

Identifying, Linking, Engaging, and Retaining Young MSM of Color in HIV Care:

Findings of the HRSA Young MSM of Color SPNS Initiative and Implications for Ryan White Program Grantees and Providers

2010 Ryan White Grantee Meeting

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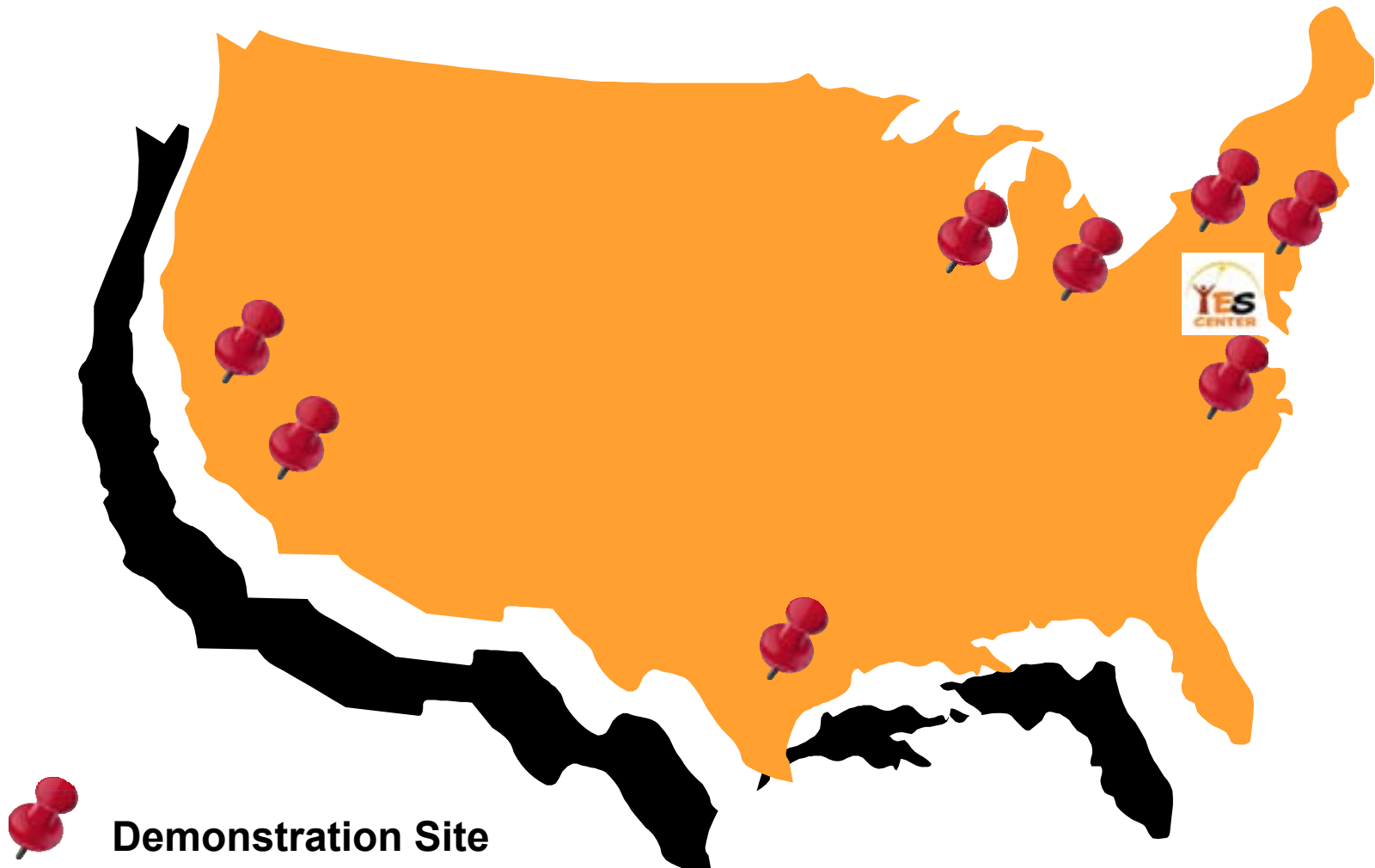
- This study is supported by the US Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) Young Men of Color who have Sex with Men (YMSM of Color): Outreach, Linkage, and Retention in Care Special Project of National Significance (SPNS)
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SPNS Initiative Quick Facts

