

HIV/AIDS in the South: Addressing
Social Issues Affecting Care

Health Equity and Social Justice in
the Deep South
Medical Advocacy & Outreach
Renaissance Montgomery Hotel and
Spa

Kathie Hiers, CEO
January 23, 2019

***“AIDS Alabama devotes its energy and resources statewide
to helping people with HIV/AIDS live healthy, independent
lives and works to prevent the spread of HIV.”***

As an agency with an over thirty-year history, AIDS Alabama has operated with the above Mission Statement. As times and community needs change, AIDS Alabama has begun programs to supplement its original mission to be more inclusive of others struggling in our community. As the largest AIDS Service Organization in the state and the only one that focuses primarily on housing and behavioral health, AIDS Alabama staff and Board of Directors acknowledge that we have always worked to prevent new transmissions and that other vulnerable populations, such as the homeless, LGBTQ populations, the uninsured, and persons living with hepatitis C and other sexually transmitted infections, need services, too.



Context

National HIV/AIDS Strategy: Executive Summary (2010)



A fellow citizen becomes
infected every 9½ minutes.



In first 30 years epidemic has
claimed more than 600,000
lives.



We have the tools and
knowledge to slow the spread
of HIV and improve the lives
of people living with HIV.



Public's sense of urgency
appears to be declining.

The Current HIV Epidemic Snapshot

In the U. S.:

- Between 1.1 and 1.2 million people living with HIV in U. S.
- About 15% don't know their status
- About 37,000 new diagnoses each year
- Life span can be expected to be within five years of U.S. average
- Almost 90% male
- Mother-to-child transmissions almost eliminated
- Black/Latinx communities disproportionately impacted

In the South:

- More than half of the U.S. epidemic
- More people living with HIV than other three regions of U. S. combined
- 43% of all new infections
- Highest death rates in country

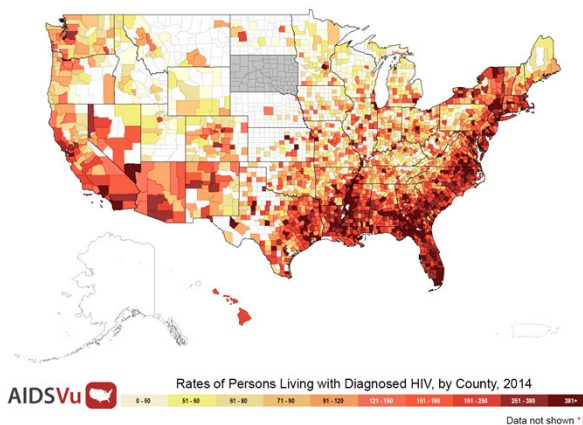
In Alabama:

- About 14,000 people living with HIV who know their status
- About 700 new cases each year
- Third-highest death rates in U. S.
- 28% women/65% black



Ford Foundation Ad in *Washington Post* Special Edition for the International AIDS Conference

A Tale of Two Epidemics A Manageable Disease?



Biomedical Advances Abound!

- Pre-Exposure Prophylaxis (PrEP)
- Post-Exposure Prophylaxis (PEP)
- Acute/Quick Testing
- One Pill/Once a Day (STR)
- Treatment as Prevention
- Suppressed Viral Load Means Undetectable = Untransmittable
- Community Viral Load Mapping
- Continued Vaccine and Microbicide Research



ZERO: No HIV Transmissions in PARTNER Study after Couples Had Sex 58,000 Times without Condoms (2016)

**Jefferson County
Health
Department is
the first in the
Deep South to
endorse U = U
Campaign!**



The Economic Reality

*...the lifetime cost of
treating HIV is estimated to be
approximately \$435,000 per
person...Dr. David Holtgrave,
Bloomberg School of Public
Health, Johns Hopkins*



Death Rate (2010) among Individuals Diagnosed with HIV

- **Death rate** among individuals living with HIV was **higher** in the **targeted states** (27.3 per 1,000) than in any other region (Northeast 24.7, Midwest 20.7, and West 18.8.)*
- In the targeted states, **suburban and rural residence at diagnosis** and **black/African American race** **significantly** predicted greater rates of death.

*Reif, Pence, Hall, et al. *HIV Diagnoses, Prevalence and Outcomes in Nine Southern States*, Journal of Community Health, 2014


A large white circle with a textured border, centered on a dark gray background. The word "Barriers" is written in the center of the circle.

Barriers

Why Does the South Lag Behind?!?

- The most people living with HIV/AIDS,
- The most poverty,
- The most vulnerable populations,
- The most minorities,
- The most rural area,
- The most sexually transmitted diseases,
- The most HIV-positive men who have sex with men,
- The most HIV-positive black women,

- The fastest growing HIV-positive Latinx populations,
- The most people without health insurance,
- Lack of affordable housing stock,
- Growing opioid crisis,
- Poor or no transportation,
- The fastest growing epidemic,
- The highest death rate,
- The least access to health care, and
- The least money to fight the epidemic.



Stigma Alive and Well in Bama!

Sir Elton John on Stigma:

"...and the stigma hasn't really changed that much in 31 years...It's a shame-based disease...based on sexual transmission...until people feel strong enough and loved enough to actually open up and say, listen, I'm HIV-positive, then we are facing an uphill battle."



