Washington University School of Medicine

Tawnya Brown: Part C Director

Kim Donica: Part D Director

Katie Plax, MD: Part D Medical Director

Transitioning Youth Into Adult Care

Session Objectives:

- ✓ Understand Critical Role of Support Services
- ✓ Understand Positive Youth Development Models
- ✓ Tools & Strategies to Assist in Transition
- ✓ Review Case Studies

20 Years of Leadership
A LEGACY OF CARE

Program Overview

St. Louis, Missouri – The Gateway to the West

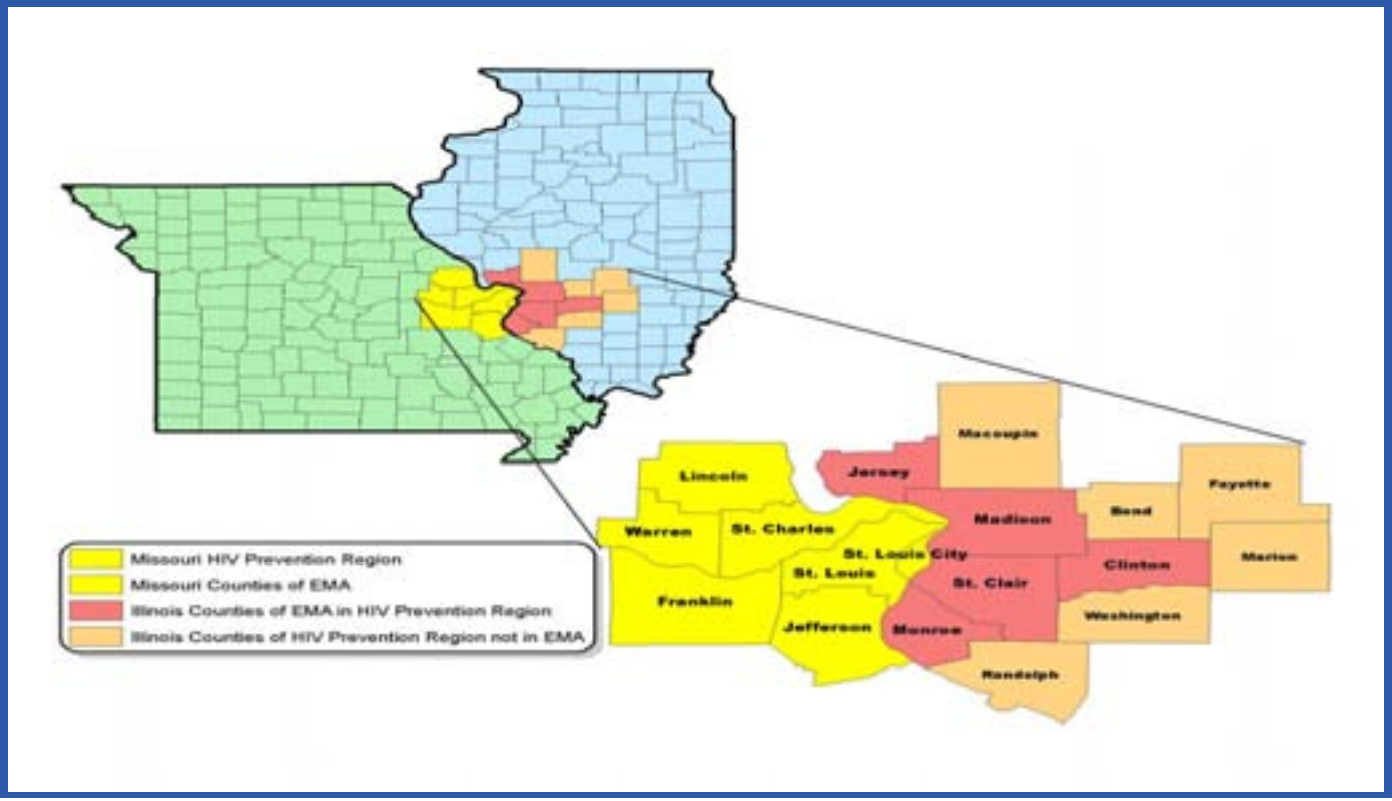
Washington University in St. Louis

Cardinals

20 Years of Leadership
A LEGACY OF CARE

Program Overview

St. Louis, Missouri – The Gateway to the West



20 Years of Leadership
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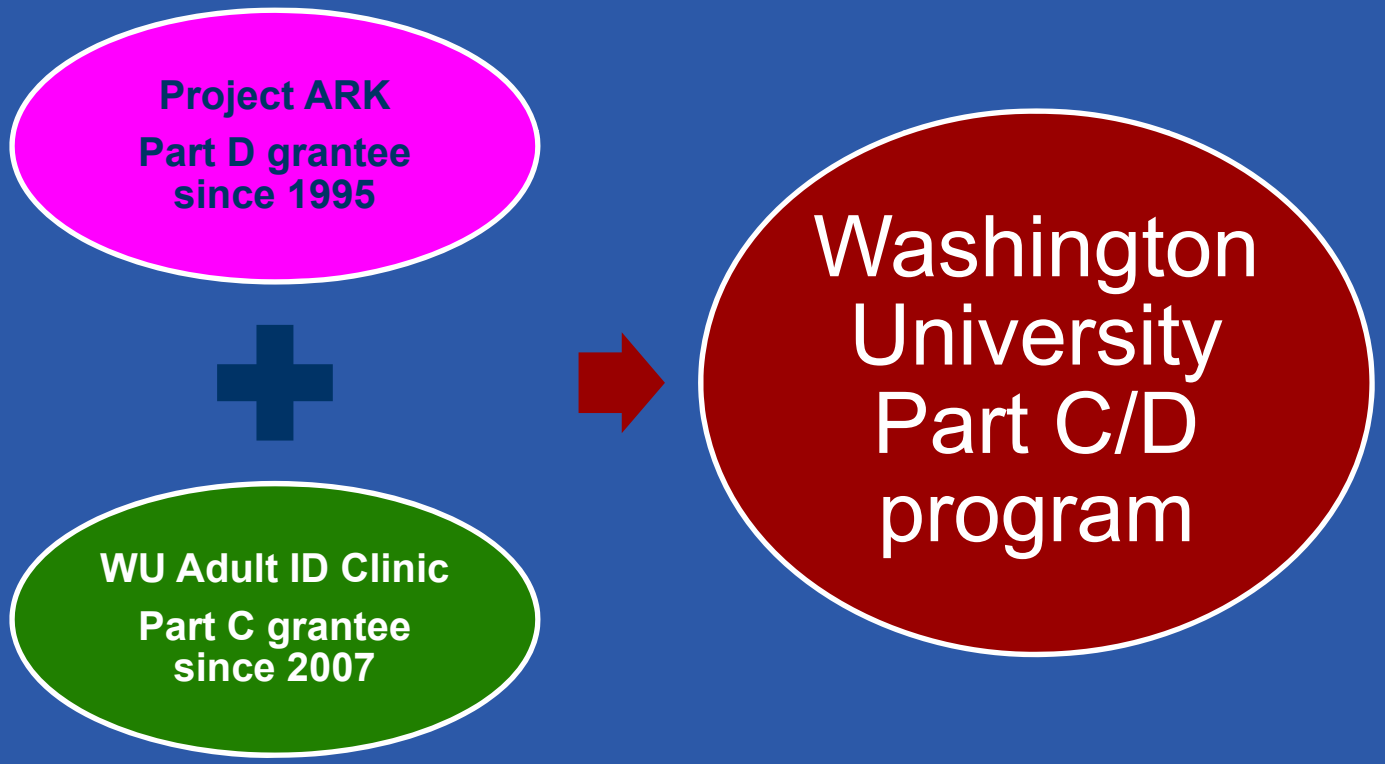
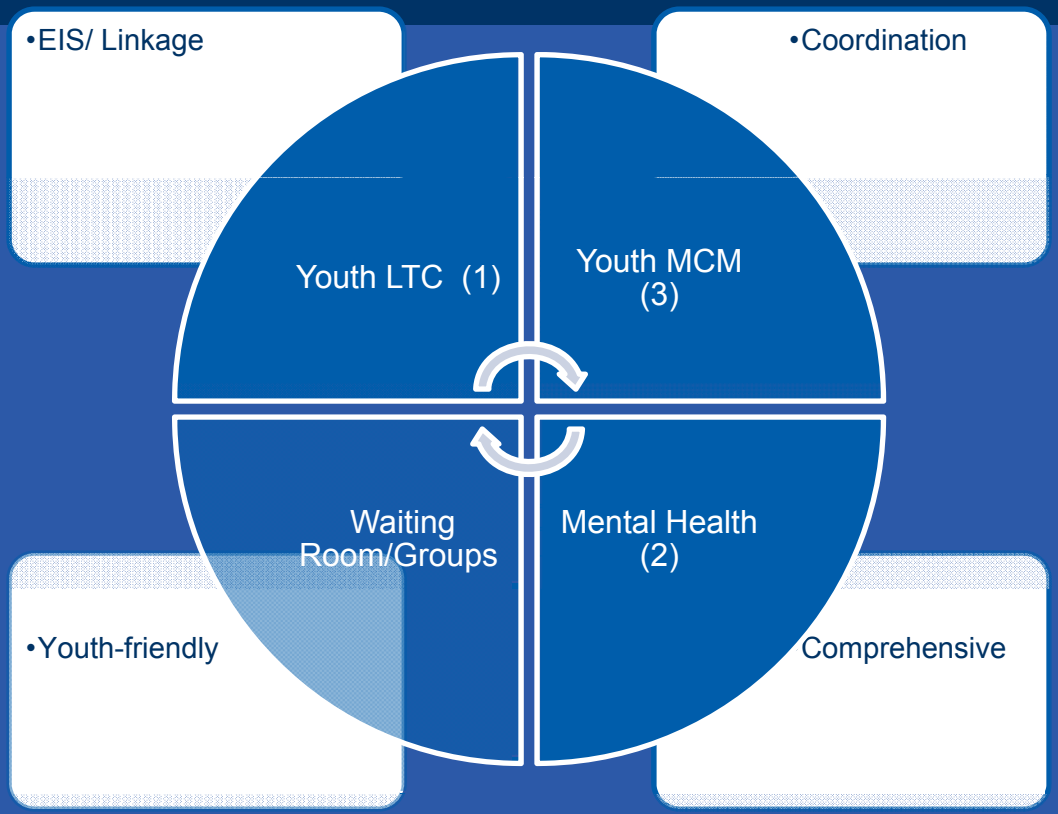
Program Overview