- The initiative funded in Fall 2004, with 5-year grants
- The initiative completed its five years of funding, with the sixth year devoted to development and dissemination of Initiative findings, best practices, and related information
- 8 demonstration sites and a technical assistance (TA) and evaluation center (GWU YES Center)
- Demonstration site grantee goals
 - ◆ Develop, implement, and evaluate innovative models of care for YMSM of color
 - ◆ Apply intervention models that identify, engage, link, and retain HIV-infected individuals in care
- GWU YES Center goals
 - ◆ Support intervention and local evaluation efforts of grantees, with capacity building, TA, and training
 - ◆ Conduct comprehensive, multi-site program evaluation



SPNS Initiative Grantee Sites



8 SPNS sites were organizationally diverse	# of Grantees
CBOs + county or community-based clinics	3
County-operated integrated health system	1
County health department epi program + two community health center HIV clinics	1
University medical school and historically black college	1
Part D (Title IV)-funded grantee prior to the Initiative	2
CDC-funded prevention grantee prior to the Initiative	3
> 3 years directly providing HIV services before SPNS grant	6
Operating in a service area also targeted by Part D and/or CDC funds	6
Defined and organized HIV care continuum	1

Methods

- **Criteria for study enrollment**
 - Confirmed HIV+, born male, non-White, and not in care within 3 months of the baseline interview
 - Identified through outreach funded by the Initiative
- **Quantitative methods used to longitudinally follow a multi-site cohort of 363 enrolled YMSM of color**
 - In-depth structured interviews at baseline and at 3-month intervals, with a mean of 3.6 follow-up (FU) interviews per respondent (range 2-12), and lab data were longitudinally collected from initial HIV clinical assessment
- **Qualitative methods used to longitudinally follow Initiative grantees to describe the evolution of their HIV care continuum**
- **Intensive TA on organizational challenges**

Outreach Methods Used to Identify YMSM of Color Evolved

- Venue-based outreach
- HIV testing vans
- Youth-focused materials
- Chat rooms and social network sites
- Community drop-in centers
- Social and sexual networks
- Community-wide HIV testing initiatives
- Use of peer or near-peer outreach workers
- Health care and youth-focused service system “in-reach,” networking with health care providers

Multisite Baseline and Follow-up Data Domains

- **Baseline Data**
- **Demographic Questions**
- **Social Support**
- **Sexual Behavior**
- **Gender Identity**
- **Sexuality Discrimination**
- **Racial Discrimination**
- **Violence and Environment**
- **Depressions and Suicide**
- **Substance Use**
- **HIV Testing**
- **Clinical Utilization**
- **Clinical Program Data**

Baseline Characteristics	%
African-American	67
Latinos	21
Mixed race/ethnicity	12
Mean age = 20 years, range: 15 – 24 years of age	
Have not completed at least high school or GED	29%
In school	37
Unemployed	54
Moved at least once in the last 3 months	41
Had to borrow money many times in the last 3 months	21
No health insurance	37
If insured, health insurance through parent or guardian	40

HIV Testing Experience at Baseline

- About one-fifth were tested for HIV once in their lifetime, 25% twice, and 75% more than twice (range 1-40), with 6% not returning for results at least once
- There were no significant associations between demographic, clinical, or behavioral characteristics and location of, or reason for, HIV testing
- After adjusting for confounders
 - Clients were more likely to get tested because they felt sick at their first HIV+ test than at their first *ever* HIV test if they had a first CD4 < 200
 - Clients were less likely to test because they felt sick at the point of first *ever* HIV test if they had parental health insurance

