TRANS FUTURES

Centering Trans Youth Voices in HIV Policy

A National Storybank & Advocacy Toolkit for Policymakers, Advocates, and Community Leaders

DeOnyae-Dior Valentina

TRANS FUTURES

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INTRODUCTION

This toolkit translates lived experiences of transgender and gender-expansive young people into policy-relevant insights to inform federal HIV, healthcare, and equity policy.

Across the United States, trans youth - especially those living with or impacted by HIV - are facing increasing barriers to healthcare access, medication continuity, housing stability, and safety. These barriers are not accidental. They are policy outcomes.

TRANS FUTURES

Developed as part of AIDS United Transgender Leadership Initiative, stories were collected from transgender and gender-expansive young people ages 16-29 across the U.S. Participants represent diverse racial, geographic, and socioeconomic backgrounds and include individuals living with HIV as well as those directly impacted by HIV-related policy.

Ending the HIV epidemic requires protecting trans lives, stabilizing access to care, and removing structural barriers created by policy.

WHAT THIS TOOLKIT PROVIDES:

Real lived-experience narratives
Identified policy failures
Clear federal solutions
Advocacy guidance

WHAT THE STORIES REVEAL - KEY NATIONAL THEMES

1. **Administrative Barriers Interrupt Care**
Paperwork errors, eligibility reviews, and renewal requirements routinely interrupt medication access.
Policy Implication: Administrative complexity is a health risk.

2. **Geography Determines Survival**
Access to HIV care and affirming providers varies drastically by state and region.
Policy Implication: Zip code should not determine healthcare access.

3. Insurance ≠ Access
Many participants technically had insurance but still experienced denials for necessary care.
Policy Implication: Coverage without access is not coverage.

4. **Theme 4 - Structural Instability Undermines Treatment**
Housing instability, employment insecurity, and transportation barriers directly affect treatment adherence.
Policy Implication: Healthcare policy cannot be separated from social policy.

WHY STORIES MATTER FOR POLICY

Policy is often discussed in statistics, but statistics cannot explain what barriers feel like in real time. The following narratives come from transgender and gender-expansive young people across the United States whose lives are shaped by healthcare policy decisions. These stories illustrate how administrative systems, legal frameworks, and funding structures directly affect access to HIV care, medication, housing, safety, and survival.

These are not isolated experiences.
They represent patterns.

ETHICAL STANDARDS & METHODOLOGY SAFEGUARDS

This project was developed using community-centered, trauma-informed, and ethics-driven practices designed to ensure participant safety, narrative integrity, and methodological transparency. The following safeguards outline the standards used in the collection, documentation, interpretation, and presentation of participant narratives.

PARTICIPANT CONFIDENTIALITY & IDENTITY PROTECTION

To protect participant safety, privacy, and autonomy, all individuals featured in this project selected either an alias or their initials in place of their legal name. This decision was voluntary and made by each participant. In certain cases, limited identifying details have been generalized or minimally modified to reduce the risk of unintended recognition while preserving the accuracy and policy relevance of each account. These measures were implemented to ensure that participants could share their lived experiences without risk to their personal safety, healthcare access, housing stability, legal status, employment, or social well-being.

VOLUNTARY PARTICIPATION

Participation in this project was entirely voluntary. Individuals chose to share their experiences and retained the right to decline questions, modify their submissions, or withdraw from participation at any point prior to publication. No participant was required or pressured to disclose personal information beyond what they felt comfortable sharing.

COMPENSATION TRANSPARENCY

All participants received modest stipends in recognition of their time, expertise, and emotional labor. Compensation was provided as appreciation for participation and was not contingent upon the content, tone, or viewpoint of any individual's story. Participants were not directed, coached, or instructed to represent specific policy positions.

EDITORIAL INTEGRITY

Narratives included in this project have been edited only for clarity, length, grammar, and readability. No substantive meaning, perspective, or factual content was altered. The intent of editing was solely to ensure accessibility for policy audiences while preserving the authentic voice, perspective, and lived experience of each participant.