Recent Stigma
Study by
Southern
HIV/AIDS
Strategy
Initiative



Journal of HIV and AIDS
ISSN 2380-5536 | Open Access

RESEARCH ARTICLE

Volume 4 - Issue 2 | DOI: <http://dx.doi.org/10.16966/2380-5536.154>

Perceptions and Impact of HIV Stigma among High Risk Populations in the US Deep South

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The Study's Abstract

This study examines community HIV-related stigma in the US Deep South, a region disproportionately affected by HIV. Study participants included individuals at higher risk for HIV, primarily African American men who have sex with men and women participating in substance use treatment. Findings from six focus groups identified a lack of knowledge and significant fear about HIV in participants' communities. A dearth of accurate information about HIV and HIV prevention, including pre-exposure prophylaxis (PrEP), was reported as widespread and contributed to myths about HIV and increased stigma. HIV-related stigma was reported as pervasive and resulted in lowered participation in HIV testing and treatment. Participant suggestions for addressing stigma included extensive media HIV education and counseling/support for individuals living with HIV. Addressing HIV-related stigma in the Deep South is critical to reducing HIV transmission and improving HIV-related outcomes.

Structural Challenges



We have so many! How do you focus on a few?



Rural Areas Hard to Serve



Lack of Medicaid Expansion



Inadequate Mental Health/Substance Use Treatment



Poor Transportation



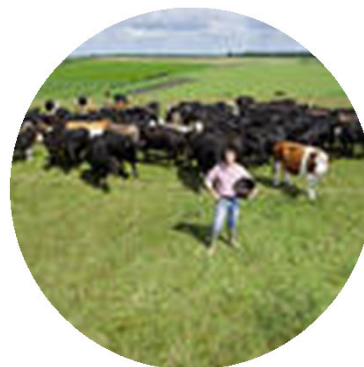
Inadequate Housing



Lack of Sexual Health Education

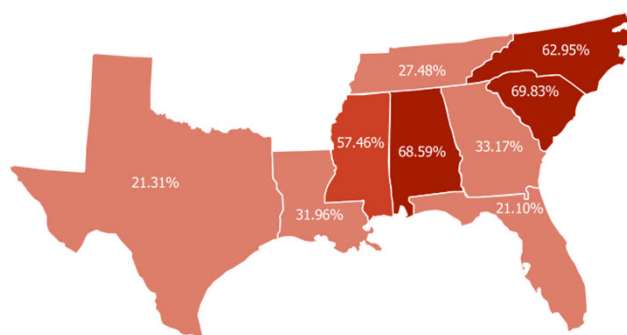
- **RURAL EPIDEMIC:**

- 64% of people with HIV living in rural areas reside in the Deep South

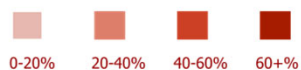


Another Hard-Hit Population

Percentage of Persons Living with HIV/AIDS Outside an Area Eligible for Community-Based Organization Funding from CDC



Percent HIV+ Population Not Living in MSA



The Rural Conundrum!



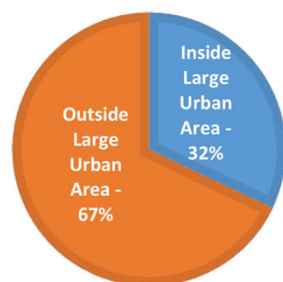
The U.S. Deep South continues to experience a heavy HIV burden outside the large urban areas.

Sixty-eight percent of people living with HIV (PLWH) in Alabama live outside a large urban area.

[Significant Percentages of People Most Impacted by HIV Live Outside Large Urban Areas Demonstrating a Need for Increased Federal Resources](#), McAllaster, Goodrow, December 2018

Black/African American People Living with HIV

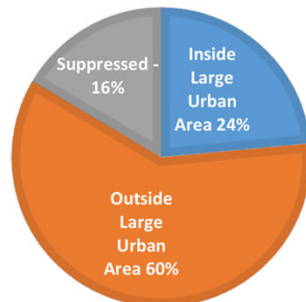
BLACK/AFRICAN AMERICAN PLWH,
ALABAMA



In Alabama, only 32% of Black/African American PLWH live in a large urban area. The remaining 67% live in suburban and rural areas that continue to suffer from funding disparities. **Over two thirds** of Black PLWH in Alabama are unable to access community-based organizations directly funded by the CDC – one of the largest disparities we found throughout the Deep South. [Since there is no data suppression for Black PLWH in the 7 urban counties of Alabama, all suppressed data could be attributed to suburban/rural counties increasing the percentage of Black PLWH who live outside large urban counties to 68%.]

Hispanic/Latino People Living with HIV

HISPANIC/LATINO PLWH IN ALABAMA

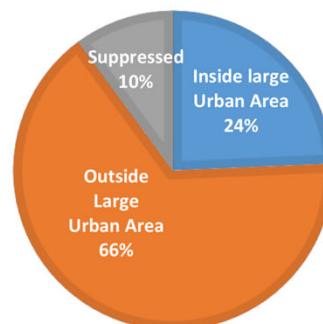


In Alabama, 60% of Hispanic/Latino PLWH live outside a large urban area, away from community organizations receiving direct prevention funding from the CDC. Only 24% live in a large urban area, with 16% of total cases having been suppressed. This means that **less than a quarter** of Hispanic/Latino PLWH in Alabama are guaranteed to have access to organizations directly funded by the CDC.