Baseline Characteristics	%
On any ARV (including prescription written that day)	23
Absolute CD4 count	
≥200	49
<200	51
HIV viral load (HIV RNA copies/mL)	
<10,000	43
10,000-100,000	41
>100,000	16
Any routine, preventive, or adolescent care in last 3 months	28
Hospitalized in last 3 months	8
Visited an ER or urgent care center	36
Had an ambulatory care visit	38

Baseline Characteristics	%
Sexual Identity: homosexual or gay	57
Sexual Identify: bisexual	23
Not only attracted to males	52
Made fun of few-many times because of sexuality	54
Sexuality few-many times hurt or embarrassed family	39
Mean age first sex with a male 14.6 years	
Male gender identity	96
Very comfortable or comfortable with sexual orientation	93

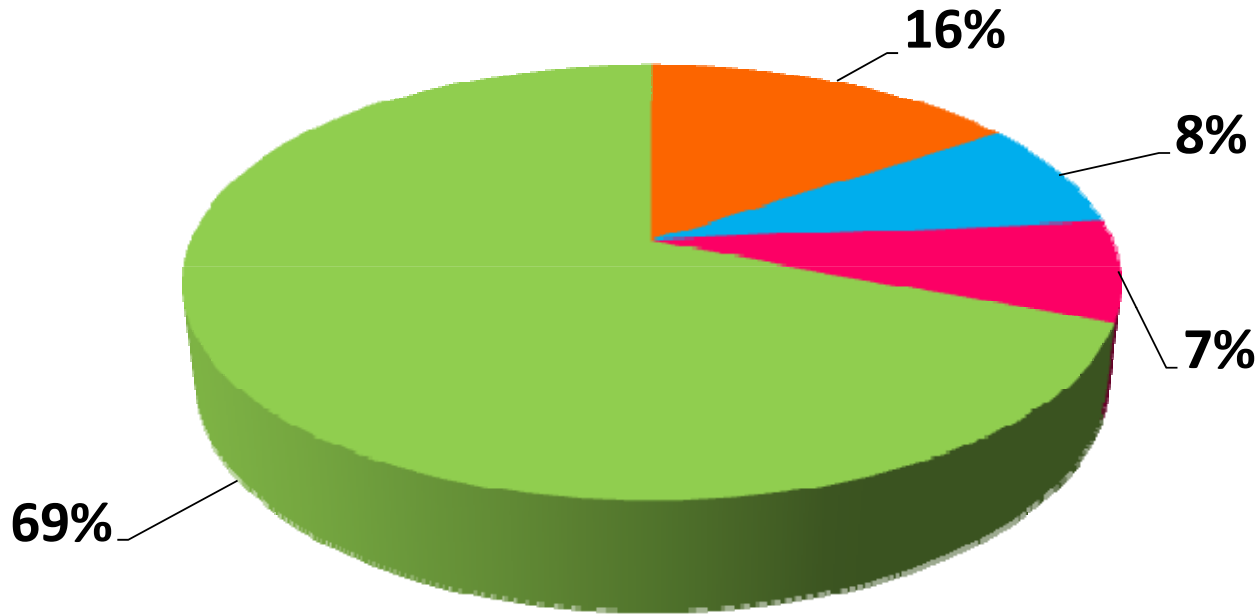
Baseline Characteristics	%
Reported sex with male, last 3 months	80 (mean 2.4)
Reported sex with female, last 3 months	8 (mean .08)
More than one sex partner, last 3 months	47
Disclosed HIV+ status to at least 1 sex partner	22
No condom use last anal sex*	31
Where met last male sexual partner?	
<p>Internet (23%), friend/acquaintance (24%), clubs (14%); others venues include school/work, community and community centers, parks, parties, sex chat phone lines, getting and HIV test</p>	

