HEALTH RESOURCES AND SERVICES ADMINISTRATION
HIV/AIDS BUREAU

BUILDING FUTURES: SUPPORTING YOUTH LIVING WITH HIV

TECHNICAL ASSISTANCE TOOLKIT

ACKNOWLEDGEMENT SECTION

The Health Services and Resources Administration (HRSA), HIV/AIDS Bureau (HAB) gratefully acknowledges the participation of the following Ryan White HIV/AIDS Program (RWHAP) providers who volunteered their time to participate in the HRSA HAB Building Futures: Supporting Youth Living with HIV project and to share lessons learned in support of youth clients, which led to the development of the HRSA HAB Building Futures: Supporting Youth Living with HIV toolkit:

- Access Community Health Network (Illinois)
- AIDS Action Coalition- dba Thrive Alabama (Alabama)
- Albany Area Primary Healthcare, Inc./Ryan White Program at Rural Model Clinic (Georgia)
- Apicha Community Health Center (New York)
- Avenue 360/Houston Area Community Services (Texas)
- CARES/Center for AIDS Research (California)
- Caresteam Plus Family Health and Specialty Care (South Carolina)
- Dignity Health St. Mary Medical Center (California)
- Dorothy Mann Center at St. Christopher's Hospital for Children (Pennsylvania)
- Harborview Medical Center (Washington)
- Prince George's County Health Department/Family Health Services Division (Maryland)
- Priority Health Care, Inc. (Louisiana)
- Southern Nevada Health District (Nevada)
- St. Michael's Medical Center/The Peter Ho Memorial Clinic (New Jersey)
- The MetroHealth System (Ohio)
- University of South Florida – Ybor Youth Clinic (Florida)
- University Medical Center/New Orleans HIV Outpatient Program (Louisiana)
- University of New Mexico (New Mexico)
- Wayne State University (Indiana)
- Eskenazi Health Services (Indiana)

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BACKGROUND

Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) funded the HRSA HAB Building Futures: Supporting Youth Living with HIV project to identify best practices for enhancing services to youth living with HIV (YLWH), contributing to better outcomes in both retention and viral suppression. Site visits were conducted with 20 HRSA HAB Ryan White HIV/AIDS Program (RWHAP)-funded providers and included interviews with clinical, support service, and administrative staff. Focus groups and 1:1 interviews were also conducted with YLWH at each site. Throughout the toolkit there are references to specific interviews, advice, and lessons reported by these providers that may benefit other youth-serving HRSA HAB RWHAP-funded programs.

GOALS OF THE TOOLKIT

The result of the project activities was the development of this toolkit, integrating the feedback and lessons learned from the 20 sites that were visited. This toolkit contains 10 topic areas, ranging from YLWH support groups to data-driven programming. Each section includes strategies to address the specific topic, and resources are provided to support the implementation. Providers can use some or all information in the toolkit to enhance their programs in an effort to better meet the needs of YLWH.

TARGET AUDIENCE

The toolkit is designed to support management, clinical, support, and administrative staff at HRSA HAB RWHAP-funded providers. That said, a given topic area may be more relevant to certain types of staff than others. For example, clinical staff may be more involved in adopting strategies described in the interdisciplinary team topic area, while case managers may be more interested in the youth support group topic area. Alternatively, a provider may have one specific staff person responsible for all areas of youth programming. Regardless of provider staffing structure, this toolkit has something for everyone. Providers are encouraged to review the content and share with appropriate staff.

STRUCTURE OF THE TOOLKIT

The 10 topic areas in the toolkit are arranged under four themes – Clinical Service Models, Infrastructure Development, Informing Program Development, and Wraparound Services. The topics within these themes are hyperlinked so users can move easily from one topic area to the next. While topic areas predominantly summarize information gathered through the HRSA HAB Building Futures project, they also contain links to other relevant resources such as the TargetHIV, formerly known as the TARGET Center

ACTION STEPS FOR IMPLEMENTATION

1. Review the toolkit and identify the area for change:
Identify a few staff in key programmatic areas to review the toolkit to identify possible area(s) in which you would like to implement new activities. Schedule time to discuss options, outlining the feasibility of implementing the activities and identifying potential barriers.

2. Engage leadership and other stakeholders:
Schedule a time to meet with leadership to discuss what you have identified and present your plan. Identify ways to engage other stakeholders at your agency, including staff and clients.

3. Develop an action plan:
Identify the tasks needed to implement the strategy. Be sure to think about what is needed to implement the change. Consider the staff that need to be involved and their specific roles, resource needs such as handouts and space, key deadlines, and any other needs.

