

# A Participatory Learning and Action (PLA) Approach to Enhancing Linkage to HIV Care Among Youth

Peggy B. Smith, MA, PhD

Ruth S. Buzi, LCSW, PhD

Baylor College of Medicine

Teen Health Clinic

Baylor  
College of  
Medicine



Texas Children's  
Hospital®

# Background

- HIV linkage to care is the initiation and receipt of HIV-related medical, psychological and social services by a newly diagnosed HIV-positive individual.
- Early linkage to care is critical for viral suppression and transmission prevention; however, adolescents are more likely to delay linkage to care than adults, and up to 60% of HIV-positive youth ages 13-24 are undiagnosed.
- Studies estimate between 66% and 75% of newly diagnosed HIV-positive individuals are linked to care.
- Only one in every four HIV-positive individuals has achieved viral suppression (low or undetectable viral load levels)

# Background

- Delayed linkage and worse retention rates are associated with younger age, higher baseline CD4 count and substance abuse.
- Issues related to HIV linkage to care among youth include individual client barriers, provider barriers, and social barriers.
- Client barriers include insufficient contact information and failure to attend appointments; provider barriers include lack of collaboration between agencies; and social barriers include HIV stigma and financial instability.

# Gaps in Knowledge

- While MSM tend to have higher rates of HIV linkage initiation and engagement in care, little information is known about linkage and retention to care of subpopulations of MSM, particularly minority, young and substance-abusing MSM.
- Other gaps in knowledge about HIV linkage in youth include lack of youth risk behavior data, especially for MSM, and few programs on how to continuously engage newly diagnosed adolescents in HIV care.

# Engagement in Care Continuum

**Not in  
HIV Care**



**Engaged in  
HIV Care**

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Unaware of  
HIV infection

Aware of HIV  
infection  
(not in care)

Receiving some  
medical care but not  
HIV care

Entered HIV  
care but lost  
to follow-up

Cyclical or  
intermittent use  
of HIV care

Fully  
engaged in  
HIV care

# Purpose

- To determine the efficacy of the Participatory Learning Action (PLA) approach as a community engagement process to identify barriers to HIV linkage to care and planning of solutions in Houston, Texas.

# Methods

## Participants:

- Community stakeholders representing various organizations were invited to engage in a Participatory Learning and Action (PLA) process to address HIV linkage to care.

## Objectives of the PLA approach:

- Identify barriers to linkage to HIV care
- Identify causes contributing to challenges
- Identify solutions for overcoming barriers to linkage to HIV care
- Generate a work plan for solutions and a timeline

# Methods

## Procedure:

Individuals participated in two meetings and completed one survey per meeting.

## Meeting I:

A brainstorming session to identify barriers and generate possible solutions.

- In groups, participants reviewed a list of barriers, assessed gaps in the list, and categorized barriers. They reported their findings to the large group .
- Participants received five dot stickers to place on their prioritized barriers. Participants discussed solutions to overcome most important barriers.

# Methods

## Meeting II:

A follow-up brainstorming session was organized to identify solutions and generate a work plan for solutions.

- In groups, participants picked five solutions for which to complete a starburst framework. They reported to the large group.
- Participants designed a work plan with two goals, objectives, a time frame, and a list of people responsible. They presented the work plan to the large group.

# Results

- Sixty-six individuals completed the first survey on barriers and 22 completed the second survey on solutions. Additionally, over 50 individuals representing various community organizations participated in the brainstorming sessions.

# Barriers to HIV Linkage to Care

## Categories Identified:

- **Health Care System:** complexity, eligibility, lack of patient friendliness, lack of staff training in providing confidential and comprehensive care
- **Lack of Collaboration** between organizations (database sharing)
- **Social Factors:** stigma, self-disclosure, lack of knowledge and awareness about HIV
- **Risk Populations:** inability to pay, health illiteracy, attitudes (YOLO), homelessness, substance use, lack of resources, lack of HIV risk perception, mental health issues

# Barriers to HIV Linkage to Care

## Disclosing Status

- Do not want to disclose HIV status
- Do not know how to disclose status to friends and family

## Stigma

- HIV/AIDS stigma; fear of stigma; HIV positive status stigma

## Personal Barriers

- Feel “invincible”/denial
- Wait until physically sick to do something
- Financial instability; homelessness; lack of transportation
- Insurance issues
- Reluctance to take medicine
- Not ready to begin treatment/accept status

## Knowledge

- Lack of knowledge about HIV/resources
- Believing HIV only affects certain populations

## Risky Behaviors

- Lack of condom use
- Substance use/abuse/addiction
- Myths about protection and looking “clean”

## Support

- Lack of strong support systems
- Lack of positive peer groups
- Belief that no one cares

## Clinic barriers

- Lack of age appropriate services
- Complex eligibility requirements
- Hours conflict with school

# Possible Solutions

- Reevaluate eligibility process and how to make it easier
- Simplify linkage process and walk clients through the process of receiving care
- Expansion and continuation of networking and establishing points of contact at different agencies
- Create a common website to describe services and list contacts
- Policy changes, retention activities, changes in RFP process, minimum standard of training and competencies (disclosure), case consultation between agencies

An evaluation of the PLA process suggests that community stakeholders value this approach as an effective way to network and collaborate to improve HIV linkage to care.

# Conclusions

- Barriers identified by community partners were related to the health care system, lack of collaboration, social factors such as stigma, and characteristics of risk populations. Suggestions for solutions will be further processed in an effort to improve linkage to care.
- Individual-, community- and societal-level factors affect linkage to care.
- HIV linkage to care is a major public health concern. Engaging community stakeholders through a PLA approach can be an effective way to learn about a community problem and how to improve engagement of HIV-positive persons in care.

# Next Steps

- Continue to meet and work in groups to identify barriers and solutions to improve HIV linkage to care among youth.
- Continue communicating and sharing information.
- Create a comprehensive plan with different accountable community organizations.
- Train site personnel to provide youth-friendly HIV testing and linkage services.

# Next Steps

- Engage outreach workers earlier in the HIV linkage to care process.
- Continue flexible yet persistent contact (i.e. texting) with adolescents regardless if they are ready to begin treatment. Provide non-HIV-related services in the meantime.
- Cultivate relationships between HIV testing and clinical care sites to enhance client information exchange and client sensitivity.

# Contact

- Dr. Peggy Smith: [peggys@bcm.edu](mailto:peggys@bcm.edu)
- Dr. Ruth Buzi: [rbuzi@bcm.edu](mailto:rbuzi@bcm.edu)

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