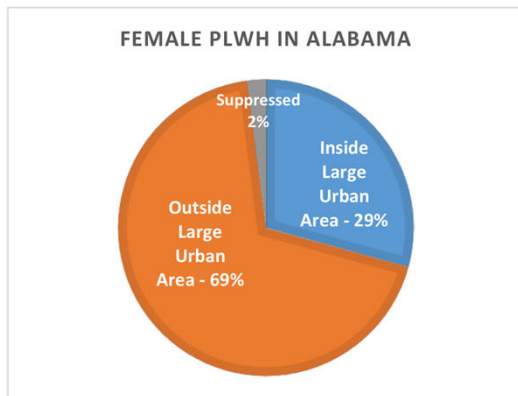
Young People (ages 13-24) Living with HIV

Young people are one of the most at-risk groups for HIV/AIDS transmission. The CDC estimates that 1 in 2 young PLWH did not know they were living with HIV,⁶ making transmission much more likely within this group. **Two-thirds** of PLWH ages 13-24 in Alabama live outside a large urban area with only 24% reported to live in large urban counties – less than a quarter.

PLWH AGES 13-24, ALABAMA



Females Living with HIV



Although new HIV diagnoses are declining among cisgender women, women in the South bear a disproportionately high burden compared to the nation as a whole, particularly Black women. In Alabama, 69% of women living with HIV live outside a large urban area – **over two thirds** of Alabama women living with HIV are unable to access organizations that receive prevention funds directly from the CDC.

Why ACA? Why Medicaid Expansion?

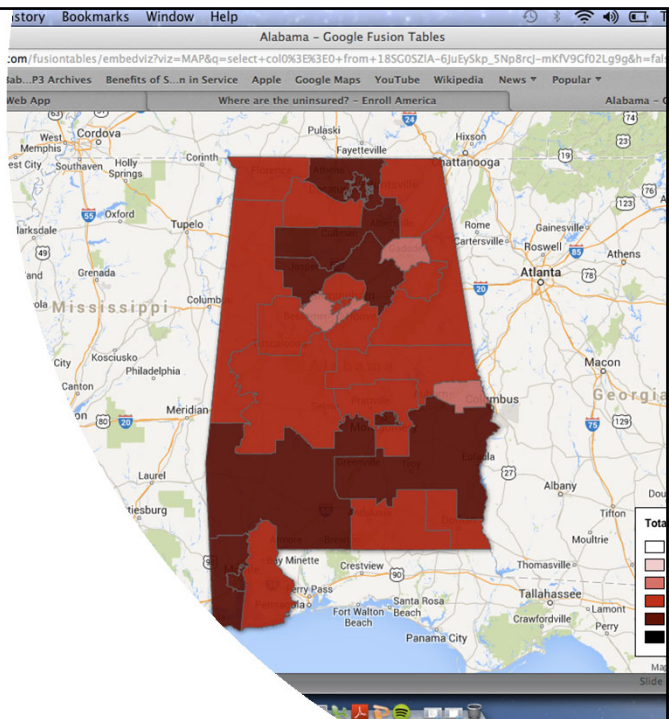
Before 2014...

660,000 Uninsured

200,000 Eligible for Tax Credits
in Marketplace

191,000 Eligible for Medicaid
Expansion

* Kaiser Family Foundation. <http://kff.org/health-reform/fact-sheet/state-profiles-uninsured-under-aca-alabama/>



Why Medicaid Expansion?

UAB Study: An Economic Evaluation of Medicaid Expansion in Alabama under the Affordable Care Act

\$. billion in federal funds and \$. million in net tax revenue in Alabama from .

ver . years, it would cost Alabama an estimated \$. million to expand . Medicaid.

Expansion would **reduce** state's **uninsured population**

by 232,000 individuals
(of **642,000** uninsured)

- National AIDS Housing Coalition research shows that more than half of people living with HIV experience homelessness or unstable housing.
- Homelessness for people living with HIV harms medical outcomes, increases risky behaviors that lead to HIV transmission, and increases costs of care.
- Homelessness affects many not living with HIV/AIDS.
- Homelessness is a risk factor for acquiring HIV and for other dangers to health.



Homelessness



In Alabama One-Third of New Infections Are Young People!

...Appropriately, it is a parent's job to instill values and to provide the moral and ethical foundation for their children, but schools have an important role in providing...a baseline of health education information that is grounded in the benefits of abstinence or delaying...sexual activity, while ensuring that the youth who make the decision to be sexually active have the information they need to take steps to protect themselves...

National HIV/AIDS Strategy

LiveStrong.com: The U. S. has the highest teen pregnancy rates in the industrialized world.



CDC: One-third of U. S. girls get pregnant before the age of 20.

Solutions

AIDS Service Network of Alabama

- AIDS Alabama
- AIDS Alabama South (Mobile)
- Birmingham AIDS Outreach
- Five Horizons (Tuscaloosa)
- Health Services Center (Anniston)
- Medical Advocacy and Outreach (Montgomery)
- Selma AIDS Information & Referral
- Thrive (Huntsville)
- Unity Wellness (Auburn)
- Commitment to talk and collaborate
- Regular meetings
- Attempt to not fall into turf wars



AIDS Alabama Strives to Make Our State Healthy!

- AIDS Alabama provides funding and assistance to all 67 counties through a partnership with the AIDS Service Organizations.
- Some states don't help in rural areas.
- Agency serves same five-county area as United Way.
- Agency took over Mobile agency and surrounding 12 counties in 2012.



Who runs your HOPWA program?

AIDS Alabama: The Umbrella Agency



In addition to helping the other seven AIDS Service Organizations with contracts for education, services, and housing, AIDS Alabama has recently acquired AIDS Alabama South in Mobile and 11 surrounding counties.

Thanks to the AIDS Alabama model, Alabama is a model to the other 49 states, because services are available in all 67 counties.

MAO: The Kings of Telemedicine!