***Among those reporting anal sex at last encounter.**



Baseline Characteristics	%
Ran out of money for basic needs many times in the last 3 months	32
Engaged in transactional sex in last 3 months	34
Afraid of violence in neighborhood	22
Ever experienced emotional abuse	38
Ever experienced physical abuse	34
Emotional or psychological problems from drugs or alcohol in last 3 months	13
Mean times used marijuana in last 3 months: 37 times	
Ever depressed	45
Depressive symptoms (CES-D score at baseline)	
 ≥ 16 (Depression)	49

Suicidation Among YMSM of Color At Baseline

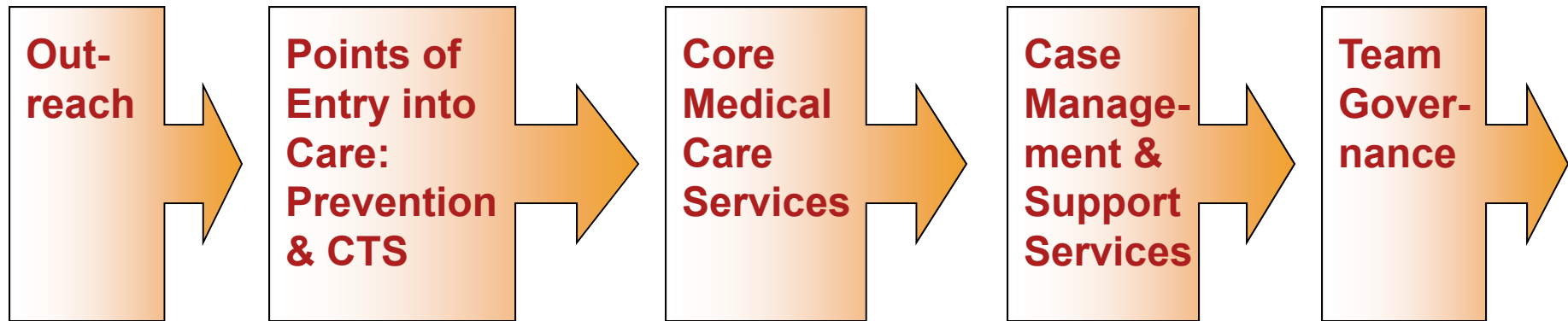


- Planned & Tried Suicide
- Tried Suicide, But No Plan
- Suicide Plan, But Did Not Try
- No Plan, Did Not Try

Designing and Implementing the Care Continuum for HIV+ YMSM of Color



Continuum of Care Exercise



- The exercise was designed because most grantees had not fully organized a youth-centered care continuum at the time of initial grant award
- Each site conducted baseline and annual exercises
- The exercise poses questions to the team to prompt them to ensure that their continuum is in place and team roles and responsibilities are clearly identified
- Expansion of the agencies participating in the continuum was an important step resulting from the exercise and YES Center TA

Treatment Interventions

- **Aware of and embraced youth culture**
- **Created youth-friendly physical site and staff**
 - ◆ **Located in non-traditional accessible locations**
- **Offered separate youth-designated waiting rooms**
- **Used multidisciplinary staffing model**
- **Employed clinicians expert in treatment of adolescent medicine AND HIV**
- **Created one-stop clinical and psychosocial support services**
 - ◆ **Addressed mental health and drug treatment needs**

Treatment Interventions

- Provided transportation and accompanied clients to their first medical appointment
- Met clients where they feel comfortable, emphasized privacy and respect, and maintained consistent contact
- Used motivational interviewing to engage clients
- Effectively and creatively addressed treatment adherence and medication education



