HRSA HAB Building Futures: Supporting Youth Living with HIV – Lessons Learned and Successes in Practice December 12, 2018

CDR Holly Berilla Public Health Analyst HIV/AIDS Bureau (HAB) Health Resources and Services Administration (HRSA)





Health Resources and Services Administration (HRSA) Overview

- Supports more than 90 programs that provide health care to people who are geographically isolated, economically or medically vulnerable through grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities
- Every year, HRSA programs serve tens of millions of people, including people living with HIV/AIDS, pregnant women, mothers and their families, and those otherwise unable to access quality health care





HRSA HIV/AIDS Bureau (HRSA HAB)

Vision

Optimal HIV/AIDS care and treatment for all.

Mission

Provide leadership and resources to assure access to and retention in high quality, integrated care, and treatment services for vulnerable people living with HIV/AIDS and their families.





Ryan White HIV/AIDS Program (RWHAP)

- Provides comprehensive system of HIV primary medical care, medications, and essential support services for low-income people living with HIV
 - More than half of people living with diagnosed HIV in the United States more than 550,000 people receive care through the Ryan White HIV/AIDS Program (RWHAP)
- Funds grants to states, cities/counties, and local community based organizations
 - Recipients determine service delivery and funding priorities based on local needs and planning process
- Payer of last resort statutory provision: RWHAP funds may not be used for services if another state or federal payer is available
- 84.9% of clients served by the RWHAP were virally suppressed in 2016, exceeding the national average of 60%

Source: HRSA. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016; CDC. HIV Surveillance Supplemental Report 2016;21(No. 4)





HRSA HAB Building Futures: Supporting Youth Living with HIV Objectives

After this presentation, participants will be able to:

- Identify purpose and scope of project;
- Describe three characteristics of youth-serving HRSA HAB RWHAP providers that have high viral suppression and retention in care rates;
- Identify three promising practices that youth-serving RWHAP providers may institute to improve health outcomes in youth served; and
- Discuss technical assistance (TA) resources available for RWHAP youthserving programs.





HRSA HAB Building Futures: Supporting Youth Living with HIV

HRSA HAB Building Futures: Supporting Youth Living with HIV

Primary Organization, Partners, and HRSA HAB Team

Primary Organization Funded for Project:

- DS Federal, Inc.
 - Consultants from CAI, Mission Analytics, and Positive Outcomes, Inc., & Deborah J. Isenberg
 - Independent youth consultants: D'Ontace D'Angelo Keyes, Jontraye Davis, Kahlib Barton, DaShawn Usher, & Antoine Crosby
 - Subject Matter Experts: Jeffrey Birnbaum & Adam Thompson

HRSA HAB Team Members:

 Antigone Dempsey; CAPT Tracy Matthews; CDR Holly Berilla, COR; R. Chris Redwood, SME; & Jhetari Carney, SME





HRSA HAB Building Futures: Supporting Youth Living with HIV Today's Presenters

- CDR Holly Berilla, HRSA HAB
- Elizabeth Coombs, Mission Analytics
- AJ Jones, Mission Analytics
- HRSA HAB RWHAP-funded providers:

 Heath A. Nicholas, LMSW, Director of Case Management Services, AIDS Action Coalition dba Thrive Alabama

o Jennifer McMillen Smith, LISW-S, MetroHealth





HRSA HAB Building Futures: Supporting Youth Living with HIV Understanding the Need

- 551,567 clients receive services from RWHAP-funded providers in 2016:
 - Approximately 4% of RWHAP clients living with HIV are youth (aged 13-24 years)

 Retention in care (76.6%) was lower than the national RWHAP average (81.7%)
 Viral suppression (71.1%) was much lower than the average (84.9%)

Source: Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. <u>http://hab.hrsa.gov/data/data-reports</u>. Published November 2017.





HRSA HAB Building Futures: Supporting Youth Living with HIV Project Purpose

The overarching goal of the project was to:

- Assess the current state of youth living with HIV (YLWH) aged 13-24 receiving RWHAP funded care and
- Develop and provide TA for youth-serving RWHAP providers to overcome barriers to care, fill gaps in care, and optimize health outcomes for this special population.