4. Monitoring and Evaluation:
Identify what you expect to happen as a result of the new activities and determine how you can monitor your progress. What would you expect to see if your new activities were successful or if they were not working as expected? Conduct regular check-ins with staff to discuss how things are going. Review data and discuss findings with your implementation team. Make modifications in implementation as needed to address challenges that arise.

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THEME 1
CLINICAL SERVICE MODELS

HRSA HAB BUILDING FUTURES:

SUPPORTING YOUTH LIVING WITH HIV TECHNICAL ASSISTANCE TOOLKIT

TOPIC 1.1 YOUTH-CENTERED SERVICES

Some Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) Ryan White HIV/AIDS Program (RWHAP) providers offer youth-centered services, that is, with hours, clinic space, and programming dedicated to youth clients. These programs include a range of provider care models and serve different sizes of the youth population. Youth-serving providers offer various experience-based options that fit a variety of operational contexts and needs. The focus of this topic is on three main strategies: 1) Youth clinics, 2) Youth-friendly hours, physical space, and staffing, and 3) Referrals to more youth-friendly providers.

Youth clinics: *Providers with large youth populations and resources to expand programming.*

Youth-friendly hours, staff, and physical space: *Providers with smaller youth populations and varying availability of resources to expand programming.*

Referrals to more youth-friendly providers: *Providers with small youth populations and no resources to expand programming.*

Need more information? Guidance on other areas of youth living with HIV (YLWH) programming, such as YLWH-focused support groups or use of social media, can be found in additional topics within this toolkit.

STRATEGY 1: YOUTH CLINICS

Providers may consider dedicating certain days and hours of the week to treating only YLWH. A youth clinic can allow providers to devote more time to their YLWH clients, concentrate YLWH programming into a single time and location, and demonstrate their commitment to caring for and supporting YLWH.

The **time dedicated to the youth clinic** will depend on the share of providers' total population that are aged 13-24. For example, a provider whose population is 10 percent YLWH may dedicate one afternoon or morning a week to its youth clinic, while a provider with a 20 percent YLWH population may set aside a full day.

The staffing model also will depend on the provider's unique context and care models. For example, providers may choose to staff the youth clinic with the same personnel (e.g., clinicians, case managers, social workers, and front desk staff) as they do during the rest of the week. In this case, providers can take steps to ensure that staff members have the appropriate training and social skills to effectively treat youth clients. Alternatively, providers may want to identify dedicated staff who have demonstrated interest in and success in working with YLWH. (See topic on Staff Recruitment and Retention.) Finally, some providers engage outside staff who specialize in working with YLWH. For example, one HRSA HAB RWHAP provider interviewed a clinician who is well-loved by YLWH clients. This clinician, who has a special interest in and talent for working with this population, travels to various providers throughout the city to treat YLWH clients.

There are advantages to staffing the youth clinic with the provider's regular staff. With this approach, YLWH can maintain the same clinicians, social workers, and case workers after they age out of the youth clinic, improving continuity of care.

ADVANTAGES OF A DEDICATED YOUTH CLINIC

- *Allows staff more time to "huddle" to discuss client needs.* Each youth clinic can begin with a staff huddle to discuss the health indicators, strengths, and barriers to care for that day's scheduled youth clients. The youth clinic's lighter case load may give staff more time to share ideas on how to address client needs and develop care plans.

- *Engages staff across disciplines in care planning and client visits.* Youth clinic huddles also can help providers engage interdisciplinary staff in client care. For example, pharmacists, psychologists, and support staff may participate in the huddle and meet with youth clients on an as-needed basis. (See Interdisciplinary Care Teams.)

- *Allows staff more time to spend with clients.* Perhaps more importantly, the youth clinic's lighter case load may allow staff to spend more individual time with youth clients, which is essential for building trust and troubleshooting adherence issues.

- *Reduces YLWH exposure to other clinic populations.* To stay engaged in care, YLWH must feel comfortable at the provider site. While staff can play a significant role in creating a welcoming environment, the provider's overall client population also can have an impact on whether YLWH "feel at home." YLWH simply may not relate to the clinic's adult population, especially if adult clients are struggling with homelessness, mental health issues, and substance use. Worse, YLWH may disengage in care if adults act inappropriately toward them. YLWH disengagement, for those aged 13-24, also is a risk at pediatric clinics if most programming is focused on younger children. A youth clinic may help YLWH feel more connected to their providers and more likely to attend appointments regularly.