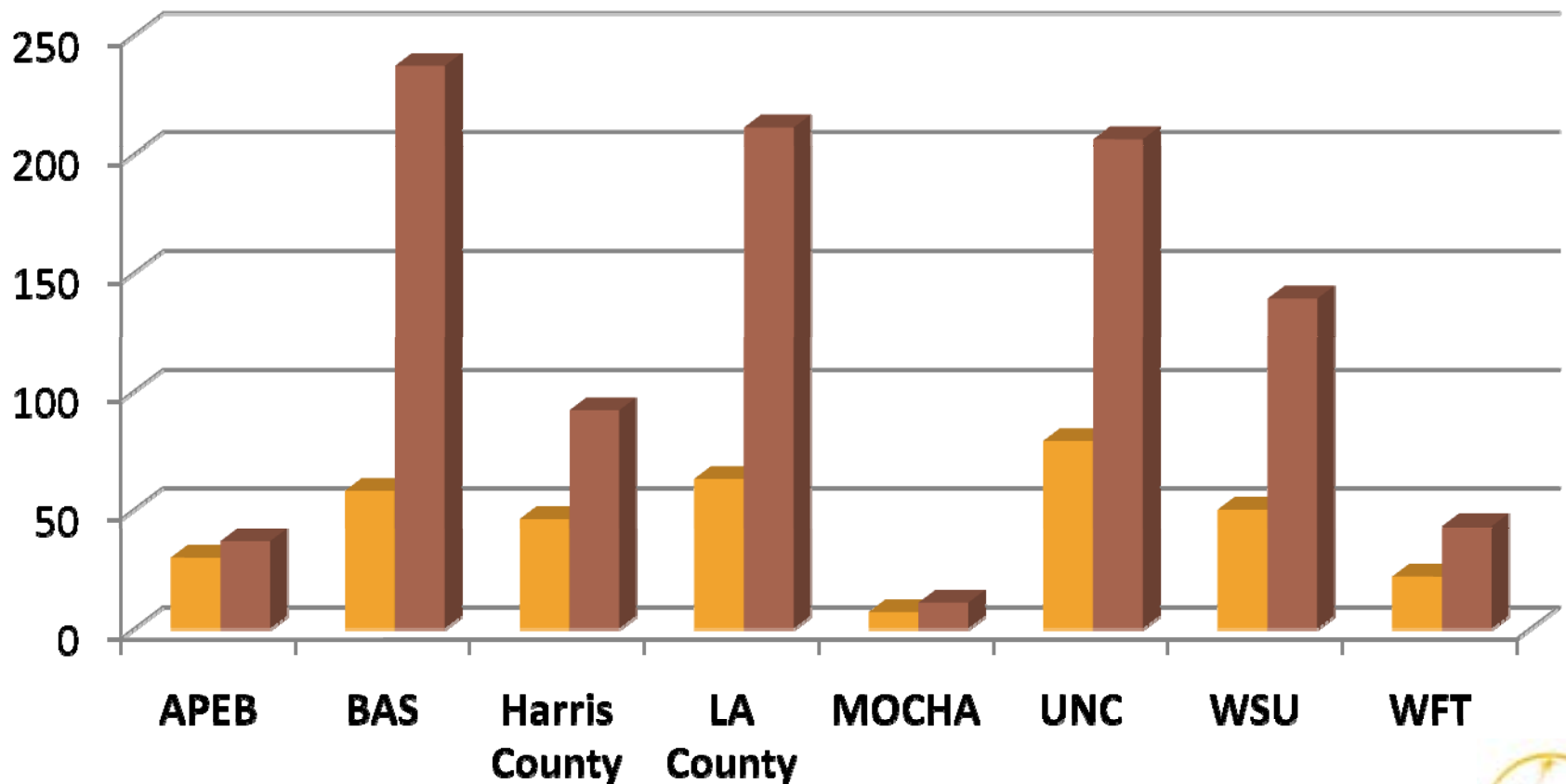
Treatment Interventions

- Client planned social events
- Peers or near-peers served as system navigators
- Decreased wait time for appointments
- Flexible scheduling- expect appointments to be missed and rescheduled
- Addressed the legal issues faced by HIV+ youth
- Anticipated and addressed loss to follow-up