Telemedicine...it's more than just primary care!

AIDS Alabama/AIDS Alabama South:
Mental Health Services

Birmingham AIDS Outreach:
Legal Services

- Partnering with Alabama Department of Public Health
- Teaching their colleagues across the country
- Building infrastructure to expand reach

The possibilities are limitless!

Who you gonna call? Stigma busters!



Southern AIDS Coalition receives \$5,000,000 to fight HIV stigma in the South!



Southern AIDS Coalition Welcomes Aquarius Gilmer as Senior Manager of Government Affairs & Advocacy



Two Stigma-Busting Projects Funded by CDC: Aimed at Hard-Hit Populations with a Safe Space, the Hub

Through GameChanger Project in 2017:

- Hosted 62 testing and education events
- Found HIV-positive : 16
- Found HEP C positive: 38
- Found cases of Syphilis: 26
- Found cases of Gonorrhea: 19
- Found cases of Trichomoniasis: 13

Through B-CHIP:

- Hosted 45 testing and education events
- Found HIV-positive: 3
- Found Hep C positive: 22





A program to enroll Alabamians
in the Health Insurance Marketplace,
Medicaid and CHIP



AIDS Alabama is an original recipient of funding under the Federal Navigator grant and has been assisting Alabamians with obtaining health insurance through the Insurance Marketplace since 2013.

In 2017 and in the one shortened enrollment period held so far in 2018, Enroll Alabama Navigators:

- Assisted 11,915 Alabamians in finding the insurance plan best suited to their unique needs.
- Held 613 statewide outreach events
- Touched 57,034 people at those outreach events

As an end result, almost 5% of Alabama's population enrolled in the Affordable Care Act Marketplace for health coverage.

Amazing 2018 Alabama Results

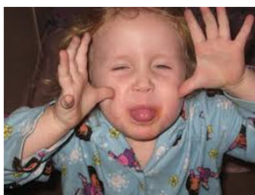
- Marketing funding slashed in 2017
- Alabama placed in lowest tier in 2018 and 75% of funding cut
- Enrollment period shortened every year; 2018 cut in half
- Attempt to remove cost-sharing backfired
- Individual mandate to buy repealed as of 2019

Alabama Insurance Marketplace withstood the onslaught!

2017: 170,211 Insured

2018: 166,128 Insured

Nationally: More than 8.4 million plan selections



ObamaCare is alive and well!



In order to address the critical shortage of options for mental health services in Jefferson County, the Living Well Outpatient Center (LWOC) opened in June 2016. LWOC provides additional resources for mental health services and shortens the wait time for HIV-positive clients to access the counseling and supportive services they need to live independent, healthy lifestyles. Clients learn to manage their HIV diagnosis through support, counseling, and medication-adherence strategies provided by caring social workers, case managers, and peer support. Ryan White provides funding to the Center, and Medicaid 340b billing is growing.



LWOC waiting room



LWOC therapist's office



LWOC medical exam room



LWOC group therapy room

2017 by the numbers:

Total number of consumers seen at LWOC: 154

Total number of group sessions held:

- 93 group therapy sessions (64 were specific to grief and/or trauma)
- 42 HIV education classes
- 32 skill-building and educational groups (financial planning, budgeting, job search, communication skills, advocacy/empowerment)

Total number of consumers helped through Living In Balance Chemical Addiction Program and substance abuse therapies: 39

Average wait time for our consumers' first appointment at LWOC is less than 2 weeks from first contact.

Safe, Decent Housing Is a Major Emphasis at AIDS Alabama



Housing Programs

Emergency and Transitional (Up to 2 Yrs.) **Permanent Service Enriched**
JASPER House

Rectory
Next Step

Rental Assistance
HOPWA

Permanent
AGAPE House
AGAPE II
Mustard Seed
Magnolia Place
Le Project
ARAP
Ascension
Transclusive
Rapid Re-Housing



Housing Opportunities for Persons with AIDS



- Annual statewide rental assistance programs for the state!
- Partnerships with ASONA and others
- Assistance to more than 500 households
- New partnership with UAB in Birmingham