Part C and D Grantee



Youth-Specific Services



Part C & D Services

HIV Primary Care

Medical Case Management

Mental Health & Substance Abuse Services

Support Groups

Peer Treatment Adherence

Linkage to Care Coordination Services

GYN Services

ACTU On-site

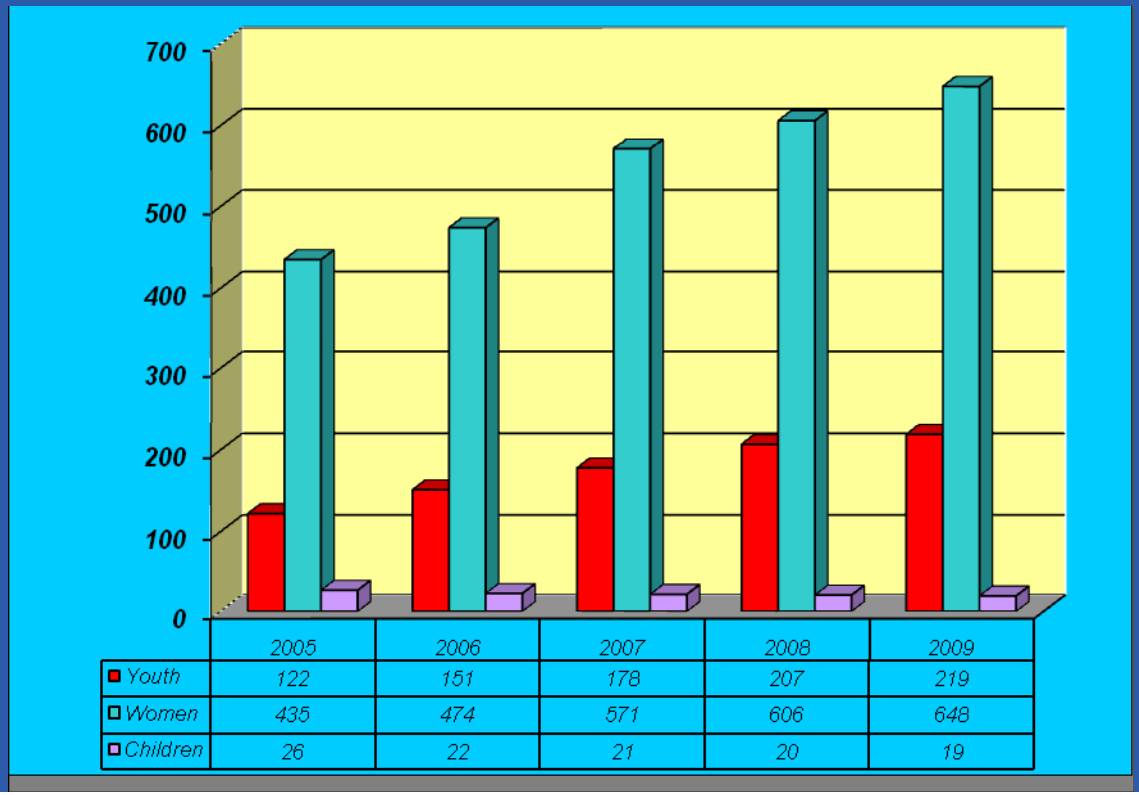
Partner Testing

Prevention Programs

Transportation

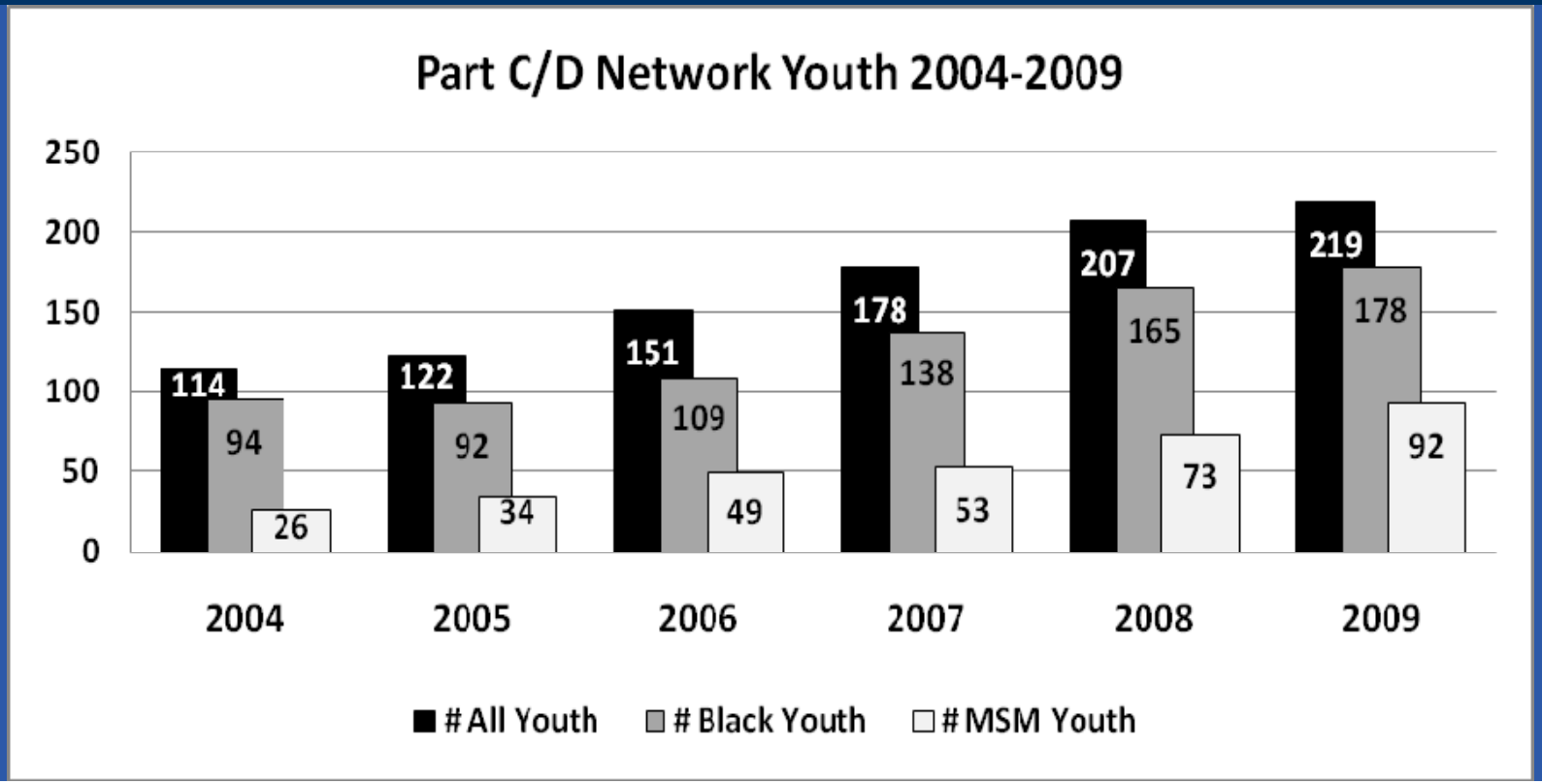
Childcare

PLWH Enrollment: Part D Network 2005-2009



	2005	2006	2007	2008	2009
Youth	122	151	178	207	219
Women	435	474	571	606	648
Children	26	22	21	20	19

HIV-infected Youth Served in Part C/D Network



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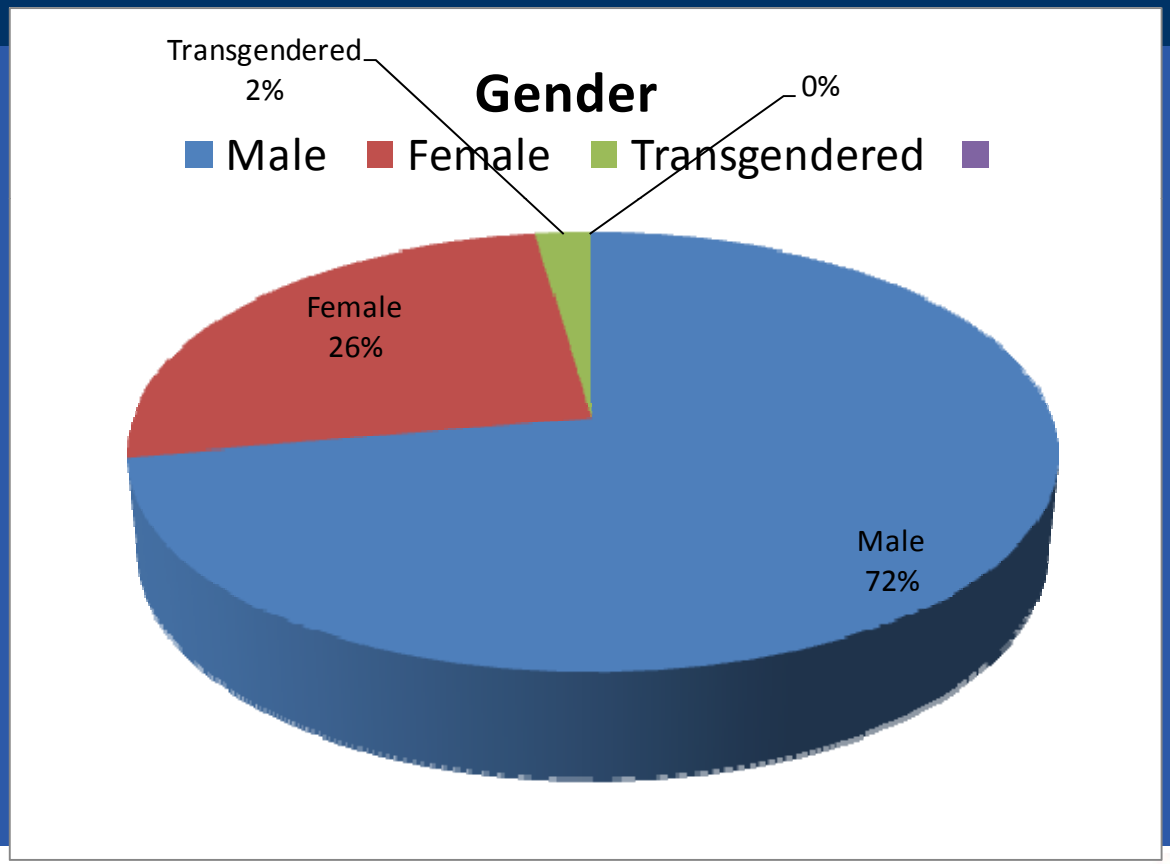
Youth Demographics

Gender (N = 219)



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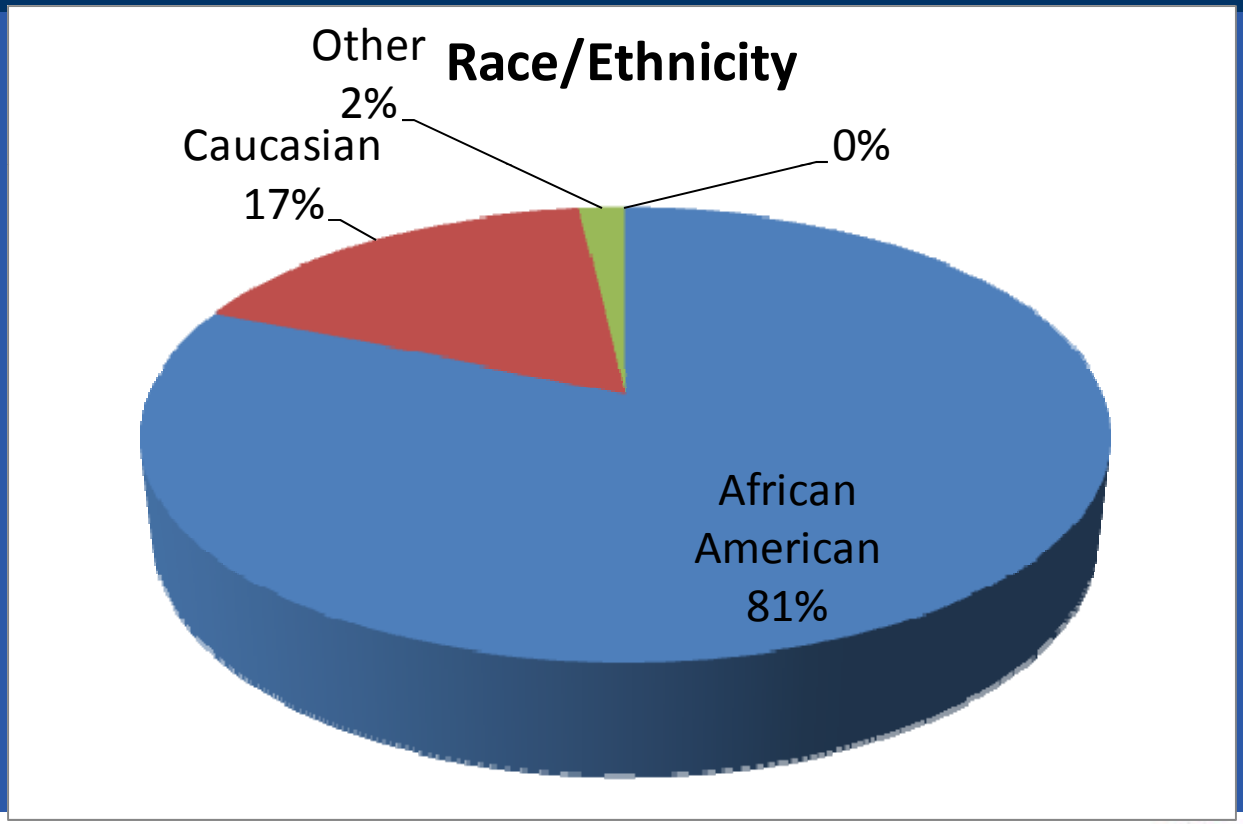
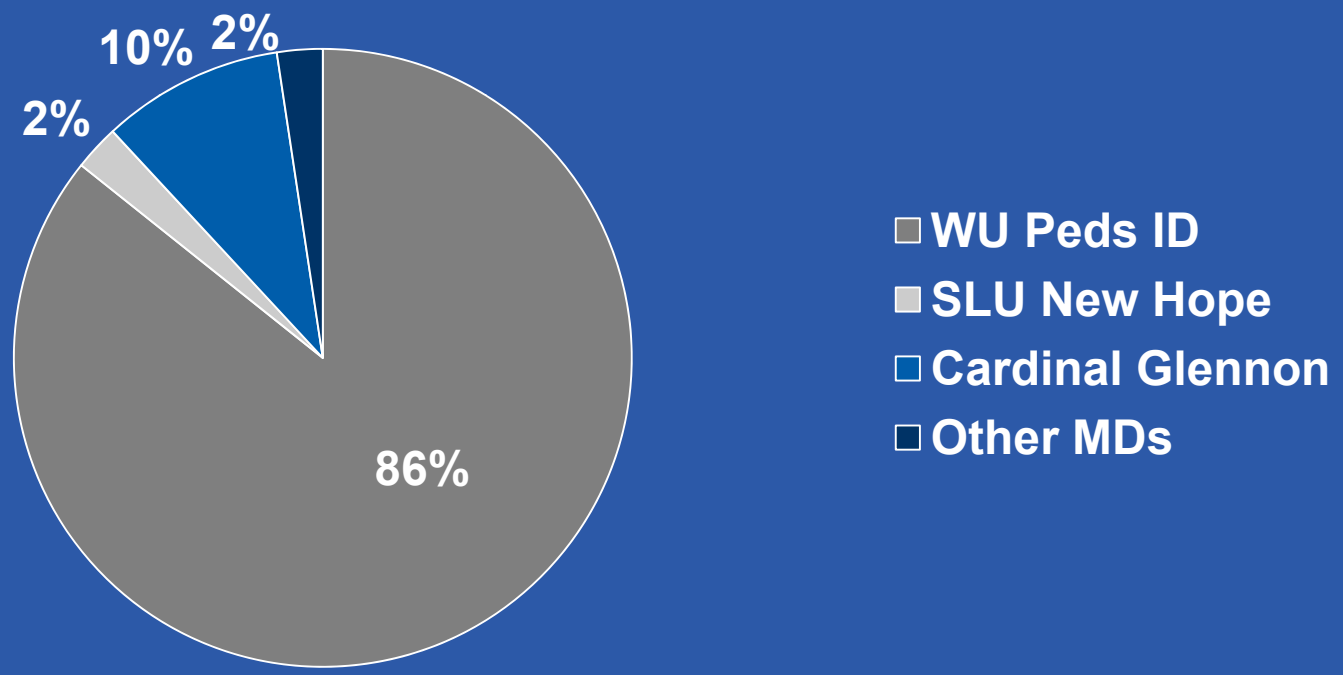
Youth Demographics

Race/Ethnicity (N = 219)