TRAUMA-INFORMED STORY COLLECTION

Stories were collected using trauma-informed practices that prioritized consent, agency, emotional safety, and participant control. Individuals determined how much they wished to share, the format in which they wished to share it, and whether any boundaries or limitations should be applied to the use of their narrative. Participants were informed in advance of how their stories would be used and retained the ability to decline uses outside that scope.

REPRESENTATION & SCOPE STATEMENT

The narratives presented in this project do not claim to represent the experiences of all transgender or HIV-impacted individuals. Instead, they document real experiences that illustrate recurring patterns of structural barriers reported across participants in multiple geographic regions. These accounts are qualitative evidence intended to complement - not replace - quantitative research and existing public health data.

POLICY INTERPRETATION NOTICE

Policy analysis included in this project reflects advocacy interpretation informed by participant testimony, publicly available policy information, and community expertise. This material is provided for educational and advocacy purposes and should not be interpreted as legal advice or clinical guidance.

ORGANIZATIONAL INDEPENDENCE

The views, interpretations, and conclusions presented in this project are those of the author and participating storytellers and do not necessarily reflect the official positions of supporting organizations, funders, partner institutions, or affiliated entities.

ETHICAL USE OF NARRATIVES

Stories shared through this project are intended for educational, advocacy, and policy-informing purposes. They should not be reproduced, excerpted, or redistributed in ways that compromise participant safety, distort meaning, sensationalize trauma, or remove context. Responsible use of lived experience narratives requires maintaining dignity, accuracy, and consent.

FEATURED NARRATIVES

DIOR (Midwest), Black & Brown Trans Woman
Medicaid Coverage Denial

I pursued gender-affirming surgeries through Medicaid by following every requirement the system set. I completed evaluations, gathered documentation, secured letters, and complied with each procedural step. I wasn't trying to bypass the system. I was trying to work within it and I was still denied.

The denial came in formal language - eligibility criteria, coverage limitations, administrative reasoning. But what it meant was simple: the care I needed to live safely and fully in my body was considered optional.

Gender-affirming care is often framed as cosmetic. For me, it was about safety, mental health, and survival. Being forced to exist in a body that doesn't align with your identity affects how providers treat you, how the public treats you, and how safe you feel navigating daily life.

When systems deny part of your care, it becomes harder to trust them with the rest. Barriers like this don't just delay treatment. They determine whether people stay engaged in healthcare at all.

Gender-affirming care is often framed as cosmetic. For me, it was about safety, mental health, and survival.

J.S. (Mississippi)
Administrative Medicaid Termination

I received a letter saying my Medicaid coverage had been terminated because they couldn't verify my eligibility, even though I had already submitted my paperwork.

My coverage stopped immediately. That meant no HIV medication. No lab work. No hormone prescription.

At the pharmacy I learned my medication would cost more than two thousand dollars out of pocket. I make eleven dollars an hour. So I started rationing pills. I skipped doses to make them last.

That wasn't a medical decision. That was a policy decision.

Administrative errors shouldn't determine whether someone has access to lifesaving medication. But right now, they do.

Administrative errors shouldn't determine whether someone has access to lifesaving medication. But right now, they do.

Angel (New York), Afro-Latine Nonbinary
Living with HIV + Undocumented

I delayed HIV testing because I was afraid my information would be entered into systems that could expose my immigration status. By the time I finally got tested, I was already sick.

Most people assume testing is a simple choice. But fear changes how you make decisions. Immigration restrictions don't just affect eligibility for programs. They affect whether people seek care at all.

Even now, every form I fill out makes me hesitate. Healthcare access shouldn't feel like a risk calculation.

Immigration restrictions don't just affect eligibility for programs. They affect whether people seek care at all.