Non-HIV-Specific Housing Programs 2017 Numbers

The Ascension Project

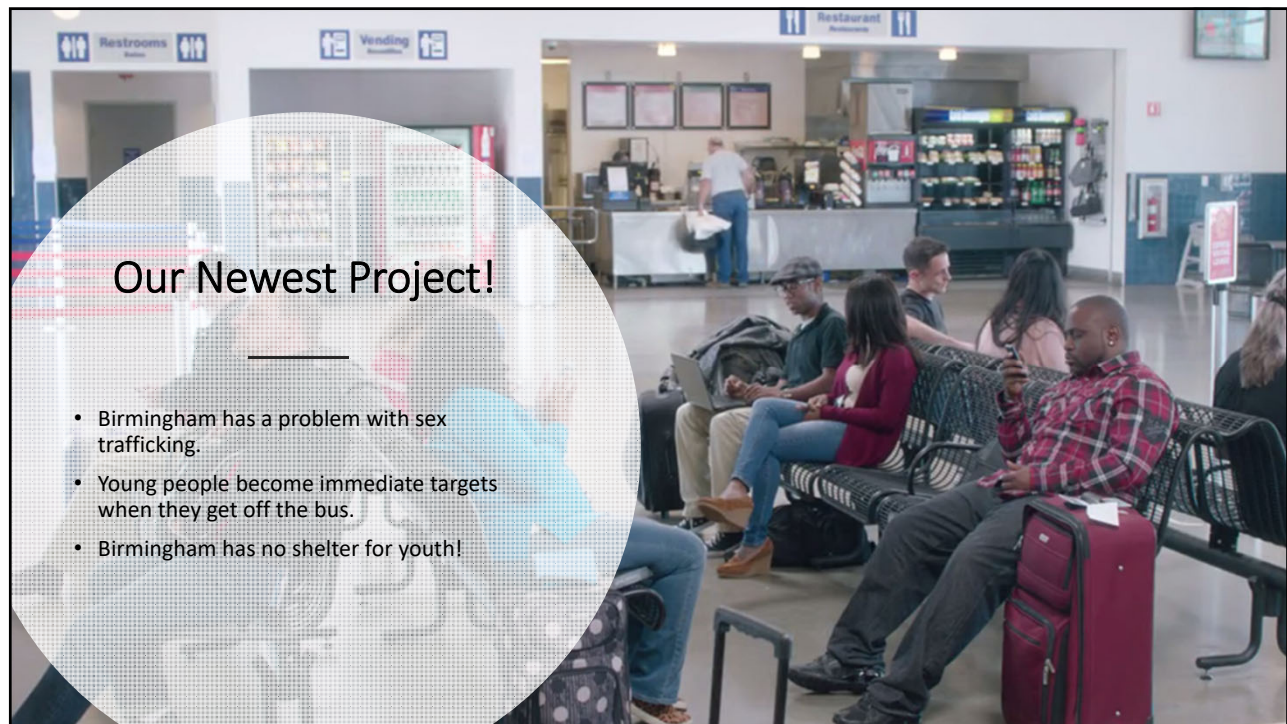
- Specifically for homeless youth 19 to 24 years of age, targeting LGBTQ youth, but not exclusively
- Total nights of housing: 9,196
- 12 clients who exited the program stayed an average of 231 days for a total of 2,772 days.
- 22 clients who remained in the program stayed an average of 292 days for a total of 6,424 days.

Transclusive

- This program began serving transgender clients specifically on September 1, 2017.
- 5 clients who remained in the program stayed an average of 103 days for a total of 515 days.

Rapid Re-housing

- Low-barrier housing placement for older adults
- Total nights of housing: 22,546
- 17 clients who exited the program stayed an average of 238 days for a total of 4,046 days.
- 74 clients who remained in the program stayed an average of 250 days for a total of 18,500 days.



THE WAY STATION



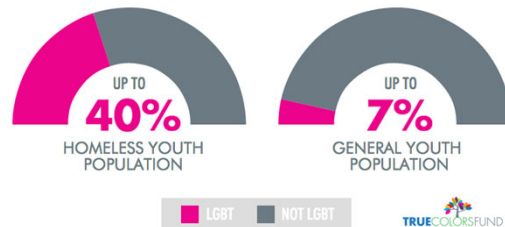
- TO BE LOCATED AT 624, 644, 650 3RD AVENUE NORTH AND 334 7TH STREET NORTH.
- A TWENTY-BED, OVERNIGHT, EMERGENCY CRISIS SHELTER FOR HOMELESS, RUNAWAY, AND AT-RISK YOUTH 24 YEARS OF AGE AND UNDER, OPEN 24 HOURS A DAY, 365 DAYS A YEAR.
- A TWENTY-BED, TRANSITIONAL LIVING PROGRAM FOR YOUTH 16 – 24 YEARS OF AGE.
- PROVIDING FOR THE IMMEDIATE NEEDS OF OUR YOUTH: SAFETY, SECURITY, MEALS, SLEEP, A WARM SHOWER, AND LOVE.



RAISED TO DATE:
\$555,486.00



LGBTQ Youth Homelessness Statistics



In America, up to 1.6 million youth experience homelessness each year.