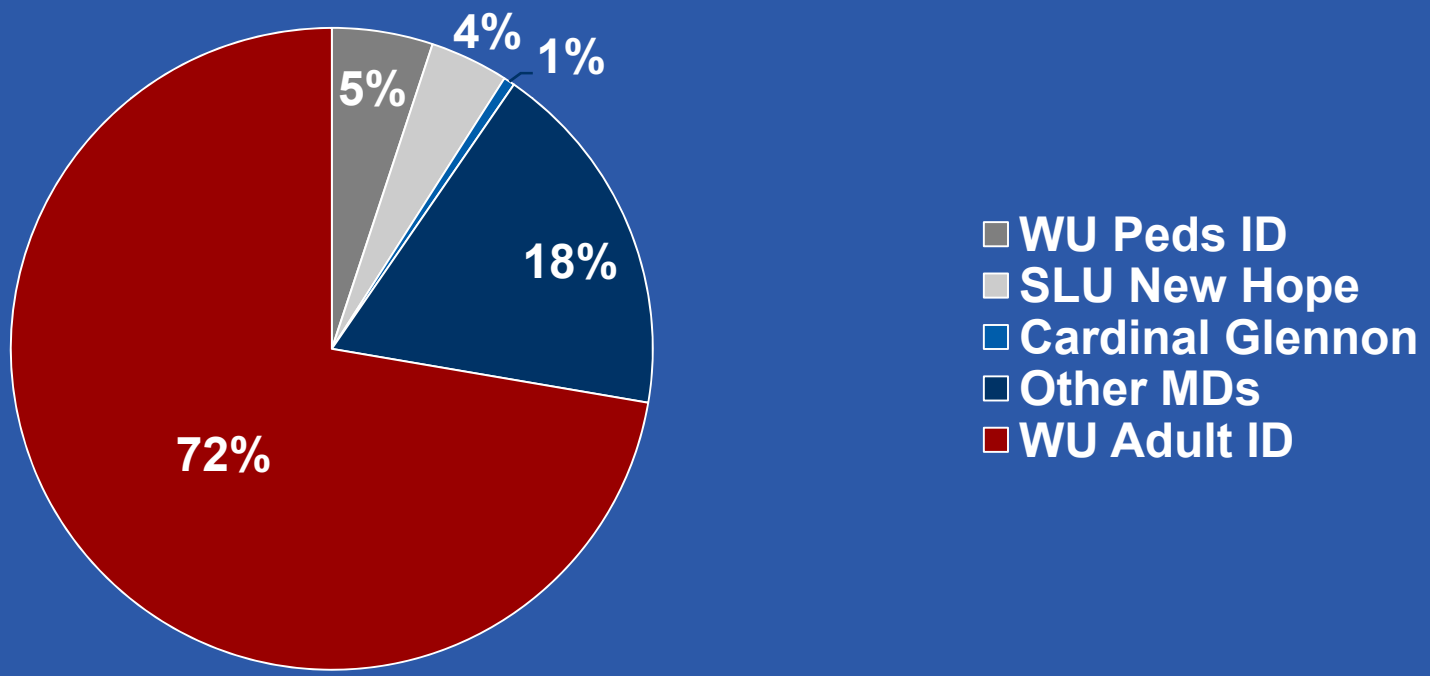
Youth by Primary Care Provider

Younger Youth, ages 13-18 yrs

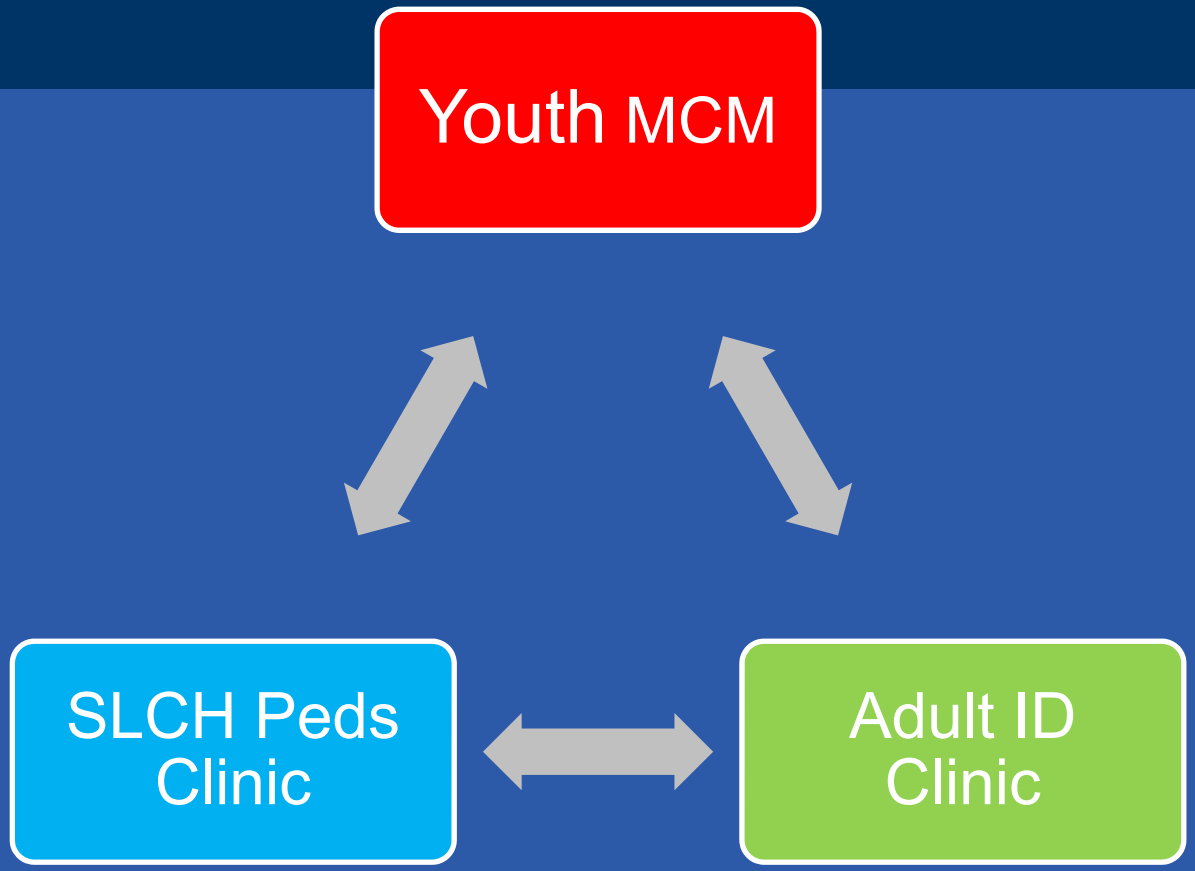


Youth by Primary Care Provider

Younger Youth, ages 19-24 yrs



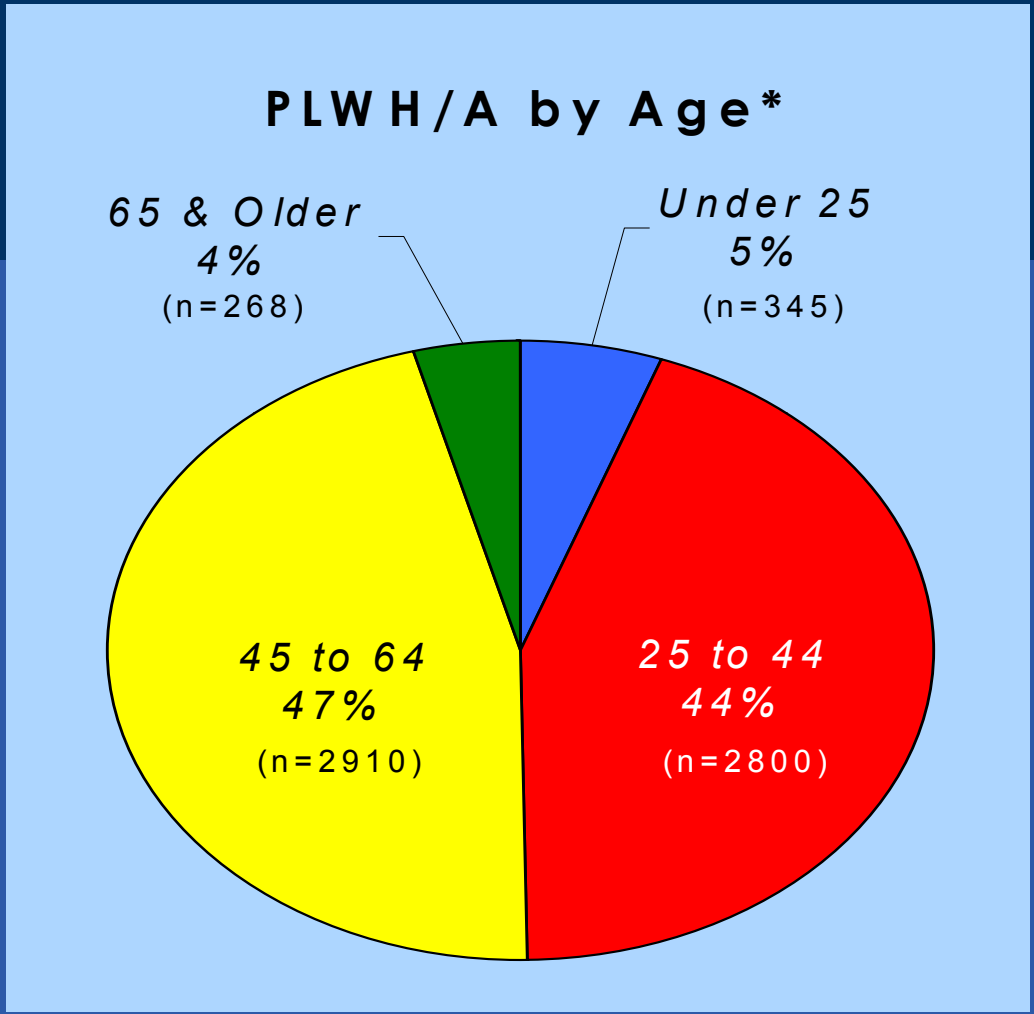
Part C/D Youth Medical Case Management



Challenges in Youth Service Delivery

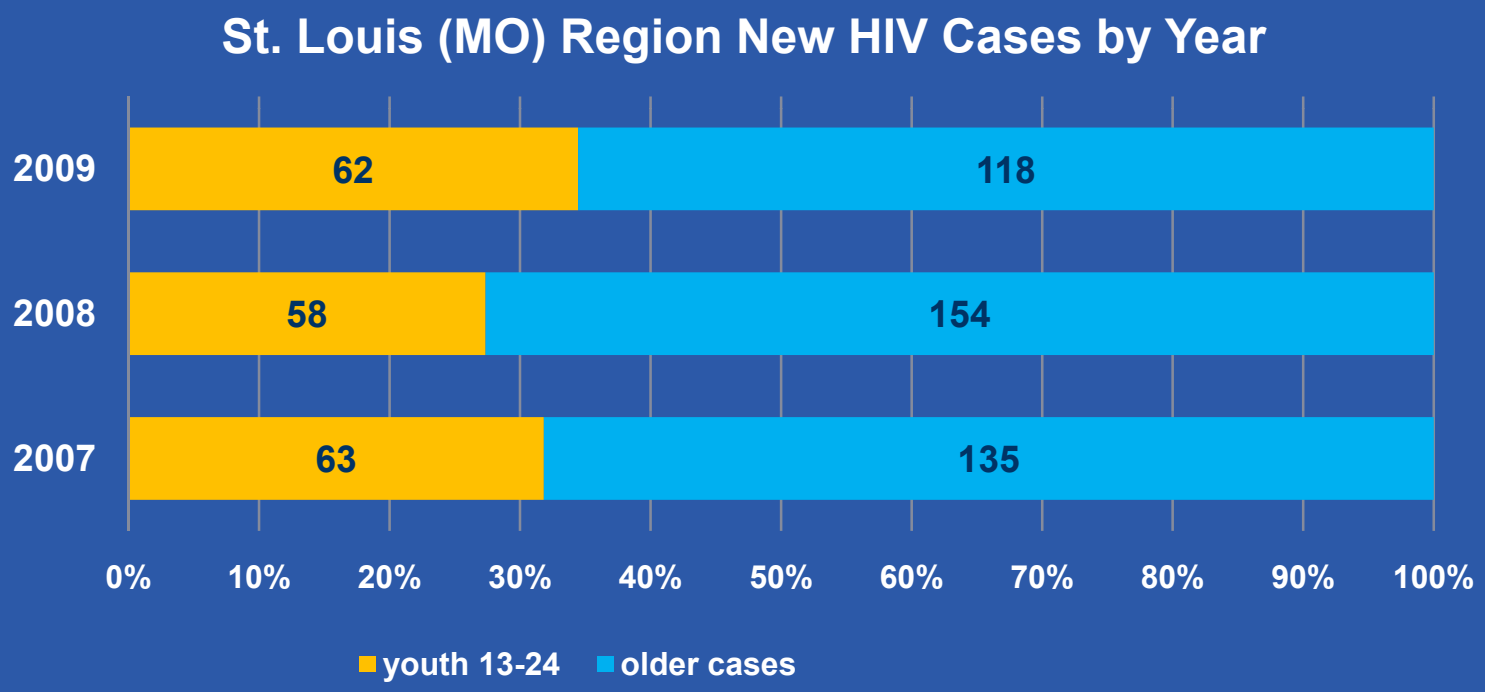
- Lower Show Rates
- Less Likely to Cancel/Reschedule
- Lower Retention Rates
- Competing Priorities

