

COMPASS Initiative

January 2019
to
February 2020



We are a
**COMPASS
INITIATIVE**
Grantee!



#GileadCOMPASS
Funded by Southern AIDS Coalition

The graphic features a green background with yellow and green confetti. The University of Memphis logo is in the top right corner. The main text is centered, with 'We are a' and 'Grantee!' in a white script font, and 'COMPASS INITIATIVE' in a large, bold, white block font with a drop shadow. A circular icon containing a white map of Tennessee is in the bottom left. The hashtag and funding information are in the bottom right.

HEADLINERS

Memphis

Headliners Memphis

- Established in 2015
- Who are we?
 - A grassroots organization comprised of community stakeholders working to Positively Transform the World without Stigma.
 - We do this through our PrEP Navigation programs, group interventions, professional development, and research participation opportunities.
 - Our “Party with a Purpose” is the heart of Headliners Memphis. At events, like our iMatter Extravaganza, Trans Girls Rock Awards, and our Sex in the Dark chats we always tie in safer sex practices, free HIV Testing, and linkage to care & PrEP.
 - We want to empower LGBTQ+ communities of color and those who are underserved to make sure they have access to quality health care.

Why was this project conducted?

- To understand internalized stigma among PLWH & to improve their management and resistance to it
- Use photovoice to create supportive anti-stigma environments for PLWH





What happened in this project?

- Session 1 – Orientation and Receipt of camera \$25
- Session 2 – Group Discussion of images taken on feelings of internalized stigma \$25 incentive
- Session 3 – Individual Interviews \$50 incentive
- Church Exhibit (attendance optional)

Photovoice

“Photovoice is a process by which you can express yourself through pictures..”

Wang, C., & Burris, M. A. (1997)



Photovoice

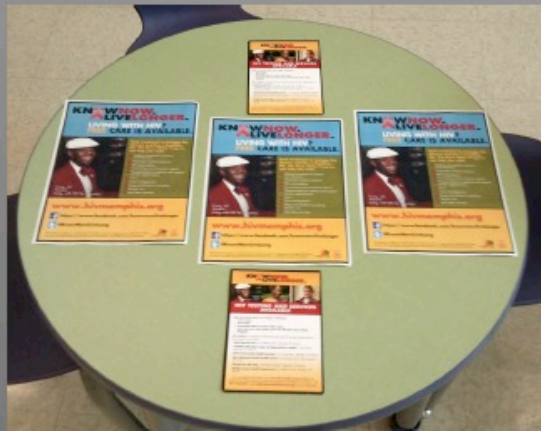
Main Goals

1. To enable people to record and reflect their community's strengths and concerns
2. To promote critical dialogue and knowledge about important issues through large and small group discussion of photographs
3. To reach policymakers.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, 24(3), 369-387. <https://doi.org/10.1177/109019819702400309>

Heaven in View: That's What My Eyes Are Set On

Stigma is still present in 2019. I'm trying to break down the doors every time I get the opportunity to **provide education**. My 2020 goal is to get into the Black church and educate the congregation about the **HIV epidemic**. It is not talked about on Sunday morning, but **HIV is in the pews of the black church**.



Many years ago, I was a billboard model. People would say, "**I can't believe you would do that.**" Oh, I know you got paid a lot of money. You're rich! **That couldn't have been me**".

I respond to that by saying, "Unless you've tried it in my shoes, **you can not judge me.**" How can you successfully preach a gospel that **you have never experienced?** Your face is not out there.

You can't even give your opinion. You can't even say anything because you **never had this experience.** Other than that, there's no conversation that we can have other than **me talking and you listening.**"



I'm very proud of my voice and I do have a voice.

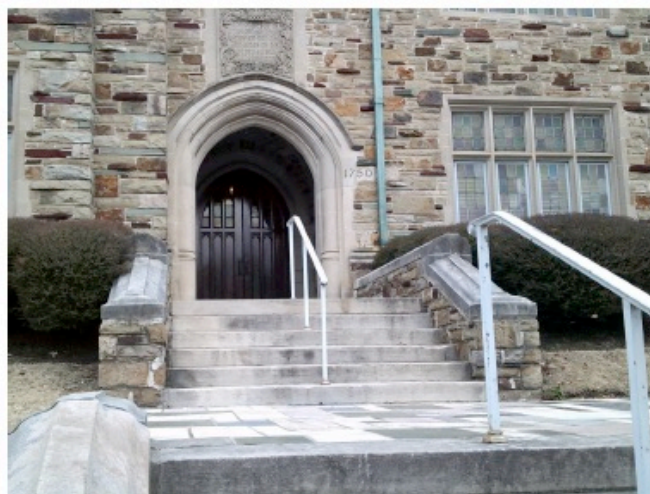
I don't really think of myself as a **trailblazer** or anything like that, but **maybe I am the first person** that people [at church] have contact with that have HIV.



[The trash can] is like what it felt like **to be different**. You're thought of **like the trash**. You're something unimportant.



After some **education**, some learning by the people that go to church and people that are working in the church, there's [potential for] a blossoming, and growth of **acceptance in the church**.



I'm almost **60 years old**. It's taken this long to get where I am. **There has been growth**, but I don't think we're ready to see acceptance in my **lifetime**.

The growth is incremental.
It is significant. It's huge.



A piece of my life, a segment of my life.

