an openness to change our ways of working, continuously challenging assumptions.

Consistent and iterative listening to youth and grantees enabled ViiV Healthcare to shift *Positive Action for Youth's* priorities from medical mentorship to whole-person engagement via leadership and advocacy development to address core barriers in ending the HIV epidemic, stigma and inequities in power. Modelling the commitment to listening and being responsive to youth priorities is an excellent way for a funder to set the tone and expectations for grant partners in terms of youth-led work.

"A challenge is when they want housing and you're trying to work on their HIV. We listen to them and put their priorities first. We listen to what people need. A lot of the time, they [clients] put up with EBIs [evidence-based interventions] when all they really want is a ride to get their meds."— Staff/Mentor, Grantee Project

Positive Action for Youth activities that brought together grantees, such as the Learning Community, worked well because they created spaces of learning that challenged grantees and ViiV Healthcare to re-think how they implemented programming. Grantees reported that these spaces helped them provide higher-quality services to support youth living with HIV. Having the peer support of other programs striving to be innovative and youth-centered allowed for more shared space for experimentation and reflection.

It is crucial to avoid traps of condescension and tokenizing of the youth voice when involving youth. While there might be a desire to have youth-designated spaces on certain

planning committees or advisory boards, it is important to not pressure youth to participate for the sake of participating. Young people may need to have some tangible successes in other areas before feeling empowered to participate fully and not tokenistically in these types of roles.

“An issue with some youth programs is that they want to be youth-led, but they don’t take the time to unpack that and don’t take the time to teach youth to use their voice in a way that feels authentic to them.” – Positive Action for Youth Grantee

Insight 7

Funders and organizations should budget for time, space, and mutual support around the realities of grassroots, youth-centered work.

Much of the youth led infrastructure fueled by *Positive Action for Youth* was new – it hadn’t existed before. Most grantees required a full year to get their programs up and running (planning, hiring, etc.) Even when fully implemented, programs faced various challenges including: grantee staffing turnover; lack of internal staff buy-in; lack of transportation; confidentiality concerns; and slow-forming partnerships.

Grantees that sought to hire, train and supervise former youth clients in staff positions realized that more support was needed to ensure the young person’s success in the role, structured boundary-setting, professional development opportunities, trauma-informed communication, navigating and communicating expectations, were some strategies used to facilitate the transition from client to staff.

Having the flexibility and patience to commit to youth-centered work is crucial. Programs must be prepared for the unexpected, and be cognizant to factor in that because of structural and societal challenges, young people have less agency over their lives and how they are able to show up on a day-to-day basis. Having a level of patience and adaptability will allow work to move more smoothly and encourages adult leadership to grow and evolve.

The amount of turnover for staff in youth-centered programs can be a barrier and challenge. It is important for leadership to provide adequate support and resources for client-facing staff in these roles to ensure that they have the support needed to build longer-term relationships with the youth with whom they work.

IMPLICATIONS FOR THE FIELD

FOR ORGANIZATIONS

- / **Dedicate clear and consistent resources to programs prioritizing and engaging young people living with or affected by HIV.** Young people live complex lives with unique concerns; they desire and deserve unique programs that are responsive to their needs, perspectives and current development. Initiatives that simply roll their younger populations into programming that ignores age differences will not successfully expand awareness of HIV and the stigma that silences discussions about HIV as part of a robust approach to sexual health and wellbeing.
- / **Consider non-traditional partners for deepening your work and filling your organization's gaps.** PAFY grantees have leveraged partnerships with HBCUs, Boys and Girls clubs, school districts and more.
- / **Use models that successfully engage young people in the public health space in a multitude of ways that respond to their needs and desires.** This means expanding safer/braver spaces, peer support models, and leadership development initiatives to reduce stigma, build confidence, increase awareness and support youth living with or impacted by HIV and AIDS.

"Young professionals who do this work, also need this work. We need to remember we are the missing link in the community as well." - Anonymous Participant

- / **Ensure that young people being brought in as peer staff have sufficient support and resources to succeed.** This includes paying them a fair wage, providing adequate training and support, providing peer support from others who have made a similar transition, and modeling good practices for setting boundaries and self-care.
- / **Create opportunities to amplify and activate expanded opportunities for HIV prevention in young people, specifically those under the age of 18.** Linkage, navigation and prevention options should meet youth where they are in terms of knowledge, awareness and readiness for engagement.
- / **Reconsider and reframe language around "risk" in messaging, communications, campaigns and services for young people.** Organizations and providers need to retire fear-based, deficit-centering language if they are to more broadly engage young people in successful prevention efforts.
- / **Seek out peer organizations that are willing to engage in network building** with the explicit goal of challenging age-based assumptions, shifting power and engaging in peer learning to improve services for young people.

FOR FUNDERS

- ✓ **Be available, be flexible and trust grantees.** Projects with built in flexibility and deepening trust often have the most meaningful and long-term impacts, whether you can measure it or not. Some grantees also want to have opportunities to talk to funders about budget and program development through step-by-step support to get to where they want to be.
- ✓ **Establish clear and transparent budgetary expectations** to address operational challenges that are typically associated with implementing community-based projects. When challenges are surfaced—and even before challenges are identified—Learning Communities can foster opportunities to brainstorm with and learn from peers, ultimately strengthening the networks essential for broad and lasting change.
- ✓ **Explore innovative avenues for incentivizing mental health opportunities to prevent burn-out.** This might include requirements for wellness “capacity building” in grant proposal budgets for the project team or organization - grant dollars for brick-and-mortar safe spaces that are unprogrammed, allowing youth to access the space in whichever way best serves them, and more.
- ✓ **Expand the typical definition of mentorship** as a tool that improves young people’s readiness for adulthood to include the transition into adult care and the ability to navigate barriers to services and resources. More capacity building around proven methods of mentorship and training can increase a young person’s trust in their ability to advocate for themselves and bolster relationships with community-based and service organizations.
- ✓ **Expand pathways to career development and pathways for employment** for youth living with or affected by HIV to be inclusive of careers outside of the healthcare or HIV space. Public health and HIV education advocates span the workforce, and funding that only allows for training in HIV-specific positions (e.g., HIV tester, peer navigator) silos future advocates.
- ✓ **Invest in education and cultural competency for youth providers,** including providers in training (e.g., nurses, medical school students, and medical residents), especially on college campuses.
- ✓ **Invest in collaboratives, cohort and shared learning opportunities** that include full-service agencies that include young people and organizations that exclusively focus on young people to bridge the gap in education, outreach, and service provision.



CONCLUSION

The arc of ViiV Healthcare's youth-focused work is evolving. Young people who were NMAC Youth Scholars in the early 2010s and attended the first Youth Summit are now leading in the HIV space and elsewhere, including government positions, founders of organizations and policy leaders. Today, youth and adult allies in *Positive Action for Youth* continue to chart new routes to our north stars. In 2023 and beyond, ViiV Healthcare is committed to building on our collective learnings with continued resources to reduce stigma and close gaps in HIV prevention and care for young people across the US and Puerto Rico.

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