HIV/AIDS Prevalence in STL (MO/IL) Region n= 6,323



Youth Comprise 1 in 3 New HIV Infections

HIV-Positive Youth



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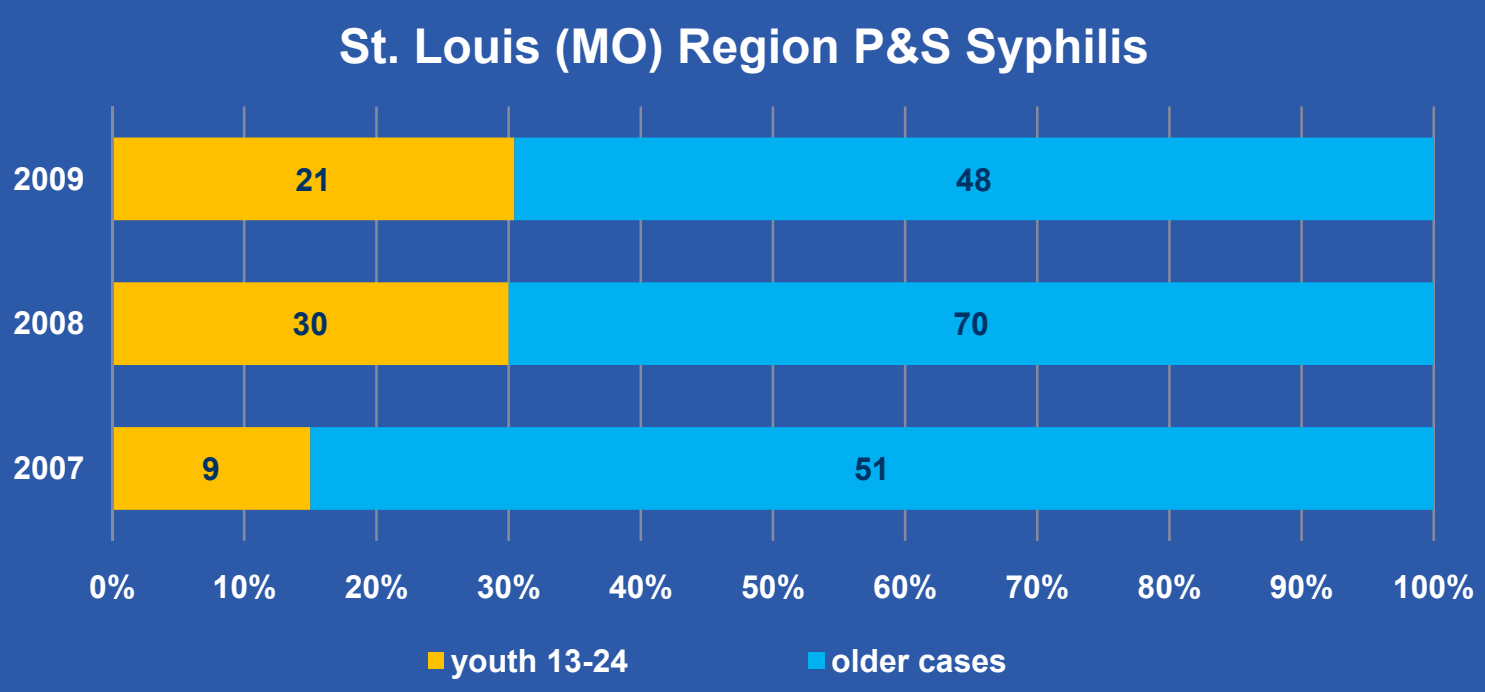
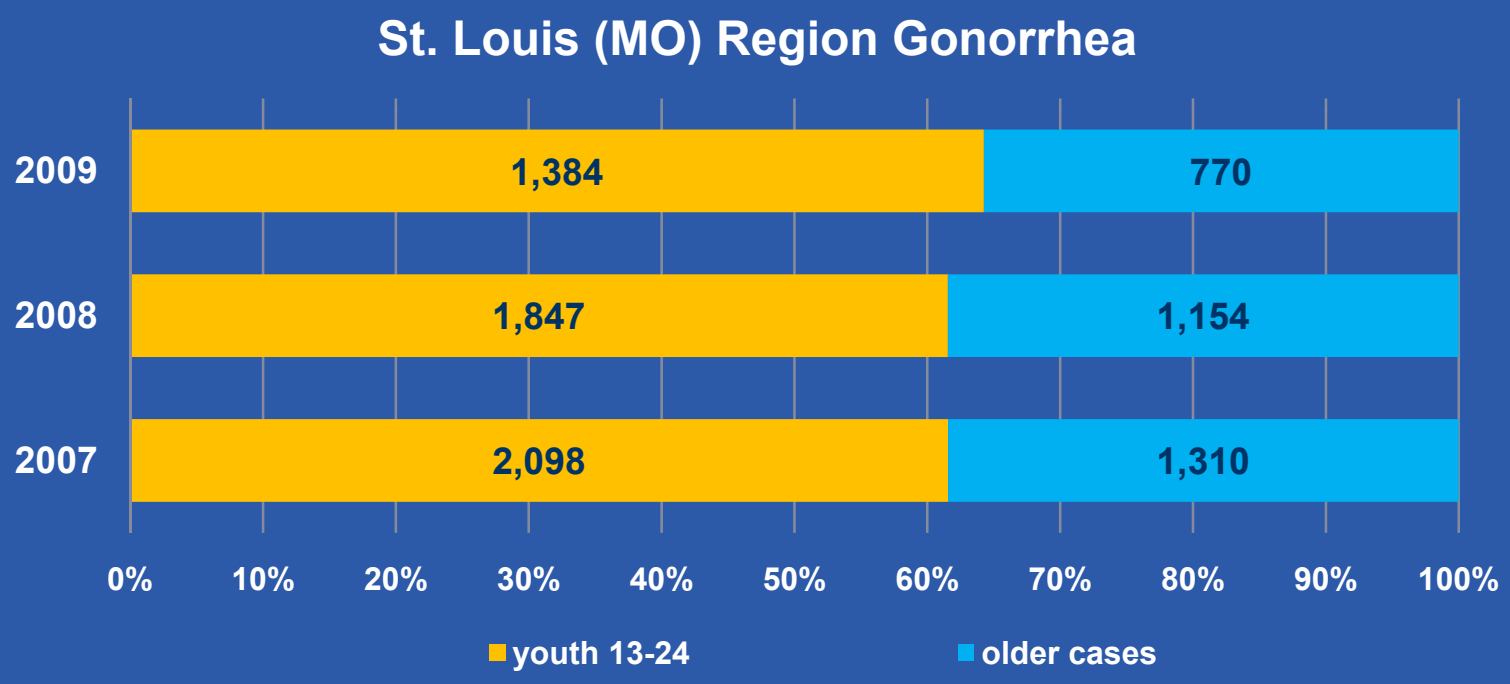
Youth HIV/STD Data

At-Risk Youth - Syphilis



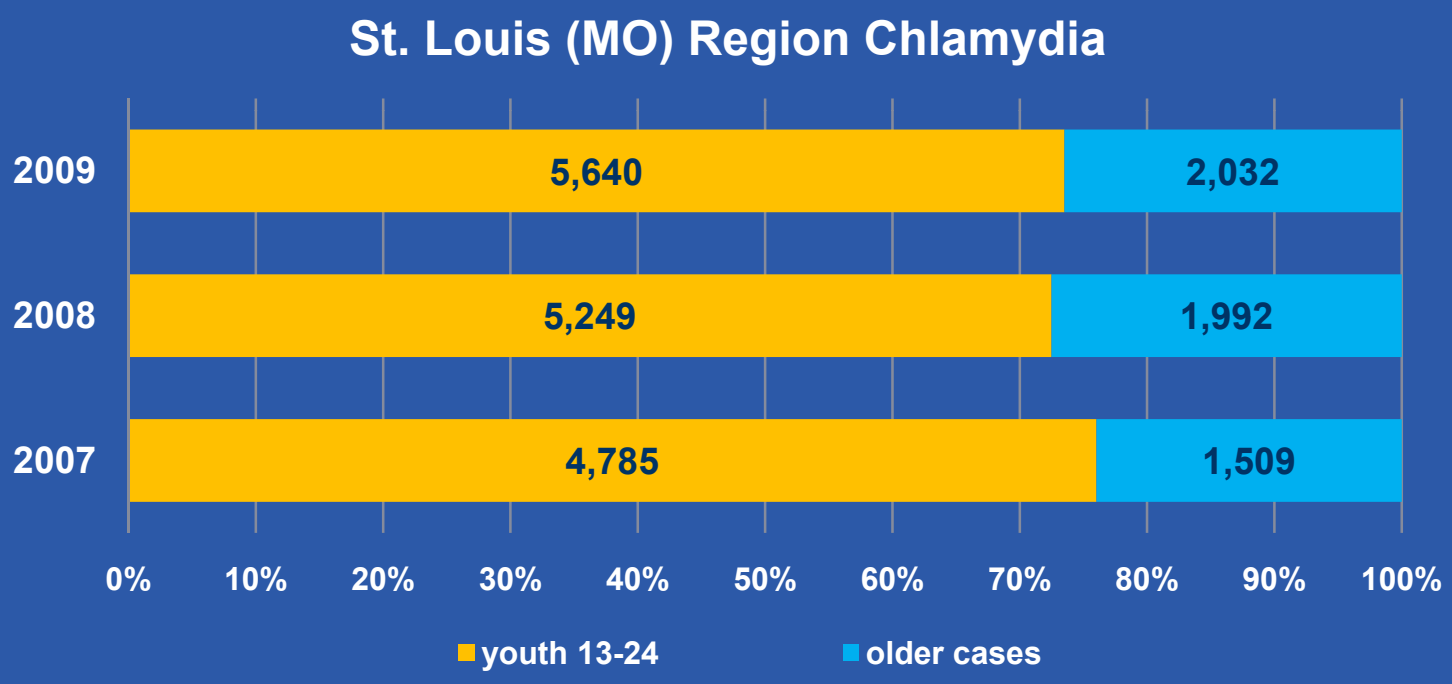
Youth HIV/STD Data

At-Risk Youth - Gonorrhea



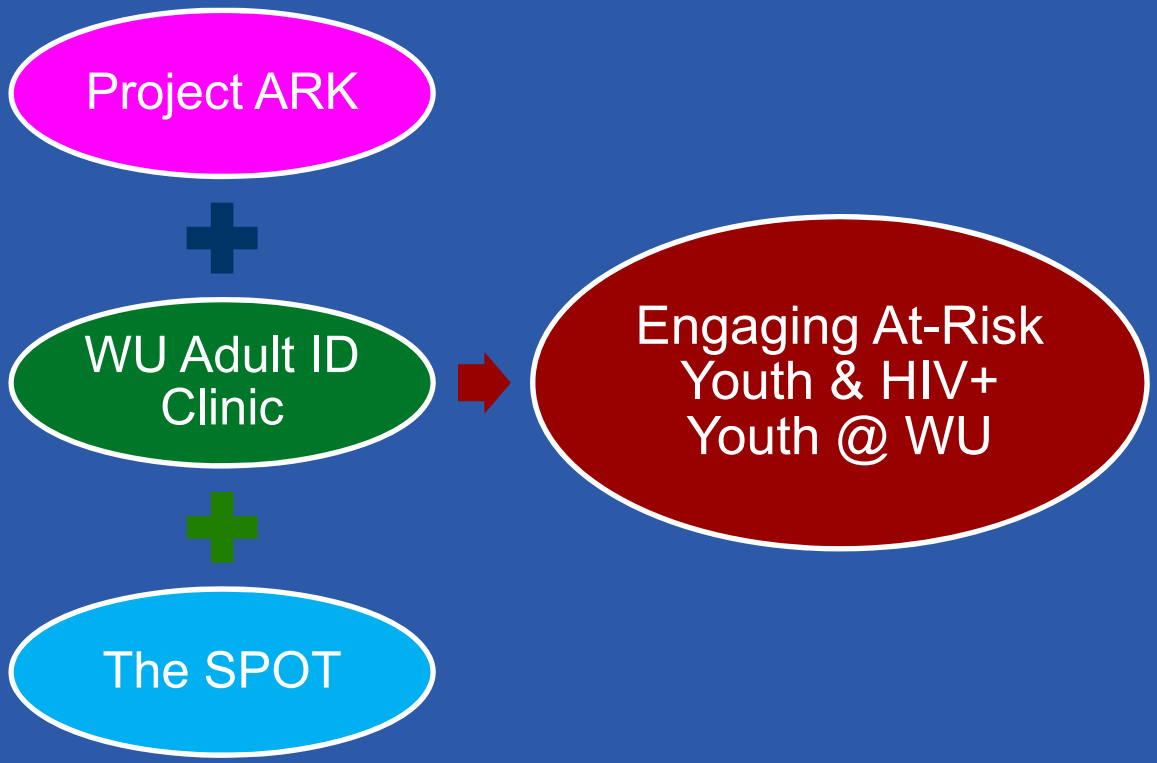
Youth HIV/STD Data

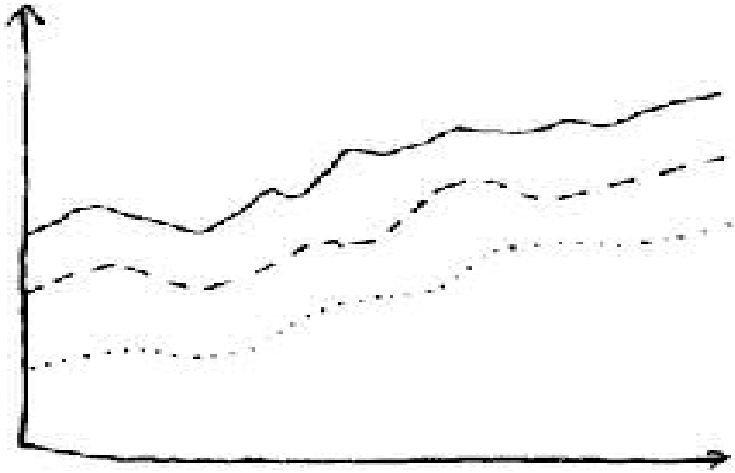
At-Risk Youth - Chlamydia



Program Overview

Components of Reaching and Serving Youth at WU





HOW BAD THINGS ARE

HOW BAD THINGS SEEM

THE 'HOW BAD THINGS ARE' LINE REVIEWED IN THE LIGHT OF SOME EVIDENCE THAT HAD HITHERTO GONE UNNOTICED

What is Positive Youth Development?

A philosophy that guides communities in the way they organize programs and supports so that young people can develop to their full potential!