HRSA HAB Building Futures: Supporting Youth Living with HIV Project Timeline

Project period: three years

- September 2015 September 2016 (Base Year)
 O HRSA HAB RSR data review and initial evaluation report
- September 2016 September 2017 (Option Year 1)

Conducted 20 site visits to HRSA HAB RWHAP-funded provider sites
 Preliminary report of findings

- September 2017 September 2018 (Option Year 2)
 - Developed, tested, and published the TA toolkit and delivered four TA webinars to youth-serving RWHAP-funded providers
 - Final report of findings





NATIONAL **S**RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT



HRSA HAB Building Futures: Supporting Youth Living with HIV Applying Lessons to the Field

Elizabeth Coombs, *Project Consultant, Mission Analytics*

Jennifer McMillen Smith, LISW-S, MetroHealth

Heath A. Nicholas, LMSW, Director of Case Management Services, AIDS Action Coalition dba Thrive Alabama

Toolkit Themes and Topics

Clinical Service Models	 Youth-centered services Interdisciplinary care teams
Infrastructure Development	 Staff recruitment and retention Improving communication with youth LGBTQ-friendly policies, environment, and culture
Informing Program Development	 Gathering structured feedback from youth Data-driven programming for youth
Wraparound Services	 Youth support groups Identifying and addressing support service needs Re-engaging youth lost to care



Something for Everyone

- Each topic represents a range of strategies and considerations
- Some topics have a clinical focus, while others are more relevant to case managers or program leadership
- The Toolkit presents concrete examples of implementation



Learn More

TargetHIV: https://targethiv.org/library/hrsahab-building-futures-supportingyouth-living-hiv

- Toolkit
- Webinar slides and recording

Tools for HRSA's Ryan White HIV/AIDS Program

 TargetHIV

 NEWS
 CALENDAR
 LIBRARY

Home » Library » HRSA HAB Building Futures: Supporting Youth Living with HIV

HRSA HAB Building Futures: Supporting Youth Living with HIV

September 10, 2018 HRSA HIV/AIDS Bureau (HAB)

The Building Futures: Supporting Youth Living with HIV project identified best practices for enhancing services to youth living with HIV (YLWH), ages 13-24, that contribute to better outcomes in retention and viral suppression.

DSFederal Inc, joined by project partners Cicatelli Associates (CAI), Mission Analytics and Positive Outcomes conducted site visits with 20 youth serving RWHAP-funded providers. Site visit activities included focus groups and 1:1 interviews with YLWH as well as interviews with site staff.

Project activities resulted in the development of a four-part webinar series and toolkit to help Ryan White HIV/AIDS Program (RWHAP) agencies improve outcomes among YLWH.

Toolkit





Lessons from the Field

• MetroHealth

- Youth-centered services and youth support groups
- Improving communication with youth

• Thrive Alabama

- Re-engaging youth lost to care
- Gathering structured feedback from youth



The MetroHealth System

- Located in Cleveland, OH
- County "safety-net" hospital
- Infectious disease clinic provides HIV care for about 1,600 people living with HIV
- About 140 patients are 13-24 years old
- Prior to Building Futures, already offered:
 - Patient-centered Medical Home-style HIV care
 - Day-time support group for <30
 - Facebook Secret Group
 - Positive Peers mobile app





Evening clinic + support group

 Toolkit topic of *Youth-Centered Services* as inspiration to offer enhanced services for youth and young adults living with HIV



- Taco Tuesday support group runs from 5:00 7:00 p.m., the same time as the youth-exclusive evening clinic hours Features:
 - Flexibility for patients to come in and out of the group to see doctor
 - Co-facilitation
 - Ability to accommodate small children
 - Low-key vibe



Other Toolkit take-aways

- From Improving Communication with Youth topic: Began work on a strategy for collecting non-traditional contact information, such as Instagram name, as alternative way to outreach patients.
- Toolkit served as an "official" reason to approach hospital's Arts in Medicine office to request artwork reflective of clinic population, using the *LGBTQ-Friendly Policies, Environment, and Culture topic.*
- From *Re-engaging Youth Lost to Care topic:*
 - Shortened window for outreach of <25 from 6 months to 4 months
 - Began weekly calls of <25 no shows



AIDS Action Coalition dba Thrive Alabama

Survey Purpose

- Find out why the younger clients want to remain in care and what services would help to keep them in care.
- Results from the survey provided some useful information for the second topic.