- *Allows the clinic to build outreach materials that target YLWH.* Finally, a youth clinic creates a marketing opportunity for the provider. The youth clinic can have a catchy name, logo, and motto that speak to YLWH and their needs. If they see a consistent theme in outreach materials, YLWH (aged 13-24) may be more likely to feel that they "belong to something" and to follow through with care.

CONSIDERATIONS

- *Time dedicated to YLWH may mean less time for other populations.* A lighter youth clinic case load may mean that providers will need to make up the time elsewhere, most likely by increasing the case load during clinic hours reserved for adult populations.

- *Dedicated hours and staff may give YLWH less flexibility in care.* Youth clients can struggle to make appointments due to competing demands. With changing or inflexible school and work schedules, some YLWH may not be able to attend a set clinic day. It is recommended that providers poll their YLWH clients to see what days and times work best for them. Additionally, YLWH appreciate the flexibility to drop in for care at their convenience. Therefore, providers may decide to allow YLWH to schedule appointments during other times of the week. Ideally, the unique care and programming that YLWH receive at the youth clinic can encourage them to stick to regular youth clinic hours, but if not, providers can adjust their approaches.

- *Youth clinics may provide less anonymity.* Some YLWH may prefer not to disclose their HIV status to peers. Others may interact socially with other YLWH outside of the provider space. Regular adolescent conflicts within these existing relationships, or fear of disclosure, could make YLWH anxious about running into friends or acquaintances during appointments. Providers that participated in the Building Futures: Supporting Youth Living with HIV project reported that youth clinic appointments must be scheduled carefully, so that youth clients who do not get along attend the clinic at different times. Another option for improving anonymity is to offer a youth clinic for all youth, regardless of HIV status, and ensure that clinicians can treat HIV.

- *Scheduling restrictions may require extra training and appointment system modifications*. One provider interviewed indicated that they had to monitor their evening youth clinic's schedule to ensure that no one outside of the target population was given an appointment during that time. This is a lesson for other providers – scheduling staff need to be trained and scheduling templates may need to be modified to ensure that the proper restrictions are implemented.

YOUTH CLINIC: PROFILE FROM THE FIELD

A university-based provider interviewed as part of the Building Futures project offers HIV and primary care to people living with HIV (PLWH) and transgender individuals. With a total population of 1,000 clients, the clinic provides care to approximately 60 clients aged 13-24. Despite this relatively small YLWH population, the clinic dedicates one afternoon a week to YLWH because of the challenges they face staying engaged in care and reaching viral suppression. The day and time for youth clinic were selected based on the day that local high school students have early release. Although the majority of the clinic's YLWH clients receive care during the allocated time, YLWH also can schedule appointments or drop in during regular clinic hours. The youth clinic is staffed by the provider's usual clinicians, case managers, social workers, and support staff, and the youth clinic case load is lighter, so staff members can spend more time with clients and huddling with fellow staff members to discuss client needs. YLWH clients interviewed at this provider site overwhelmingly reported that the clinic "felt like home" and that they appreciated the staff's commitment to their needs.

Another large health system interviewed recently launched a youth clinic one evening a week to target PLWH aged 16-30. Once the youth established a name for the clinic, it was marketed through email listservs, social media, and outreach conducted by the case manager. The clinic takes place on the same night as a youth support group, so YLWH can receive their medical care and psychosocial supports together. A co-facilitator helps escort YLWH in and out of the youth group session to attend their medical appointments. The provider is careful not to overschedule the youth clinic, to permit walk-ins and allow clinicians more time with their patients.

STRATEGY 2: YOUTH-FRIENDLY HOURS, STAFF, AND PHYSICAL SPACE

If providers do not have sufficient resources or a large-enough YLWH population to create a youth clinic, they can implement other strategies to appeal to YLWH. Additionally, even providers that do offer a youth clinic may want to consider ways to make their locations more accessible to youth.

OFFERING FLEXIBLE SCHEDULING

All providers interviewed reported struggling with high no-show rates among youth clients, who often miss appointments. Providers try to reduce the number of missed appointments with multiple reminders, convenient clinic hours, straightforward appointment scheduling, and short wait times. In addition, providers suggested allowing walk-ins for certain YLWH that tend to struggle with keeping appointments. One provider reported that YLWH struggle to start their daily activities early and therefore appreciate evening clinic hours. However, evening or weekend hours are not feasible for all providers. Community-based providers appear to have more flexibility in operating hours than university or hospital-based systems. See the next section for strategies to partner with organizations that may be more accommodating in serving youth.