Key Principles of Youth Development

- Highlights Positive Outcomes
- Youth Voice- **with** not **for**
- Strategies Aim To Involve All Youth
- Long Term Involvement- years not months
- Community Involvement-neighborhoods, schools, etc.
- Focus On Collaboration

Results of Resiliency Research-What Explains Success Despite the Odds

Werner and Smith's classic study looking at close to 700 infants born in Hawaii in 1955 and followed over 40 years

INDIVIDUAL TRAITS

Social Competence

Problem Solving Skills

Autonomy

Sense of Purpose, Belief in a Bright Future

ENVIRONMENTAL TRAITS

Caring Relationships

High Expectations

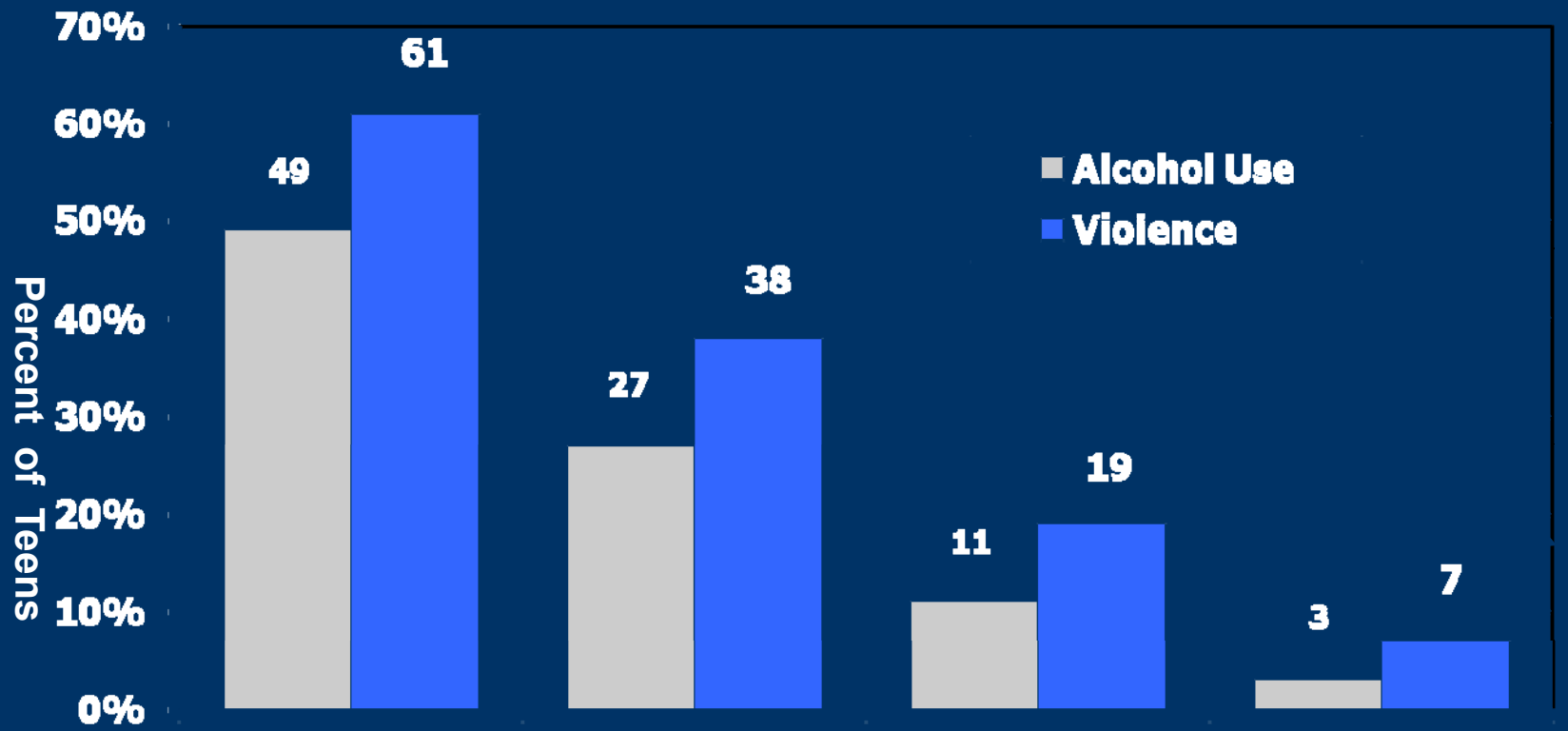
Opportunities for Participation

What promotes young people's success?

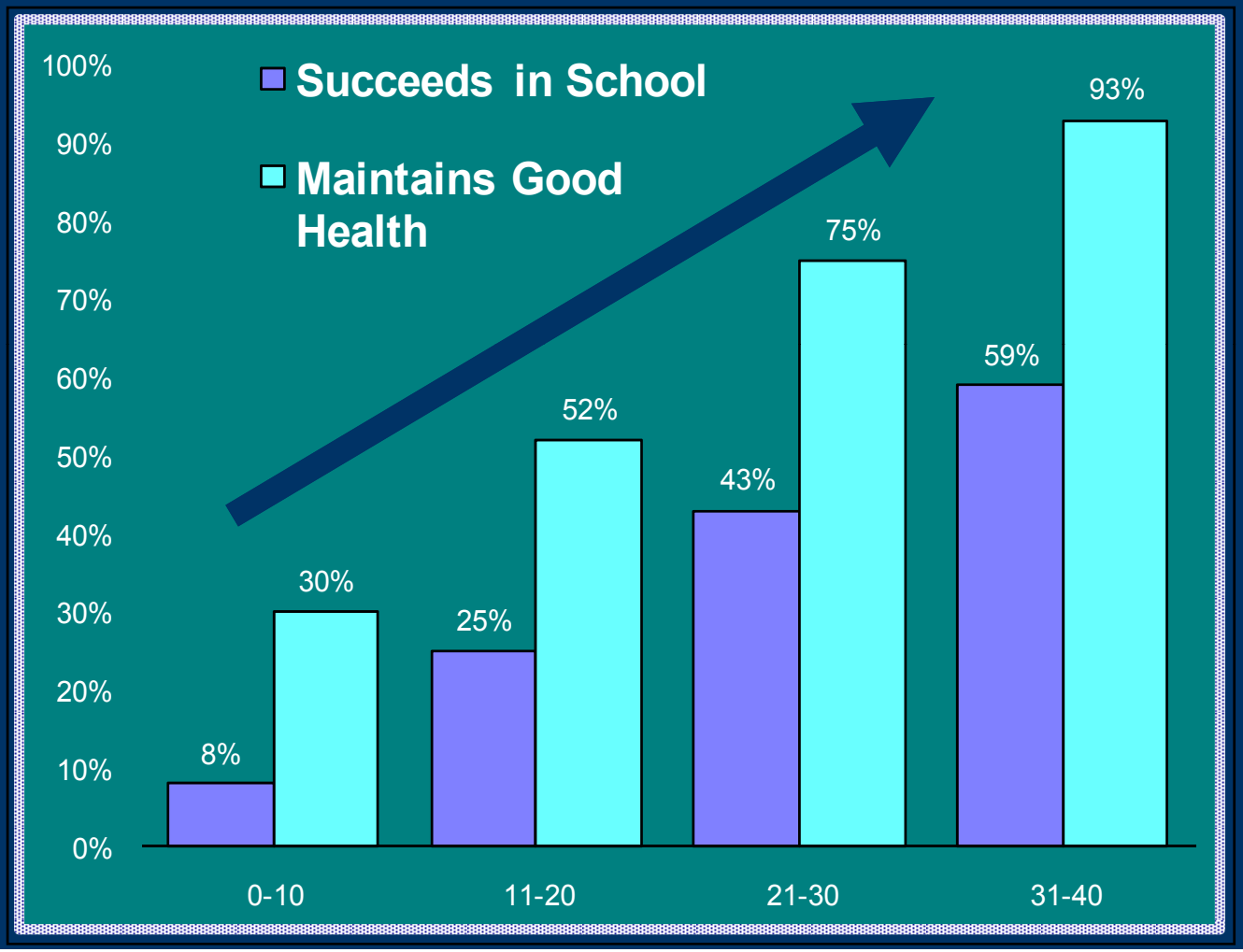
Search Institute's: The Origin of "Assets"

External Assets	Internal Assets
Support	Commitment to Learning
Empowerment	Positive Values
Boundaries and Expectations	Social Competencies
Constructive Use of Time	Positive Identity

Relationship of Assets to Negative Outcomes



Thriving Indicators by Asset Level



Risk and Protective Factors at Work

Risk Factors

Positive Life Outcomes

Protective Factors

Put another way

What is a Strengths Based Approach?

- People are active in their own helping - empowerment.
- An assumption that all people have strengths, but sometimes they are not recognized or utilized.
- Strengths are often a source of motivation to make change.
- Strengths can be internal or environmental

Saleebey, Dennis, "The Strengths Perspective In Social Work" 1992.

What are Strengths

- Talents
- Skills
- Dreams
- Connections
- Creativity
- Culture
- Interests

The 7 C's

- Competence
- Confidence
- Character
- Connection
- Contribution
- Coping
- Control

"A Parent's Guide to Building Resilience in Children and Teens" by Ken Ginsburg MD, MSEd

Circle of Courage

Dr. Larry Brendtro, Dr. Martin Brokenleg, and Dr. Steve Van Bockern, published *Reclaiming Youth at Risk: Our Hope for the Future*.

generosity

independence

belonging

mastery

Steps Toward Adopting a Strengths Approach

- Identify/ask about youth strengths
- Comment on youth strengths to youth
- Use a strength-based framework drawn from the literature
- If a behavior change is needed, use a shared decision-making strategy
- Ask for feedback from youth to establish a youth friendly practice environment

A Case

A 16 year old young man presents after testing positive for HIV infection. He lives with his grandmother and has been out of school for two years taking care of her as she has hepatitis C. His father is a minister and lives with his mother but kicked him out of the house because of his “lifestyle”. He also has type one diabetes and has been in good control with a hgb A1c of 6.1.

How to be a Trustworthy Adult

- Explain why we ask personal questions
- Explain privacy policies, including limitations
- Be non-judgmental
- “It’s your choice to respond”

Back to our case....

He has not used cigarettes or any other drugs and he has tried alcohol but does not like it. He has been sexually active over the past 2 years with several male partners. He uses condoms “some of the time”. Sex is consensual. He let his last partner know about his new HIV diagnosis.

What strengths does our patient have?

- Desires medical care because came to the appointment himself
- Told his last partner about HIV infection
- Uses condoms at least some of the time
- Has a generous spirit as cares for his grandmother
- Has experience managing a chronic disease as his hgb A1c is 6.1

GAPS

- **G** - gather information
- **A** - assess situation
- **P** - problems to address
- **S** – solutions/shared decision making
  - What could you do?
  - What would happen if you did that?
  - What would you like to try?

So what about in practice?

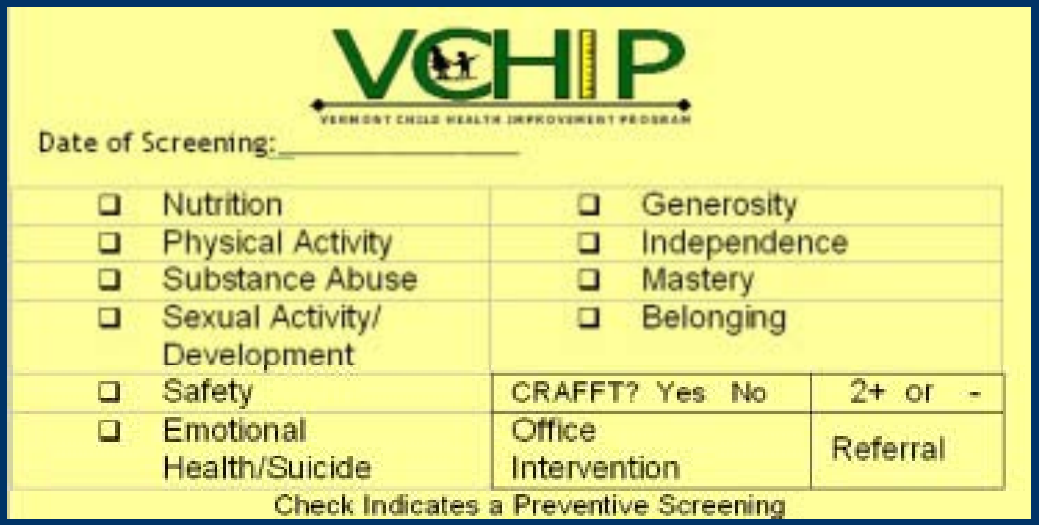
Duncan PM et al. Journal of Adolescent Health 41:525-535, 2007.

Setting the stage in your office:

1. Youth friendly setting and materials (belonging)
2. Confidentiality (independence and mastery)
3. Respecting the adolescent and talking with them directly (independence, mastery and belonging)
4. Discuss strengths (independence and mastery)
5. Post relevant volunteer opportunities and community events (generosity)

Duncan PM et al. Journal of Adolescent Health 41:525-535, 2007

- Risk and Strength Assessment



VCHIP

VERMONT CHILD HEALTH IMPROVEMENT PROGRAM

Date of Screening:_____

❑	Nutrition	❑	Generosity
❑	Physical Activity	❑	Independence
❑	Substance Abuse	❑	Mastery
❑	Sexual Activity/ Development	❑	Belonging
❑	Safety	CRAFFT? Yes No	2+ or -
❑	Emotional Health/Suicide	Office Intervention	Referral

Check Indicates a Preventive Screening

Figure 1. Vermont Child Health Improvement Program (VCHIP) reminder sticker. Sticker is attached to patient charts to remind primary care practitioners to track a set of six risk behaviors and four wellness-promoting assets during patient screening visits.

Another case

A sixteen year old young woman presents for dysmenorrhea. She has been sexually active with one male partner and they use safer sex practices. She wants birth control but her parents will not allow it and she cannot afford cash payments every month. She is a straight A student and a star on the field hockey team.

Another Case

A 16 year old young man comes for STD/HIV testing. As I go to do his abdominal exam I notice a large healing scar with sutures. He says he got involved with the "wrong crowd" and was stabbed a few weeks ago. Six months ago he gave up his violin despite winning the state title a year ago.