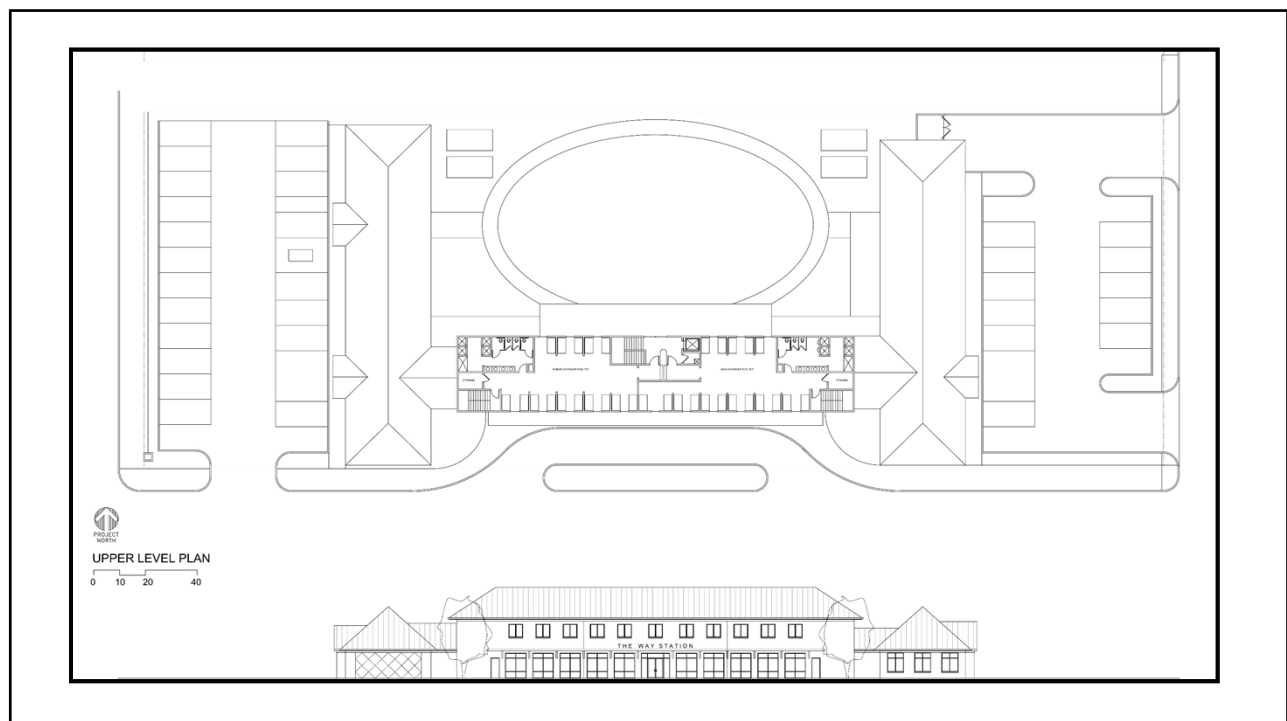
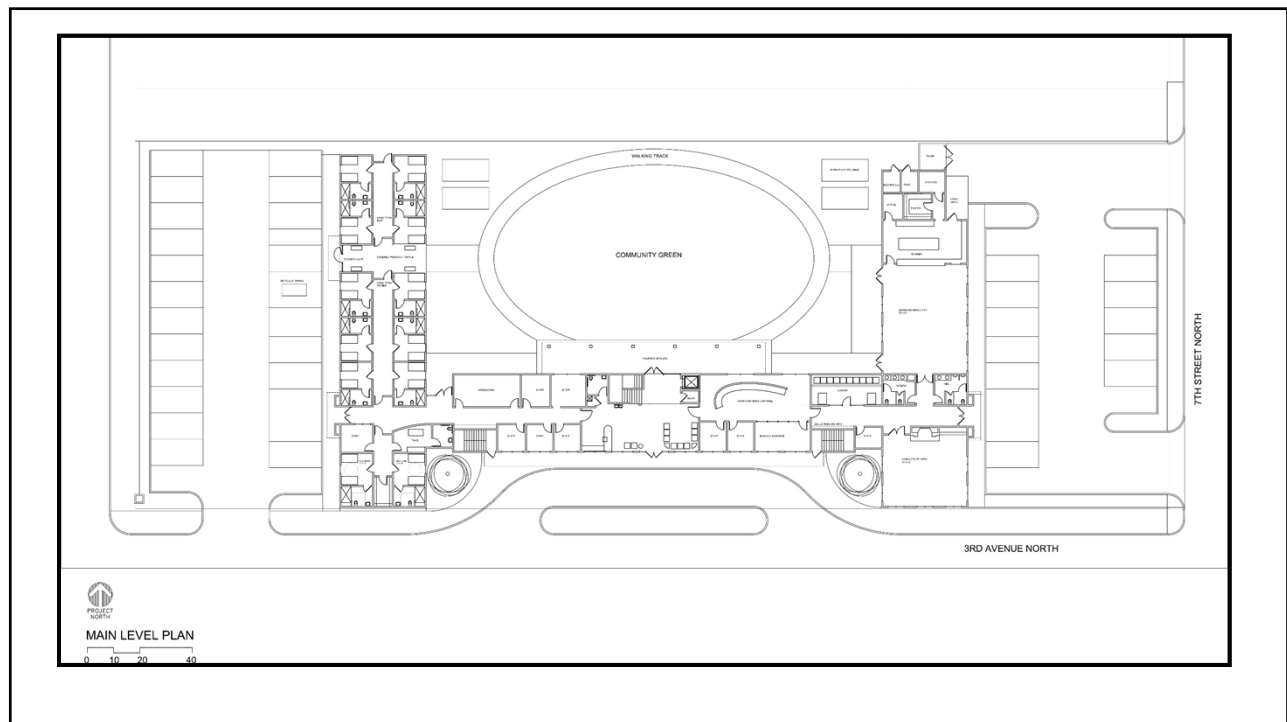
40% of youth experiencing homelessness identify as Lesbian, Gay, Bisexual, or Transgender (LGBT). Considering that LGBT youth represent an estimated 7% of the total youth population, these numbers are disproportionately high.

Once they are out of their homes, LGBT youth are even more vulnerable. They are at a great risk for victimization, unsafe sexual practices, and increased mental health issues.

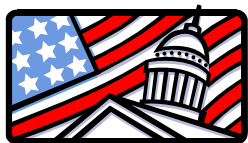


FRONT (SOUTH) ELEVATION
0 10 20 40

The Way Station
Front Elevation
Facing 3rd Avenue North



SUPPORT GROUPS



It's All about Advocacy

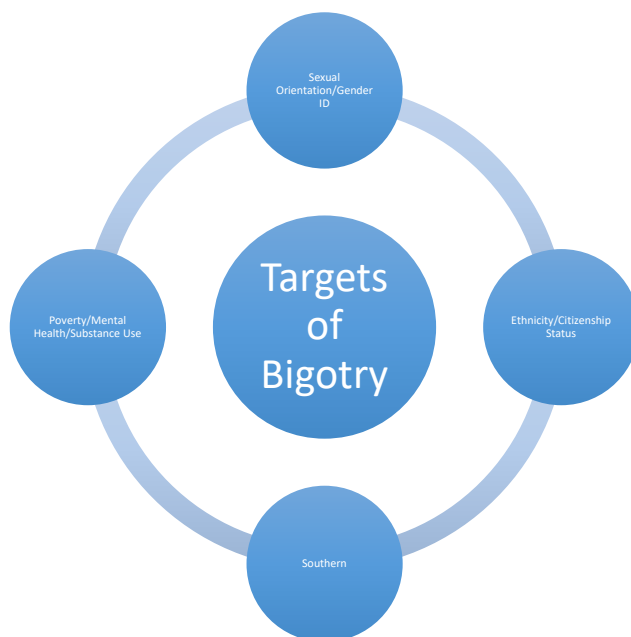
- Statewide
- Regionally
- Nationally
- Globally