STRUCTURAL REALITY SNAPSHOTS

Workplace Policy Barrier
"I missed a clinic visit because my supervisor said if I left early again I'd lose my job. Later I was marked 'non-compliant.' Nobody asked why." ***- Day Day, Michigan***

Clinic Closure Impact
"My provider stopped offering gender-affirming care because they feared legal consequences. Overnight I lost access to a doctor I trusted." ***- Fi, Florida***

Geographic Barrier
"The closest HIV provider is three hours away. Missing an appointment isn't neglect. It's distance." ***- AJ, Montana***

Indigenous Cultural Access Barrier
"I spend half my appointments explaining who I am instead of discussing my health."
- Allen, South Dakota

Housing Instability + Treatment
"I've stayed awake at night just to make sure my medication wouldn't be stolen." **- K.T., New York**

Insurance ≠ Access
"My insurance covers HIV medication but denies hormones. Survival is covered. Stability isn't."
- D.M., Texas

> *"Even though my care is stable right now, I still save medication because I'm scared I could lose access in the future. Every time I hear about new legislation targeting healthcare, my chest tightens."*
>
> *Mal, New Jersey*

Policies don't have to pass to hurt people.
Sometimes the threat alone changes how you live.

KEY TAKEAWAYS FOR POLICYMAKERS

These narratives demonstrate that barriers to HIV prevention, treatment, and gender-affirming care are not individual failures. They are systemic outcomes shaped by policy design, funding decisions, and administrative structures.

When policy changes, outcomes change.

FEDERAL POLICY RECOMMENDATIONS

Priority Actions for Policymakers

1. Strengthen Medicaid Protections

- Standardize eligibility processes
- Prevent abrupt terminations
- Require continuity-of-care protections

2. Protect Access to Gender-Affirming Care

- Enforce nondiscrimination protections
- Prohibit categorical coverage exclusions
- Expand provider training funding

3. Address Geographic Disparities

- Increase funding for rural HIV care access
- Expand telehealth infrastructure
- Support transportation assistance programs

4. Reform HIV Criminalization Laws

- Incentivize states to modernize statutes
- Align legal frameworks with current science

5. Integrate Housing + Health Policy

- Expand housing programs for people living with HIV
- Fund supportive housing models

HOW TO USE STORIES ETHICALLY

Stories are powerful, but they must be used responsibly. The following standards outline how lived-experience narratives should be handled to ensure participant safety, dignity, and integrity while maintaining credibility and accountability in advocacy work.

OBTAIN CONSENT BEFORE SHARING

Definition: Consent means participants clearly understand how their story will be used, where it may appear, who may see it, and that they have agreed to those uses before their narrative is shared.

What this looks like in practice: Consent is informed, voluntary, specific, and documented, not assumed or implied.

Example: Before including a story in a report or presentation, the organizer confirms in writing that the participant agrees to have their narrative used for advocacy materials.

DO NOT EDIT MEANING

Definition:Editing for grammar, length, or clarity is acceptable; altering tone, perspective, or substance is not.

What this looks like in practice: Changes improve readability without changing the participant's message, intent, or viewpoint.

Example: Shortening a story for length while keeping the participant's original wording and message intact.

AVOID SENSATIONALIZING TRAUMA

Definition:Stories should never be presented in ways that exaggerate harm, dramatize pain, or frame participants primarily through their suffering.

What this looks like in practice: Narratives highlight systemic issues rather than using distressing details to provoke emotional reactions.

Example: Describing a policy's impact on someone's care access without graphic or unnecessary details about their medical or personal trauma.

PROTECT ANONYMITY WHEN REQUESTED

Definition: If a participant requests anonymity or confidentiality, identifying details must be removed or changed before their story is shared.

What this looks like in practice: Names, locations, workplaces, or other identifying information are altered or omitted.

Example: Replacing a participant's name with initials and generalizing their city to "Midwestern state" when publishing their narrative.

CENTER PARTICIPANT AGENCY

Definition: Participant agency means individuals retain control over how their story is shared, represented, and used.

What this looks like in practice:
Participants choose:

- what to share
- how to share it
- whether it can be used publicly
- and if they want to withdraw it later

Example: A participant approves the final version of their story before it is included in a report.