Social Toxicity

VIOLENCE

HOMOPHOBIA

SEXUAL EXPLOITATION

Social factors that poison youth well being and healthy development

DISRUPTED FAMILY RELATIONSHIPS

HEALTH THREATS

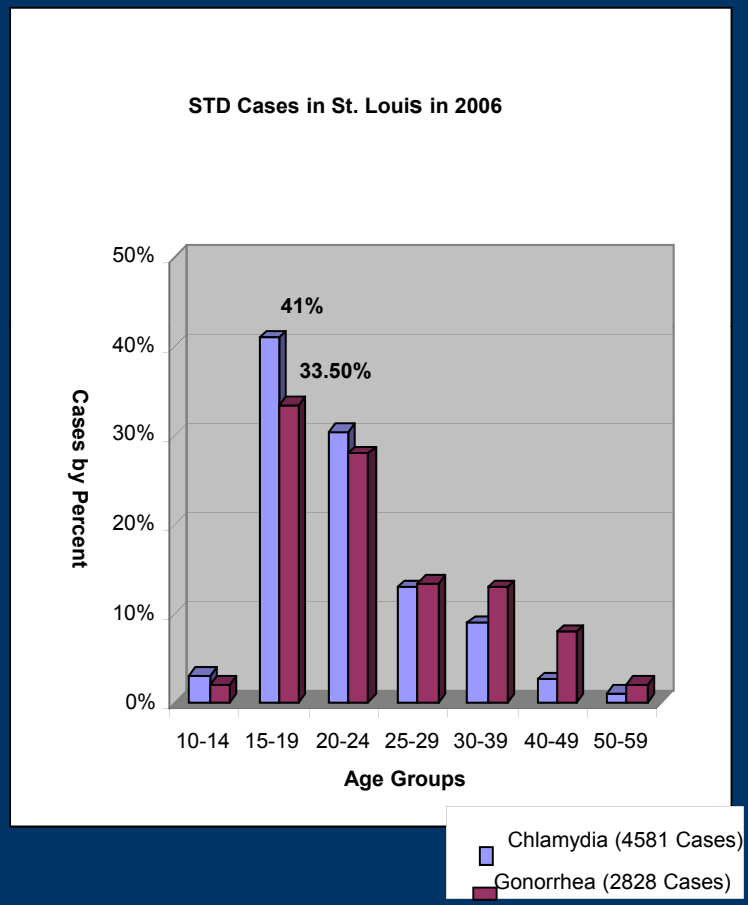
SEXISM

RACISM

LACK OF BENEVOLENT ADULT AUTHORITY

Our Youth Center Effort

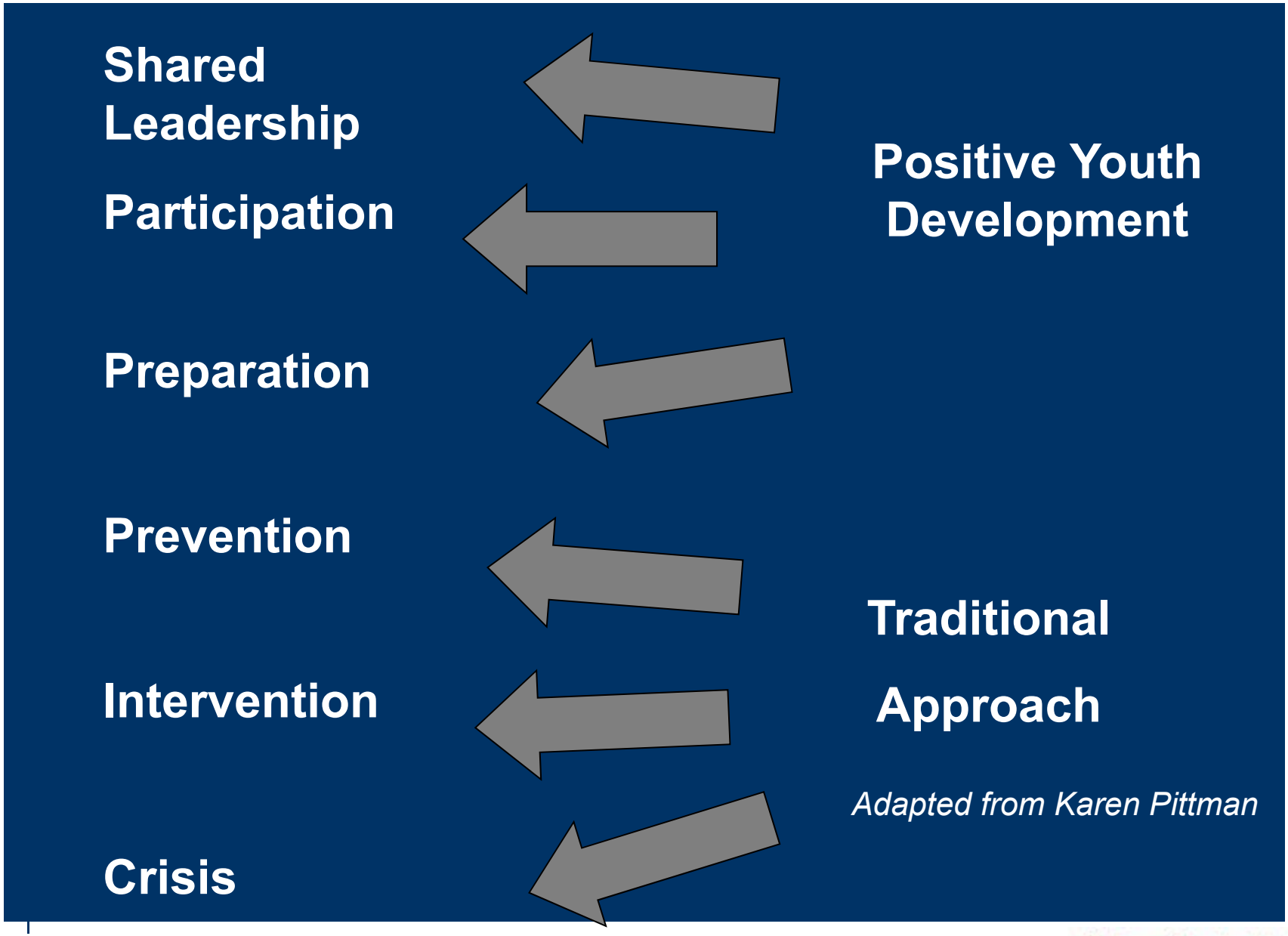
- Huge STD rates in St. Louis-we're #1
- Growing HIV rate in ages 13-24, 30% of the total of new HIV infections
- A teen pregnancy rate of 17.6% vs. 12% national average for the 50 largest cities in the US.



Barriers to Care for Youth

- Cost
- Lack of insurance
- Worries about confidentiality
- Transportation
- Fragmented services
- Disenchantment with adults

Rosenfeld, S et al. Primary Care Experiences and Preferences of urban Youth, J of Pediatric Health Care, 10(4):151-160, 1996.



What the research tells us

- Wide range of services under one roof
- Team Approach to care
- Efficient division of responsibility
- Staff sensitivity
- Teen friendly environment
- Focus on positive youth development

Incenter Strategies Report "Under One Roof", Sandmaier et al, 2007.

What do youth tell us they want from us?

Profiles of Youth Engagement & Voice in New York State: Current Strategies, 2002.

> *"If you had a problem in the Black community, and you brought in a group of White people to discuss how to solve it, almost nobody would take that panel seriously. In fact, there'd probably be a public outcry. It would be the same thing for women's issues or gay issues. But every day, in local arenas all the way to the White House, adults sit around and decide what problems youth have and what youth need, without ever consulting us."*
>
> *Jason, 17 years old*
> *Youth Force Member*

What do teens tell us they want?

Teens from Inner City Philadelphia in school grades 8-12. Asked in both survey (likert scale) and focus groups what they think would be most likely to help them achieve a positive future.

- Help to get into college
- Creation of more jobs
- Job training
- Opportunities to spend free time productively and connect with adults.
- Of note items for reduction of risk or disruptive surroundings were rated lower.

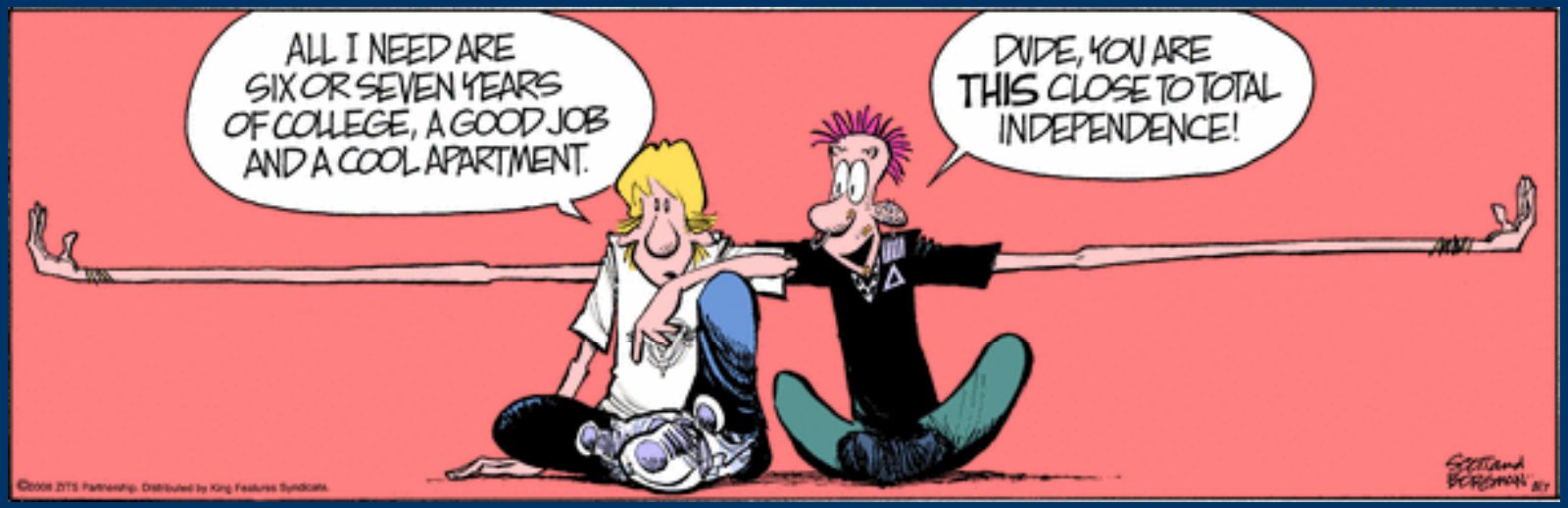
Ginsburg, K et al Pediatrics 109(6) 2002, pages 1136-1143 and e95.

What do teens tell us that they want- St. Louis

- Services desired-
  - Job Training 17.9%
  - Mental health Counseling 14.3%
  - STD and HIV testing 14.3%

Lessons Learned/How we did it

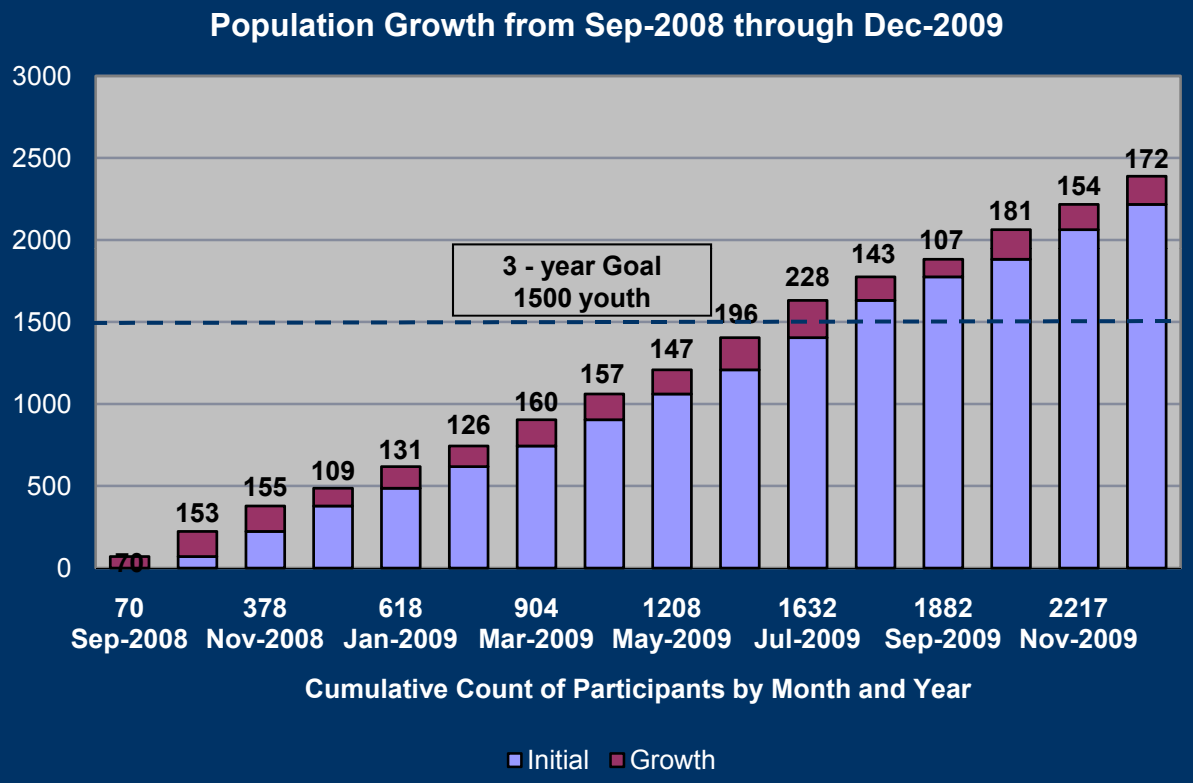
- Do your homework- Lit Search/Research National Model Programs (Hint – Part D)
- Who better than us to know the population needs? Part D Comprehensive Model = Effective HIV Prevention
- Create a sense of community involvement/partner don't duplicate
- Always recognize the strengths of youth


ALL I NEED ARE SIX OR SEVEN YEARS OF COLLEGE, A GOOD JOB AND A COOL APARTMENT.
DUDE, YOU ARE THIS CLOSE TO TOTAL INDEPENDENCE!
©2008 ZITS Partnership. Distributed by King Features Syndicate.
Scott and Borgman

What we are doing

- Drop in center with free health and social services with and for youth 13-24.
- Foster adult-youth interaction in a safe space.
- Active Youth Advocacy Committee
- Free STD/HIV testing and treatment.
- Free contraception and pregnancy tests
- Mental Health Services
- Case Management Services- Crisis Intervention
- Drop in/Walk in- low threshold, high engagement
- Linkage to Care-primary care and other services.
- Partnership with SLATE for job training and career development skill building.
- Supported by a wide variety of community and federal funders

Shattered Original Projections
N= 2,389



Data Source: Washington University-The SPOT

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Comprehensive Positive Youth Development Model

Youth Involvement

- ✓ Assist with design, hours, services
- ✓ Helped interview staff
- ✓ Participate in policy making events
- ✓ Consult with Youth Advocacy Committee
- ✓ Hire Peer Educators
- ✓ Help connect to services and make linkages; not do it *for* them

Our Partner Network

Collaborations Include:

- Health Department
- Agency for Training and Employment
- Children's Division
- Youth In Need (Runaway and Homeless Youth)
- NCADA
- Schools
- Youth serving agencies