"You should have never been born." **Why do you tell a 10 year old kid that?**

I went through beatings with extension cords. If I look at that house, that's what it brought me back to, just shame, resentment, and brought me to today, like **the person I am today is because of that house.**

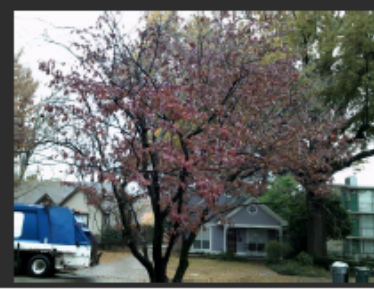
It took a lot out of me **to go to this house** and take that picture. **It took a lot out of me.**



When I was small, that's all we did was **stay in the church**, from sun up to sundown...**that's where I was supposed to have been protected**, but I was not protected, **I was abused**. Just evil in my eyesight because the things I went through...It still bothers me right now, so that's where **a little of my stigma comes from, the church**, because there's a lot of things that happened to me in church...



That [tree] represents to me **life within myself**. It was like I had to grow, so the tree showed me growth. **I branched out** even though I had hard conflicts, but I still branched out. **I bloomed and I blossom still**, but I still have faults within myself because I still have a dark side within me.



I want them to "Lay hands on me, too."



My personal church...does a lot of praying for people in the church that have cancer. I feel if I was to tell them I had HIV, **it wouldn't be the same prayer.** It would be a prayer, but it would be a little bit different. *You know what I mean?*



Some churches very seldom embrace you living with HIV.



They [church] are **either judgmental or they will embrace you.** When you walk into a church, it's beautiful. It's shining. It's clean. It's got the chandelier, but you get a lot of judgment in that place.



Stigma comes from family members...

...that ask their HIV+ family members **to use paper plates and plasticware.** They are probably afraid of catching HIV. **They don't have any knowledge of HIV.**

My family is a huge support. If you're living with HIV, and your family supports you, who cares about what anybody else thinks? But when you **don't have family support it can take you on a mind trip.** Family that supports you gives you that power to deal with people that don't support you... **"That is a difference, and that's why I have been able to cope."**



- no more ignorance. I think a lot of the stigma that comes with HIV is people not being simply educated...
People still do not know what undetectable means.

What would MLK Do?

... "How would he have come and been an advocate for those living with HIV because of African American's being the number one demographic that's primarily affected by this?"



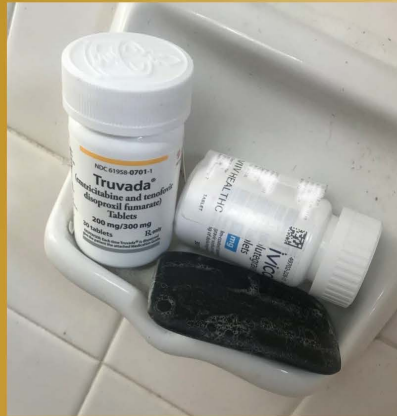
I was diagnosed when I was 22.

I was in relationship with somebody who was positive. I was on PrEP. There was a period when I was missing dosages frequently. **Of course, when you're in your 20s, you're like, "I'm invincible..."**



The thing that helped me become undetectable as soon as I did was **sticking to my medication regimen...and I had friends that were [HIV] positive that were encouraging me.** They were like, "It's going to be OK. You'll be fine." ...It was having camaraderie and family around you saying, "You'll be OK. **Everything is going to be OK...**"

They always ask you, "Are you clean?"

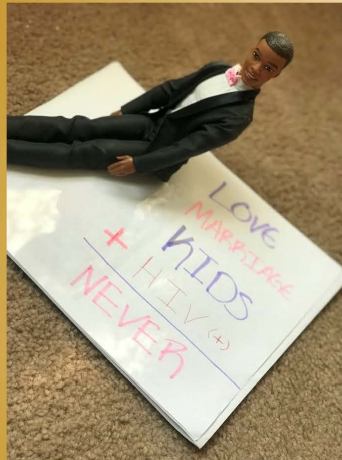


"Are You Clean?" When dating and meeting people, they always ask you, "Are you clean?"

They're insinuating, "Are you negative?"

When you ask me that, it really puts me in a place like, just because I have HIV **doesn't mean I'm any worse than you**. Like I'm dirty and not worthy of this thing (relationship).

A dream deferred?



When I found out my status at 20, I thought that was the end. I was like, "Oh my God, nobody wants to marry a young, vibrant [HIV] positive little boy. I definitely want a marriage. I want just genuine love. I know that it's possible, but getting to that point knowing and making sure that someone is comfortable with you...**really got to do some soul searching and digging deep within yourself.**

Life does go on after being positive. It's up to you what you decide to do with it. You can still have that love, that marriage, those kids.



That's my original pill case...**my daily reminder...** it gave me a **new outlook on life.**

If I don't take these two little pills **every single day** like clockwork for **the rest of my life.** I can't play. I can't work. I can't love. I can't get to that marriage or the kids. **It's my lifeline unfortunately.**

4 Common Themes

1. Medical care as support and stigma
2. Social support as support and stigma
3. Church as support and stigma
4. Self as support and stigma

Acknowledgements

- 35 photovoice volunteers
- Team: Daniel Thompson, DeMarcus Jones, Dr. Michelle Teti, Ashley Yacoubian, Marshun Redmond, Ms. Bettina Campbell
- The Hill-Hernando Baptist Church, Pastor Minor & Sis. Lottie
- Christ Missionary Baptist Church, Dr. Gina M. Stewart
- PEAS, WeCareTN, Hope House, and H-CAP
- Funded by Southern AIDS Coalition, 2019 Transformative Grant partner by the Gilead COMPASS Initiative
 - CDC MARI 1 U01PS005211-01-00
 - Dr. Roger S. and Mary E. LaBonte Endowed Professor of Urban Health