Baseline and Follow-up Interviews By Grantee, As of October 2010

■ Baseline ■ Follow-up



Impact of Intervention: Longitudinal Findings

- Rates of enrollment in school were stable
- Employment rate rose, number of hours worked remained stable
- Rate of no health insurance decreased, enrollment in Medicaid increased, commercial insurance was stable
- Rate of drinking increased slightly, reported marijuana use increased

At baseline and follow-up, percentage of respondents that report disclosing their HIV+ status to...	% Base-line	% 3rd Follow-up
Mother*	54	66
Father	25	33
Sister*	31	41
Brother*	23	32
Friends**	59	58
Sex Partners**	21	25

*** Improved over time **No significant change**

At baseline, 91% of respondents had disclosed HIV+ status to at least 1 person

Impact of Intervention: Longitudinal Findings

- Rate of clients with CD4 less than 200 decreased
- Viral loads remained stable, percent undetectable increased slightly
- Inpatient admission rates dropped
- ER utilization rates dropped
- Number of HIV primary care visits in last three months dropped slightly by the third follow-up
- Missed primary medical care appointment rates increased slightly, with missing an appointment due to having to work increasing

Lessons Learned in Serving YMSM of Color



Service Goals

- The goal is to keep YMSM of color in medical care, reducing harmful behaviors that impact themselves and their sexual partners
 - ◆ Retention in medical care and adherence to ARVs is critical to achieve undetectable viral load and reconstitute the immune system
- A youth-centered environment is critical to ensure that YMSM of color engage and remain in care
 - ◆ Young females, straight males, and MSM differ in their biopsychosocial presentation and ongoing needs

Recognize and address fatalism and the struggle for daily survival among YMSM of color

- ◆ Address self-imposed social isolation
- ◆ Correct myths about HIV transmission and treatment
- ◆ Mental health services may need to be initiated before HIV care, particularly among clients with PTSD or acute depression
- ◆ Ensure that YMSM of color can envision a future
- ◆ Commonly, intensive outreach and linkage occurs before the first clinic visit, with multiple actions taken by outreach workers

Create a friendly, safe, youth-centered space, with separate youth waiting rooms

- **Some YMSM of color avoid being seen at an HIV clinic due to fear of disclosure to social and sexual networks**
- **Create opportunities for positive social interactions**
- **Youth community advisory board members can provide ideas to make the HIV clinical environment youth-friendly**
 - ◆ **Youth generally respond well to highly visual and auditory environments**
 - ◆ **Wall art, materials in the waiting and interview rooms, music, and other design features can be used to create a friendly youth-centered experience**

A youth-centered model differs from an adult model

- **Biopsychosocial assessment may take place over a period of time, not during the first encounter**
 - ◆ **Assessment forms may need to be modified to be relevant to youth**
 - ◆ **Assessment forms may not be completed during several initial appointments because the focus must be on keeping eye contact, active listening, and establishing a relationship**
 - **Write as little as possible to ensure a visual connection with the client**
 - ◆ **Address positive or negative roles that parents may play**

A youth-centered model differs from an adult model

- ◆ Understand the important roles that surrogate family structures play for some YMSM of color, including houses and house parents
- ◆ Clients may want to talk about other things than the items on an assessment form
- ◆ Youth are asked very personal questions that they may not have addressed with anyone before
- For some YMSM of color, staff may be the only individuals aware of the clients' HIV serostatus

Consistent adherence to their medication regimens is critical

- Recognize that we are asking YMSM of color to make a long-term commitment to therapeutic regimens that are commonly difficult
 - ◆ Since some YMSM of color have not disclosed their HIV serostatus to family members or friends, they may wish to hide their medication
- Ideally, medication regimens should be streamlined and assistive devices used to ensure medications are taken on a timely basis