Department Collaboration

- Pediatrics
- Internal Medicine
- Psychiatry
- Obstetrics/Gynecology


PROJECT ARK
AIDS / HIV RESOURCES AND KNOWLEDGE
the spot
supporting positive opportunities with teens

Welcome to The SPOT

The SPOT on YouTube

http://www.youtube.com/watch?v=vXr8Zuxw6Kk

Summary of Activities for The SPOT 2009

2389 Unduplicated Clients over 8914 visits

- (43%) Males (56%) Females (1%)Transgender
- (78%)Black (15%)White (1%)Asian/Pacific Islander (2%) Multiracial (1%)Latino
- Minimum Age 13 years Max 25 years Median 19 years
- Average daily census 37 youth

20 Years of Leadership
A LEGACY OF CARE

Summary of Activities, The SPOT Year 1 Top 10 List

More than 21,276 Total Encounters

- Drop In
- Food
- Phones/computers
- STD Testing/Medical/HIV
- Transportation
- Case Management
- Job search
- Mental Health
- Pregnancy Test
- Contraception

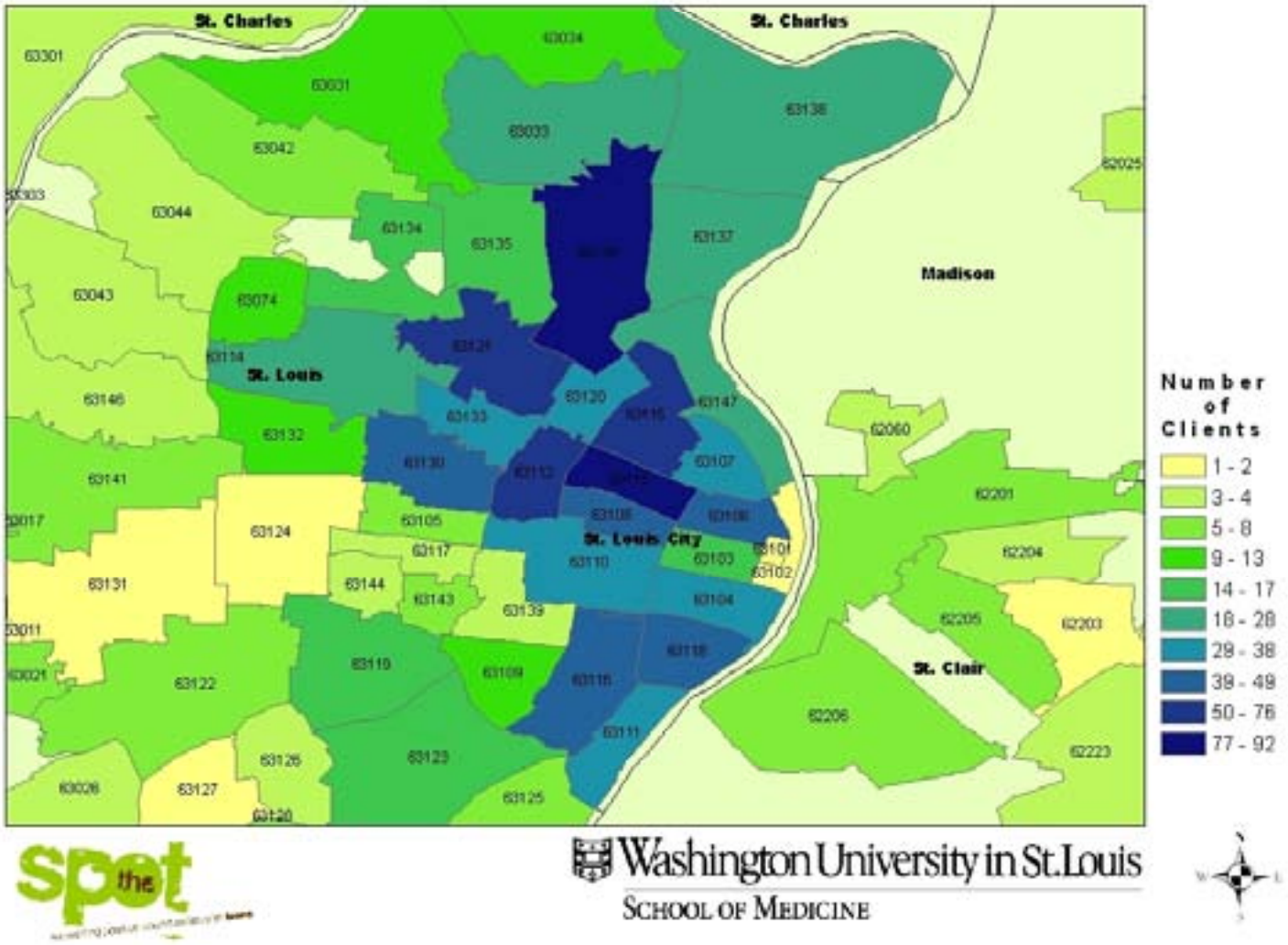
Summary of Activities for The SPOT 2009

Outcomes

- 209/1665- 12.5% Chlamydia prevalence
- 358/1665- 3.4% Gonorrhea prevalence
- 14/1257 -1.1% HIV prevalence

  (Highest HIV prevalence among all testing sites in Missouri)
- 22/1257-1.7% Syphilis prevalence
- **96% treatment rate of all positives**
- Average time for treatment **5 days** from test
- Almost 25% of all HIV positive youth seen by Part C/D have used a SPOT service

The SPOT 2008-2009
Number of Clients by Zip Code



spot the

Washington University in St. Louis
School of Medicine

20 Years of Leadership
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The SPOT 2008-2009
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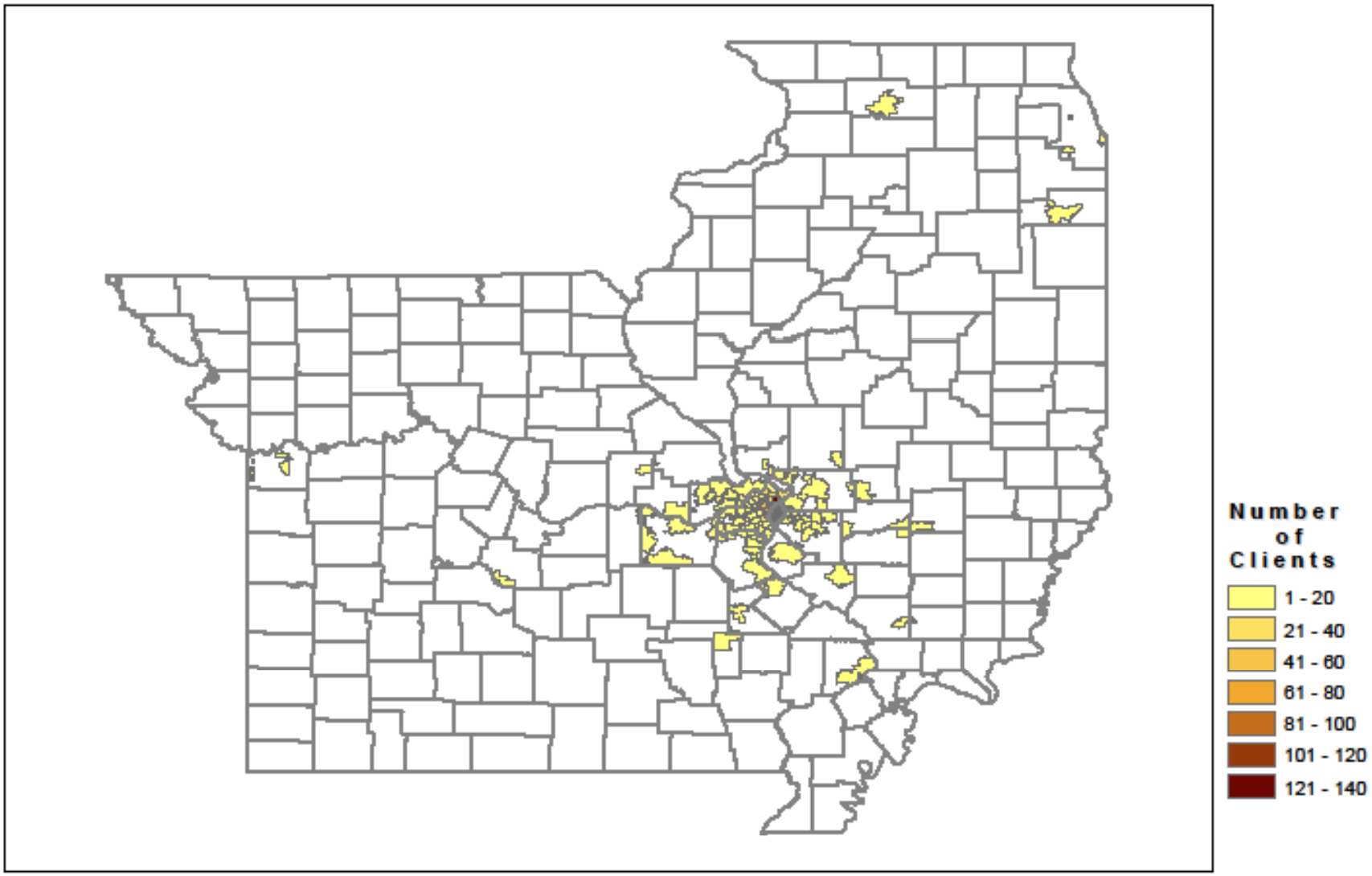

the spot

Washington University in St. Louis
School of Medicine

Integrating HIV/SA Prevention Services

- Positive STI = Referral to Health Educator
- Health Educator- offer individual and group intervention
- SAMHSA Grant integrates SA Prevention with HIV Prevention
- Substance Abuse counselor is on-site

What is Next?

- More prevention groups and outreach
- Greater partnership with the Health Departments
- Advocacy/Youth led Public Accountability meeting
- Youth in and around foster care
- Morning clinics for HIV positive clinics for youth

Summary

- Recognize the value of a strengths based approach.
- Have a better understanding of positive youth development.
- Positive youth development strategies are evidence based and help youth transition successfully.
- A plug for following your dream.

"Don't ask yourself what the world needs. Ask yourself what makes you come alive. And go do that. Because the world needs people who have come alive." *- Howard Thurman, civil rights leader*

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Transition to Adult Services among Behaviorally Infected Adolescents with HIV—A Qualitative Study

- Jessica M. Valenzuela, PhD[1], Cindy L. Buchanan, PhD[2], Jerilynn Radcliffe, PhD, ABPP[3,4], Christine Ambrose, MSW, LSW[4], Linda A. Hawkins, MSEd[4], Mary Tanney, RN, MSN, CRNP, MPH[4] and Bret J. Rudy, MD[5]

Journal of Pediatric Psychology Advance Access published online on June 19,2009; Journal of Pediatric Psychology

Study Objectives

- Describe experiences of behaviorally infected youth transitioning to adult HIV care
- Identify the challenges they encountered
- Explore youth recommendations for improvement

Goal: Use findings to test intervention strategies

Findings:
Phases of Transition Experience

(Phase 1) Youth Care:

- **Described strong relationship to team**
  - *Referred to team as "family"; more than just doctors*
  - *Developed feeling of "trust" and "faith" in provider and team over time*
  - *Ongoing communication even after transition*
- **Viewed as time of learning and growth**
  - *How to cope with diagnosis and care for self ("do things better and think things through more clearly")*

Findings:
Phases of Transition Experience

(Phase 2) Transition Process:

- Feeling Unprepared for Transition
- Short Transition Notice Led to Anxiety/Shock
- Concerns about Privacy (will they tell my business? ID signs)
- Worries about Health Status (will I get sick now?)

Findings:
Phases of Transition Experience

(Phase 3) Adult Care:

- Having to be more independent and responsible:
  - *Dealing with insurance and co-pays*
  - *Care more fragmented*
  - *Higher provider expectations re scheduling/keeping appts, arriving on time, making decisions (can be a +)*
- Longer wait times in adult waiting rooms
- Less time with providers
- Being around older adults viewed as +/-

Findings: Recommended Strategies

- Define a transition process - include youth patients and adolescent/adult providers in planning
- Discuss transition early and multiple times
- Convene team conferences to develop individualized transition plans- collaborate with the patient
- Accompany young adult patients on visits to adult providers (shop around) while still in adolescent care

Findings: Strategies to Support Transition to Adult Care

- Maintain as much continuity of support & mental health services as possible
- Providers (Youth & Adult) should play an active role in assisting with successful transfer of records and sharing of key information.
- Prepare youth to navigate the adult health care world- understand what is expected of them

WU Part C/D Transition Process (a work in progress . . .)

How we have applied findings:

- Individualized transition plans – goal is by age 21, but based on "readiness"
- Multidisciplinary staffing as established setting to develop and review transition plan
- Continuity of youth-specific services during transition – medical case management and mental health remain the same from pediatric/youth clinic to adult clinic.

WU Part C/D Transition Process (a work in progress . . .)

How we have applied findings, cont'd:

- It never stops . . . Recognizing the need to build capacity to serve growing number of youth throughout the network.
- Planned pilot of clinic sessions for HIV-infected youth and young adults at The SPOT (integrating HIV care team w/ The SPOT team).