We have signs in every exam room to ensure that all clients are aware of the majority of the services provided at Thrive.



Step One

- Gathered structured feedback by completing a survey with our actively engaged youth at Thrive.
- Used the results of the survey and brainstormed additional ideas about youth engagement.



Step Two

- Develop a youth-friendly intake packet.
- Create a psychosocial assessment that is youth-focused.
- Designate a social worker strictly for our youth.



0. 00

STAY HEALTHY +LIVE WELL

thrivealabama.org





Youth Social Worker

- Completes all intakes on youth.
- Follows up on any missed appointments.
- Checks in monthly.
- Meets briefly after each appointment.



Small Group Activity

- Select a topic you are most interested in exploring:
 - LGBTQ-friendly policies, environment, and culture
 - Improving communication with youth
 - Youth support groups
 - Re-engaging youth lost to care
 - Your choice: group vote on another topic
- Work with other attendees also interested in that topic to develop an Action Plan.
- Take your Action Plan home to implement within your agency.



LGBTQ-Friendly Policies, Environment, and Culture

- Youth who are LGBTQ face psychosocial and structural challenges including:
 - Mental health issues
 - Trauma
 - Homelessness
 - Substance use
 - Stigma and discrimination
- Challenges make coping and living with HIV diagnosis more complex



How Do You Know If Your Agency is LGBTQ-Friendly?

- Organizational Culture
- Culturally Competent Care and Treatment Services
 - Environment
 - Disclosure and Inclusivity
 - Training
 - Data Management Systems
 - LGBTQ-Focused Activities and Services



Improving Communication with Youth

- Phone calls do not work well for youth.
- Difficulty navigating Health Insurance Portability and Accountability Act (HIPAA) regulations for using text messaging or social media.
- Not sure how social media can help.
- Lack of relevant best practices to properly manage a social media account.



Communication Strategies

Text messaging

- HIPAA-compliant text messaging using a regular cellphone
- Secure text messaging
- Using social media platforms
 - Social media messaging
 - Pushing content on social media
 - Social media groups



Youth Support Group Goals

- Help YLWH achieve viral suppression and stay in care
- Build social networks
- Increase the knowledge and skills of participants
- Decrease social isolation



Steps to Establish a Youth Support Group

- Refine logistics
 - Select a location
 - Identify a time
 - Determine number of meetings or end date
 - Decide what, if any, additional services will be provided
- Establish a recruitment and sustainability plan
- Identify the right facilitator



Reengaging Youth Lost to Care

- YLWH often lead more transient lifestyles than older clients
- Challenging to determine when YLWH are out of care versus at another provider, moved, incarcerated, etc.
- What works for identifying and re-engaging adult clients might not work for youth



Steps to Reengagement

- Identifying out-of-care clients
 - Cross-check YLWH identified in measures with other sources.
 - Consider establishing a relationship with Data to Care or other local programs (e.g., local health departments).
- Intensive outreach and linkage
 - Who is responsible (e.g., peers)?
 - Meet youth where they are / understand what happened.
- Retention in care
 - Strategy for first appointment.
 - Enhanced support services.
 - Celebrate victors, no matter how small!



Another Topic of Interest?

- Youth-centered services
- Interdisciplinary care teams
- Staff recruitment and retention
- Gathering structured feedback from youth
- Data-driven programming for youth
- Identifying and addressing support service needs



Small Group Activity – Break-out

- Find your group
- Develop the Action Plan
- Take it home for implementation!



Questions and Answers





- **CDR Holly Berilla**
- **Public Health Analyst**
- HIV/AIDS Bureau (HAB)
- Health Resources and Services Administration (HRSA)
- Email: HBerilla@hrsa.gov
- Phone: 301-443-6695
- Web: <u>hab.hrsa.gov</u>







To learn more about our agency, visit www.HRSA.gov