Retention in medical care is critical

- Recognize that some YMSM of color do not trust older adults or authority figures
 - ◆ Do not lecture, preach, blame, or judge
 - ◆ Avoid fear, shame, or guilt
 - ◆ Their agendas may not be yours
- Alternatively, some YMSM of color may seek positive parental figures—the “parents they never had”
- Do not let clients drift away due to repeated broken appointments

Retention in medical care is critical

- Appointment scheduling must be flexible, with walk-in and work-in appointments available
- Avoid unfacilitated referrals
- Some YMSM of color are very transient, ensure that clients remember to keep in touch
- Never make them feel that they are wrong, or cannot come back for services
- You may have to address ethical dilemmas presented by YMSM of color that do not use safe sexual practices or engage in survival sex with older adults

Meeting the needs of YMSM of color can be challenging

- Basic life survival issues must be addressed
- Youth-centered and gay-friendly services are particularly hard to find in some communities
 - ◆ Mental health and addiction, coupled with risk reduction
 - ◆ Housing
 - ◆ Health insurance
 - ◆ Education and employment opportunities
 - ◆ Transportation
 - ◆ Legal services
 - ◆ Support services
 - ◆ Undocumented status further impedes getting services
- Do not assume that YMSM of color are in the early stages of HIV infection

Meeting the needs of YMSM of color can be challenging

- **Avoid attachment issues with staff**
 - ◆ **Turnover among staff on the care team may be destabilizing**
- **Prepare clients early and periodically to “age-out” of youth programs**
 - ◆ **Strict criteria should not be applied, as youth vary considerably in their maturity**
 - ◆ **Transition may take place over many months, with some clients seen in by an adult HIV clinic provider in their HIV youth setting**
 - ◆ **Some clients are likely to be angry during and after transition**

Other critical elements in designing programs for YMSM of color

- Establish strong care teams of individuals interested in working with YMSM of color
 - ◆ Clear roles and responsibilities among team members
- Training in adolescent development, motivational interviewing, and mental health and addiction screening are important
- Awareness of youth culture
- Adopt new technologies, such as texting
- Assign experienced social workers to YMSM of color
- Develop community resources

Other recommendations for program design

- **Maintain small case management caseloads, with intensive intervention**
- **Careful supervision to ensure high quality services**
- **Employ peer workers to conduct outreach and case finding**
 - ◆ **Some clients may prefer to work directly with peers**
- **Ensure that the whole team provides a positive youth-centered environment**

Employment of Peer Workers Presented Unique Challenges and Interventions

Grantee	Total Turnover	% Staff Left Voluntarily	% Staff Terminated
APEB	9	11%	89%
BAS	0	0%	0%
Harris County	1	100%	0%
LA County	1	100%	0%
MOCHA	5	20%	80%
UNC	3	33%	67%
WFT	6	33%	67%
WSU	4	75%	25%
Total	29	34%	66%
Mean including BAS	3.6	1.3	2.4

Total and Components of Costs Associated With Replacement of One Peer Worker: SPHERE Institute Study

Components of Cost	Median \$
Separation	\$273
Hiring	\$1,086
Training	\$1,951
Total Staff Hours to Rehire	129 hours
Total Cost Per Replacement	\$3,943
Total Cost Per Grantee	\$18,690
Total Cost Incurred by Initiative	\$216,663

Interventions to Address Turnover:

- YES Center convened three peer worker retreats, helped develop internet outreach protocols, and provided on-site technical assistance
- Demonstration sites worked together to develop job descriptions policies and procedures

Group Discussion

- **To what extent has Part A and Part B funds been used to identify, engage, and retain YMSM of color in care?**
- **What are your experiences in identifying HIV+ YMSM of color? What works, what does not?**
- **What steps has your program taken to create a youth-friendly HIV care model? What strategies have been the most successful?**
- **How does your program retain HIV+ YMSM of color in care?**
- **What are the unique cultural challenges presented by YMSM of color that you serve?**