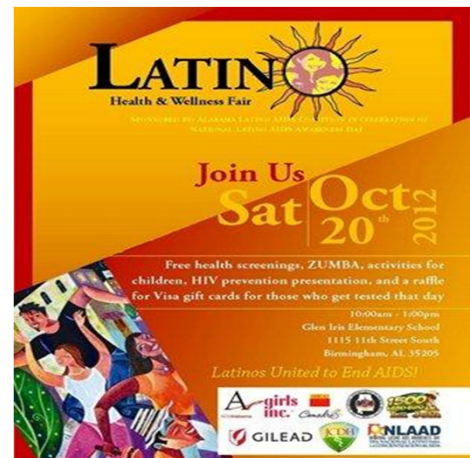


*Never underestimate
the power of a small
group of committed
people to change the
world. In fact, it is
the only thing that
ever has.*

Margaret Mead



Advocacy Matters! Policies Filter Down to the Front Lines!



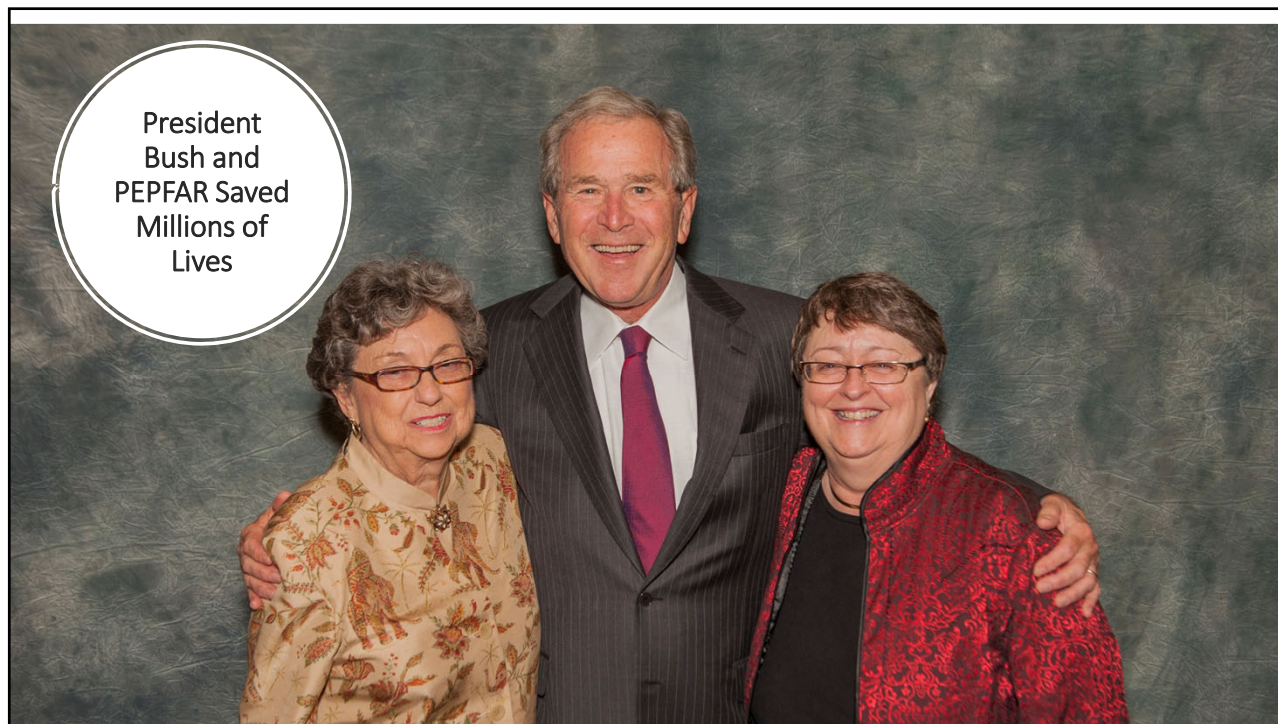
Successful Advocacy Requires Appropriate Gatekeepers

The AIDS Alabama promise:

Nothing about you without you!

- Positive Leadership Council (Birmingham and Mobile)
- Positive-led advocacy, including annual HIV Awareness Day
- Positive employees
- Positive leadership positions
- Development opportunities





Presidential Advisory Council on HIV/AIDS



**AIDS Alabama Featured on
PYLON
at
The International AIDS
Conference
Washington, DC
July 22-29, 2012**



2015 Strategy Update includes South!!!

THE UPDATED STRATEGY DETAILS **11 STEPS** AND **37 ACTIONS** THAT FOCUS ON

RIGHT **PEOPLE**, RIGHT **PLACES**, RIGHT **PRACTICES**

RIGHT **PEOPLE**

KEY POPULATIONS

- **Gay, bisexual, and other men who have sex with men of all races and ethnicities** (noting the particularly high burden of HIV among Black gay and bisexual men)
- **Black women and men**
- **Latino men and women**
- **People who inject drugs**
- **Youth aged 13 to 24 years** (noting the particularly high burden of HIV among young Black gay and bisexual men)
- **People in the Southern United States**
- **Transgender women** (noting the particularly high burden of HIV among Black transgender women)



RIGHT **PLACES**

PRIORITY AREAS

- **Major metropolitan areas** have higher rates of HIV than other areas of the country.
- **Southern United States:** more than 1/3 of the population lives in southern states, but the region accounts for more than 1/2 of all HIV diagnoses.