ADVOCACY TALKING POINTS (FOR MEETINGS)

If speaking to legislators, say:

- "Trans youth are not hard to reach. Care systems are hard to access."
- "Administrative barriers function as healthcare denial."
- "Coverage without usable access is policy failure."
- "Healthcare stability determines treatment success."

ONE-PARAGRAPH ELEVATOR SUMMARY YOU CAN USE!:

"Trans youth living with or impacted by HIV are facing systemic barriers to healthcare access across the United States, including insurance denials, clinic closures, geographic isolation, and administrative Medicaid terminations. These barriers are not individual failures—they are policy outcomes. Addressing them requires federal action that protects healthcare access, stabilizes coverage, and removes structural obstacles that prevent people from remaining in care."

WHAT POLICY MAKERS CAN DO NOW

LOCAL POLICY MAKERS

(City councils, county officials, local health departments, school boards)

Protect Medicaid Access

Local governments should fund enrollment navigators and renewal assistance programs to help residents maintain coverage and prevent administrative terminations.

Example: J.S. lost coverage due to paperwork despite submitting documents, which forced him to ration HIV medication. Local assistance programs could have prevented this interruption in care.

Invest in Housing Stability

Local leaders should expand housing assistance programs, emergency rental funds, and supportive housing options for people living with or impacted by HIV.

Example: K.T. reported losing medication while couch-surfing because he had no secure place to store it. Stable housing would have protected his treatment access.

Listen to Trans Youth

Local agencies should establish youth advisory councils to guide public health planning and policy implementation.

Example: Multiple participants described systems that failed to address real barriers because decision-makers never consulted affected youth directly.

STATE POLICY MAKERS

(Governors, state legislatures, Medicaid agencies)

Protect Medicaid Access

States should adopt 12-month continuous eligibility policies to prevent mid-year coverage terminations.

Example: J.S. lost medication access when his Medicaid coverage was terminated during an administrative review period.

Modernize HIV Laws

States should repeal or reform HIV criminalization laws that are outdated and inconsistent with current medical science.

Example: An unfeatured participant described fear of relationships and disclosure because existing criminalization laws could still expose her to prosecution despite taking precautions.

Expand Provider Access

States should increase funding for HIV clinics and gender-affirming care providers and ensure provider protections so clinics can safely offer services.

Example: Fi lost access to her provider when a clinic stopped offering care due to policy-driven legal concerns.

FEDERAL POLICY MAKERS

(Congress, federal agencies, CMS, HHS)

Protect Medicaid Access

Federal policymakers should establish national continuity-of-coverage standards and simplify renewal requirements to prevent administrative coverage loss.
Example: J.S. was forced to ration medication after losing coverage due to paperwork issues, demonstrating how administrative barriers can create medical risk.

Ensure Coverage of Gender-Affirming Care

Federal agencies should prohibit categorical exclusions of gender-affirming care in federally funded health programs.

Example: Despite completing every required step, Dior was denied Medicaid coverage for surgery, showing that compliance does not guarantee access.

Address Geographic Care Gaps

Federal policymakers should increase funding for rural HIV services, telehealth access, and transportation support programs.

Example: AJ must travel hours for care, making missed appointments unavoidable and increasing risk of treatment interruption.