Need for Ongoing Monitoring

Retention Challenges

In 2009, the Part C/D Network held a Youth Strategic Planning Meeting with key Peds ID, Adult ID and The SPOT staff: physicians, nurses, medical case managers, prevention/outreach, mental health, quality/data, and administrators

Given influx of new youth, and implementation of The SPOT, it was important to take time to identify challenges, successes, and areas in need of improvement or additional coordination

Need for Ongoing Monitoring

Retention Challenges

3 of the key findings from the Strategic Planning Meeting:

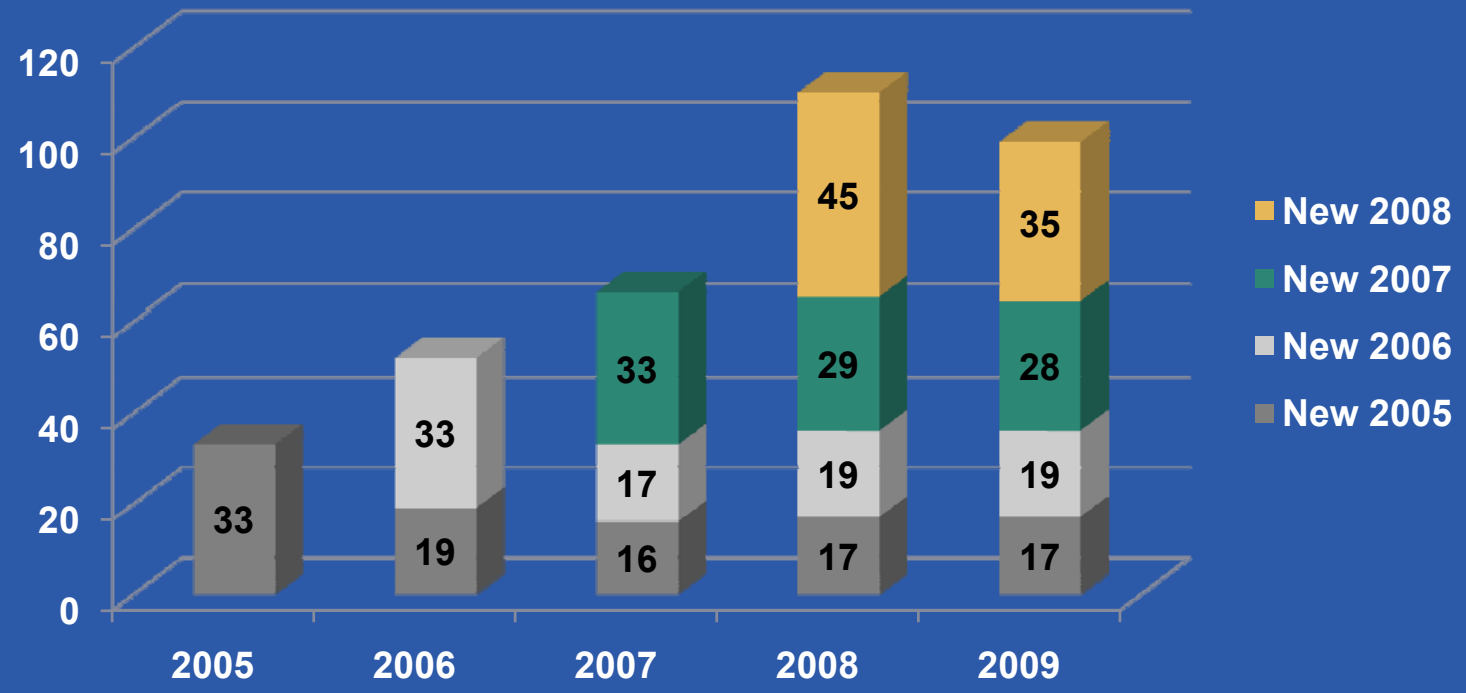
- Retaining youth from Year 1 – Year 2 in HIV medical care seemed to predict longer term retention

- Youth tend to have a lower show rate than adults, with a group of chronic no-showers driving down the show rate

- Providers need to be aware of the special needs and issues for YMSM of Color diagnosed with HIV

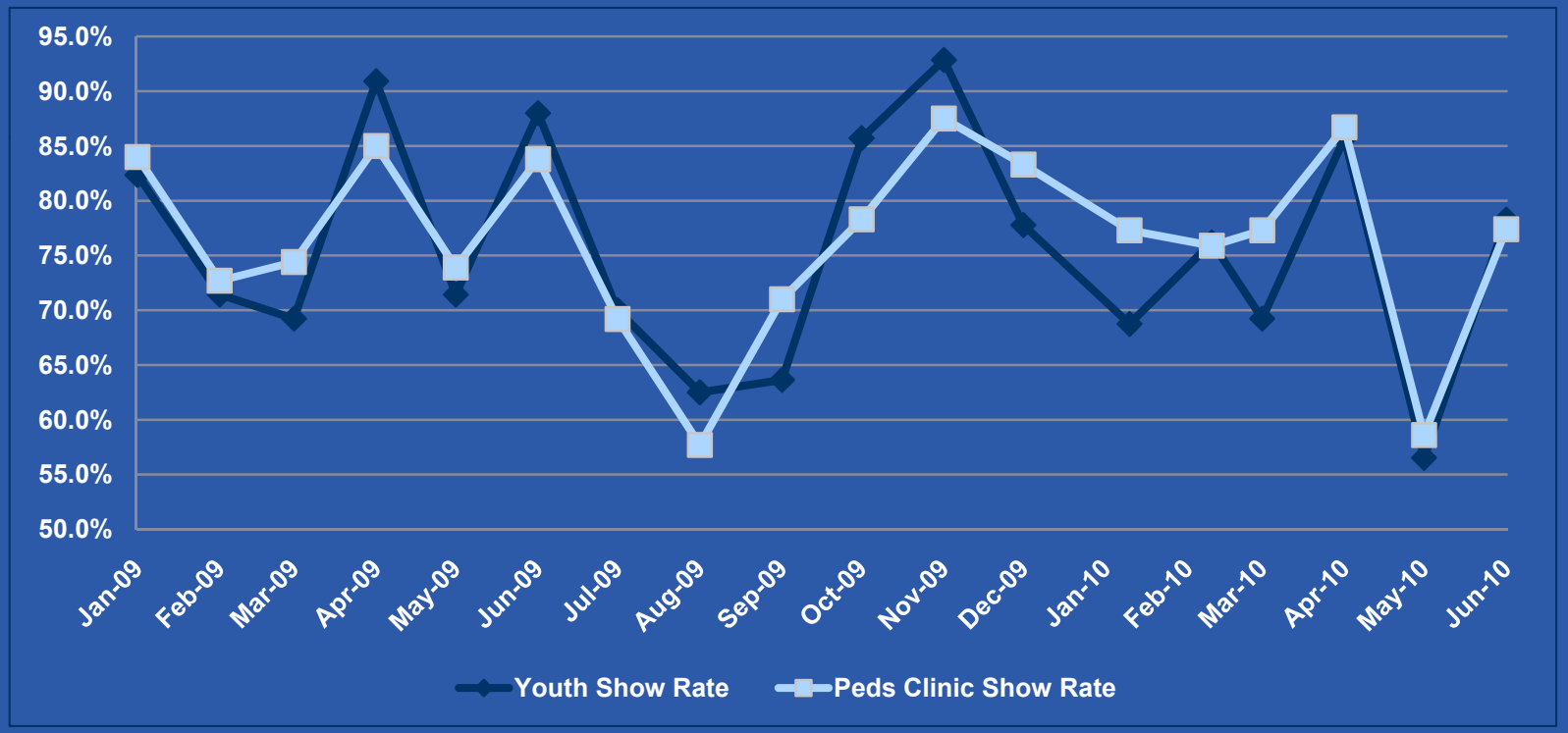
Need for Ongoing Monitoring

Retention Challenges: Year 1 to Year 2



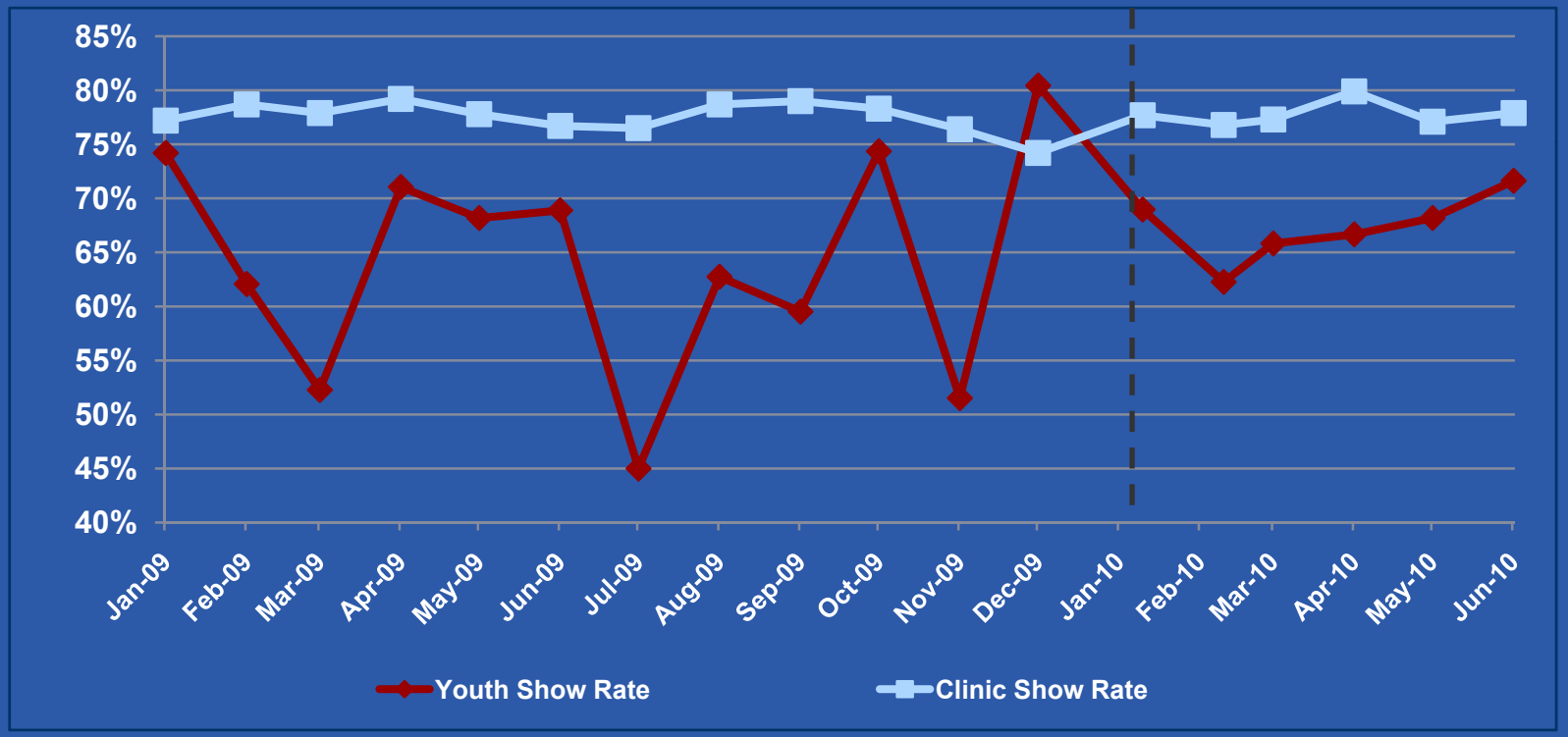
Need for Ongoing Monitoring

Retention Challenges: Youth Show Rate @ WU Pediatric ID Clinic



Need for Ongoing Monitoring

Retention Challenges: Youth Show Rate @ WU Adult ID Clinic



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Need for Ongoing Monitoring

Retention Challenges: Young MSM of Color

Given the increase both regionally and within the Part C/D Network of young MSM of color, the strategic planning meeting identified some suggestions for responding to this special group:

- ***Reinvigorate the Youth Support Group***: the youth case managers and men's mental health specialist collaborated to create a Young MSM Support Group (ages 18-29), which began April 2010.
- ***Address Cultural Competency***: the network has tapped into our own prevention/outreach staff to provide an in-service on the House/Ball Community that is a common factor among young MSM of color; to be held September 2010.
- ***Increase Staff Coordination***: the youth case managers began a monthly staffing meeting with The SPOT staff so that common clients can be discussed proactively to ensure effective engagement in HIV care.

Need for Ongoing Monitoring

Quality Management

WU Adult and Pediatric ID Clinics HIV/AIDS Clinical Quality Management Report
Youth Patients - January 2009 thru April 2010

Indicator	Definition	#	Achieved	Goal
HIV Clinical Visits	Numerator: # of patients with at least 1 HIV clinical visit < last 4 months	**122**	**75%**	**85%**
	Denominator: # of patients with at least 1 HIV clinical visit in review period	**163**		
HIV Viral Load	Numerator: # of patients with at least 1 HIV clinical visit < last 4 months who also have an HIV VL result < last 4 months	**115**	**94%**	**90%**
	Denominator: # of patients with at least 1 HIV clinical visit < last 4 months	**122**		
CD4 Count	Numerator: # of patients with at least 1 HIV clinical visit < 4 last months who also have a CD4 count < 4 last months	**118**	**97%**	**90%**
	Denominator: # of patients with at least 1 HIV clinical visit < last 4 months	**122**		

Take Home Messages

Ideas for Any Region

Don't rely on anecdotes, use data.

❖Resist the temptation to use the most challenging or recent experience to define the problem.

❖Look to epidemiological and service data to describe what is going on with the youth in your program, region.

Ask, ask, ask.

❖Organize focus groups for case managers to identify common challenges working with youth as well as what works well.

❖Conduct brief phone surveys with nurses, or send them a survey they can complete online and quickly (e.g., survey monkey).

❖Find creative ways to get input from youth directly (e.g., brief surveys at visits or during support groups), rather than expect them to come to a "focus group." Ask them which providers they connect with and why.

Take Home Messages

Ideas for Any Region

Promote a youth-specific environment.

❖ Recognize that appearances matter to youth and adult-focused environments can be intimidating.

❖Simple things like posters, bright colors, a bulletin board focused on youth resources, etc can help youth connect with your space and feel a bit more at ease.

❖Have case managers arrange to meet youth at their doctor's appointments so they don't have to sit alone in the waiting room.

❖Put condoms out in the exam rooms so youth know they are available and invite a conversation about proper use, disclosure.

Take Home Messages

Ideas for Any Region

Build youth expertise within the HIV service community.

❖Collaborate with youth-serving agencies to cross-train staff and identify opportunities to coordinate on shared clients and funding opportunities.

❖Request the regional AETC bring adolescent/youth experts to offer training to medical providers on the unique issues youth face in adult care settings (www.aidsetc.org)

❖Suggest your Planning Council and/or local HIV Prevention Planning Group develop a youth subcommittee to keep youth issues on the radar screen in community planning and needs assessment.

❖Create an email newsletter to send to providers incorporating information about local youth resources, epi trends, tips for working with youth, de-identified case studies and success stories, etc.

Take Home Messages

A Helpful Resource – www.hivcareforyouth.org

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