Federally Ryan White Funding Provides a Crucial Safety Net for Persons Living with HIV/AIDS



Many states are **not** expanding Medicaid;



AIDS Drug Assistance Program (part of Ryan White) is used as a resource to fill many **insurance coverage gaps** that will continue to exist even in expansion States; and



Ryan White is a resource to provide **essential services** for HIV-positive people who are not covered by new insurance plans;



Ryan White must be used as the payer of last resort.

Ryan White Reauthorization? Why Now?

- Ryan White doesn't "sunset" or end, but appropriations must be approved annually by Congress.
- How has the Affordable Care Act changed Ryan White?
- Does anyone remember that Ryan White funding was supposed to offset the cost of the Affordable Care Act?
- How do we agree as an HIV community on what changes need to be made when we reauthorize the bill?



Addressing the “Medicaid Gap” in Non-Expansion States

69% of AIDS Drug Assistance Program clients in non-Medicaid expansion states have an income below 138% FPL.

To help fill the gap...

Ryan White programs are:

- Purchasing insurance for those in the “Medicaid Gap.”
- Providing safety net for those who cannot afford insurance or who are not otherwise eligible.



Endless Education of our Federally Elected Officials Pays Off

Advocacy Efforts on Federal, State, and Local Levels

- AIDS United Public Policy Council (PPC)
- AIDSWatch 2019
- Federal AIDS Policy Partnership
- National AIDS Housing Coalition
- Southern AIDS Coalition
- U. S. Conference On AIDS 2019
- Alabama HIV/AIDS Policy Partnership

Two major pieces of HIV legislation have been changed to be fair and to bring more funding to the South:

Ryan White Act

Housing Opportunities for Persons with AIDS



Unexpected Warriors: Three Republican Senators!

Alabamians Co-sponsor HOPWA Modernization Legislation

Congressman Aderholt



Congressman Bachus



Congressman Quigley



Congressman McDermott

HIV/AIDS Advocacy Day Montgomery, Alabama



Two Alabama Issues

Syringe Service Program (SSP):

AIDS Alabama staff drafted legislation to authorize Alabama Department of Public Health to establish SSPs in consultation with local communities to fight the opioid epidemic.

- HB455 was successfully introduced during the 2017 legislative session and passed out of the House Health Committee and the full House unanimously. It passed the Senate Health and Human Services Committee by a majority vote but was filibustered on the Senate floor as the Session was ending (Note: no previous SSP bill had even received a committee vote.)
- During the 2018 session, we succeeded in getting the bill pre-filed and introduced in the State House (HB37) and identified a sponsor to introduce a twin bill in the state Senate (SB169.) The bill passed out of the House Health and Senate Health and Human Services Committee but the Legislature adjourned before they could come to a full floor vote.


AIDS Alabama staff have been working with our State Legislature for many years in attempts to modernize Alabama's sexual health education statute to bring it up to date with current scientific developments and to remove stigmatizing and medically inaccurate language.

- In 2017 AIDS Alabama staff drafted new legislation to modernize Alabama's sexual health education statute. This legislation would require that if public schools opt to provide sexual health education, they must use curricula that are medically accurate and culturally competent.
- HB505 was successfully introduced in the Alabama House for the 2017 legislative session and passed out of the House Education Policy Committee before running out of time for a floor vote. This movement marked the first time any such bill had even received a committee vote.
- Legislation (SB269) was reintroduced in the Alabama Senate for the 2018 Regular Legislative Session where it passed out of the Senate Education Committee before running out of time for a full floor vote.



The Squeaky Wheel Gets the Oil

- Become that squeaky wheel!
- Be respectful, but never go away.
- Develop grassroots networks locally, statewide, regionally, and federally.
- Your voice and your story are just as important as anyone else's.



Where Can You Plug into Federal Advocacy?

- Federal AIDS Policy Partnership (for organizations): www.federalaidspolicy.org – Must be approved by two member organizations – work in committees:
 - Ryan White
 - Access to Care
 - HIV Prevention (HPAC)
 - Housing
 - Appropriations and Budget (ABAC)
 - Research
- Southern AIDS Coalition: www.southernaidscoalition.org
- National AIDS Housing Coalition: www.nationalaidshousing.org
- AIDS United Public Policy Committee: wmccoll@aidsunited.org

Regional and State Opportunities

- Southern HIV/AIDS Strategy Initiative
 - Sign up for SASI list serve: sasi@law.duke.edu
 - Sign up for SAC list serve: info@southernaidscoalition.org
 - SASI website: www.southernaidsstrategy.org
- Southern AIDS Coalition
 - www.southernaidscoalition.org
- Alabama HIV/AIDS Policy Partnership
 - (matthew.pagnotti@aidsalabama.org)
- Know who your members of Congress are (see <http://votesmart.org/>)

Thank You MAO!

Now Let's Talk...

Questions?