Strengthen Protections for Immigrant Patients

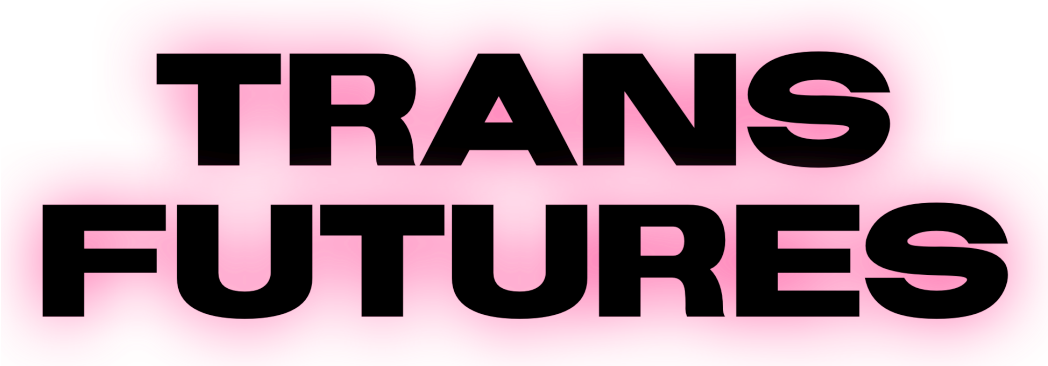
Federal policy should ensure healthcare access does not expose patients to immigration enforcement risks.

Example: Angel delayed HIV testing because he feared his personal information could be used against him.

Invest in Housing as Healthcare

Federal policymakers should expand housing programs for people living with HIV and recognize housing as a core health intervention.

Example: K.T.'s's ability to safely store medication depended on whether he had stable housing.



ACKNOWLEDGEMENTS

This project was made possible through funding from AIDS United's Transgender Leadership Initiative (TLI), a national program dedicated to strengthening the leadership, advocacy capacity, and policy engagement of transgender leaders of color working at the intersections of public health, equity, and justice. The resources, mentorship, and institutional support provided through the Transgender Leadership Initiative directly enabled the development of this work, including the collection, documentation, and translation of lived experiences into policy-relevant analysis. The investment of AIDS United reflects a broader commitment to advancing community-led solutions and ensuring that those most impacted by health disparities are positioned as leaders in shaping policy responses.

This project was further strengthened through the support, partnership, and advocacy infrastructure of Positive Women's Network-USA (PWN-USA), a national organization led by and for women living with HIV. Through its policy fellowship, leadership development programming, and movement-building initiatives, PWN-USA cultivates advocates who translate lived experience into systems-level change. The organization's commitment to reproductive justice, health equity, and community-driven policy reform provided both the political framework and strategic grounding that informed this project's national advocacy focus.

Additional support was provided by Advocates for Youth, whose leadership development programs and youth-centered policy initiatives equip young people with the tools, training, and platforms necessary to advance sexual health, rights, and justice. Their investment in youth leadership ensures that emerging advocates, particularly those from marginalized communities, have access to the resources and opportunities needed to influence public discourse, policy development, and institutional decision-making. The skills, network connections, and capacity-building opportunities offered through their network of programs contributed meaningfully to the execution and national scope of this project.

Together, these organizations represent a collective commitment to community-led leadership, intersectional justice, and evidence-informed advocacy. Their support reflects an understanding that sustainable policy change requires not only research and data, but also the leadership, insight, and lived expertise of those directly impacted by structural inequities. This project stands as a direct result of that shared investment in empowering community voices, strengthening advocacy infrastructure, and advancing equitable policy solutions.

STAY CONNECTED!

Advocacy does not end when a report is published. Policy change requires ongoing engagement, follow-up, and collective participation. To stay informed about updates, future publications, advocacy opportunities, and project developments, you can:

- Request updates directly from the project lead
- Join future advocacy briefings and workshops
- Participate in upcoming storybank initiatives
- Share this toolkit with policymakers, organizations, and community leaders
- Attend future presentations and policy convenings where findings will be shared

For updates, collaboration inquiries, or partnership opportunities, contact:

DeOnyae-Dior Valentina (she/her/ella)
AIDS United Transgender Leadership Initiative
PWN-USA Policy Fellowship Cohort
Advocates For Youth TASP & ECHO
Founder, Strength Over Struggle, Inc
deonyaedior@strengthoverstruggleinc.org | 224.716.3424

strengthoverstruggleinc.org
LinkedIn: DeOnyae-Dior Valentina
Instagram: DeOnyae-Dior Valentina
Instagram: Strength Over Struggle

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