YLWH-FRIENDLY PHYSICAL SPACE

YLWH may be more likely to engage in care if providers offer a comfortable physical space. The most resource-intensive approach to creating a YLWH-friendly space is to establish a separate entrance and waiting room for youth clients. This approach may especially benefit youth clients when providers also have difficult-to-manage older populations and need to keep them apart. Providers that lack the space for a separate waiting room can facilitate a calm and YLWH-friendly environment by employing peers (or even security guards) who monitor waiting room activities, offer a friendly face, and provide information. Front desk staff also can ensure that youth clients feel safe and comfortable with a welcoming attitude and can intervene when clients appear anxious or tense.

Providers also recommend offering a warm and inviting environment by including YLWH in the decorating process. Providers interviewed suggested using YLWH artwork, allowing YLWH to make creative decisions, or working with local artists who might be able to donate their more youth-focused pieces. Using YLWH artwork not only creates a more relatable environment but serves “as a point of pride” for the young artists. One HRSA HAB RWHAP-funded provider used a slideshow in the waiting room to entertain clients and provide useful information about the clinic’s services.

STAFF DEDICATED TO YLWH

Providers may choose to assign certain clinicians, social workers, and case managers to serve YLWH. Many providers interviewed gradually adopted this approach. In most cases, a particular clinician or social worker took on an increasing number of YLWH clients, until they eventually served most of the YLWH at the clinic.

This strategy has multiple benefits. For one, these staff members may have the best rapport with YLWH and can benefit most from formal YLWH-specific training (see Staff Recruitment and Retention). In addition, staff members who target YLWH can better communicate about care and coordinate follow-up efforts. Finally, YLWH may develop a stronger connection to the provider – an important component in retention in care.

Providers also suggest caution if programs adopt this approach to ensure that YLWH are not overly attached to certain staff members. In this scenario, YLWH may experience negative outcomes if there is staff turnover or when they transition into adult care. Providers should ensure that the clinic as a whole is welcoming to YLWH, in addition to providing intensive support from dedicated staff. (See Staff Recruitment and Retention topic.)

WHAT'S THE RIGHT STRATEGY FOR PROVIDERS?

Not sure? Ask your clients! Providers suggest beginning by gaining an understanding of the size, needs, and wants of their YLWH population. Two topics in the toolkit (see Data-driven Programming and Gathering Structured Feedback from Youth topics) can help providers gather additional data and make informed choices. Providers also may benefit from using the Empathy Map as a tool to work with youth.

STRATEGY 3: REFERRALS TO MORE YLWH-FRIENDLY PROVIDERS

If providers simply do not have enough YLWH clients or lack the capacity to invest in the strategies described above, they may decide to refer YLWH clients to a nearby YLWH-friendly provider. This strategy may not be feasible for providers that are the only HRSA HAB RWHAP-funded organizations in their surrounding areas. However, providers interviewed revealed that many urban areas have multiple HRSA HAB RWHAP-funded providers with different types of care; some are YLWH-focused.

WHEN ADOPTING THIS STRATEGY, PROVIDERS SHOULD CONSIDER THE FOLLOWING:

1. SELECT THE REFERRAL PARTNER:

Providers should first determine whether there are other services in their area that have more capacity and expertise to treat YLWH. For example, a provider may receive HRSA HAB RWHAP Part D funding, which targets women, infants, and children; as well as YLWH. This provider may have greater resources for youth-specific programming.

2. ESTABLISH A FORMAL MEMORANDUM OF UNDERSTANDING (MOU):

Many HRSA HAB RWHAP-funded providers already coordinate efforts or communicate on a regular basis, especially if they receive funding from the same source (e.g., HRSA HAB RWHAP Part A or Part B recipients). Providers can leverage these relationships to set up initial conversations, and then move forward with a formal Memorandum of Understanding (MOU). An agreement should describe the referral process and define the referring provider's participation in ongoing care (if any).

3. ESTABLISH MEASURES TO ENSURE THAT YLWH ARE FULLY ENGAGED WITH NEW PROVIDERS:

YLWH often struggle to follow up when they are referred to care at new locations. Providers may wish to maintain contact with clients for a certain period of time to ensure that they are engaged in care at the referral provider.

STRATEGY 3: REFERRALS TO MORE YLWH-FRIENDLY PROVIDERS (CONTINUED)

4. INVOLVE YLWH IN DECISIONS REGARDING THE STRATEGY:

Providers recommend giving new or existing YLWH clients the option to remain at the current site or receive care at the referral provider site. During this conversation, the referring provider should clearly articulate the challenges that YLWH face in engaging in care and achieving viral suppression, and explain the supports that the other clinic can offer to address those challenges.

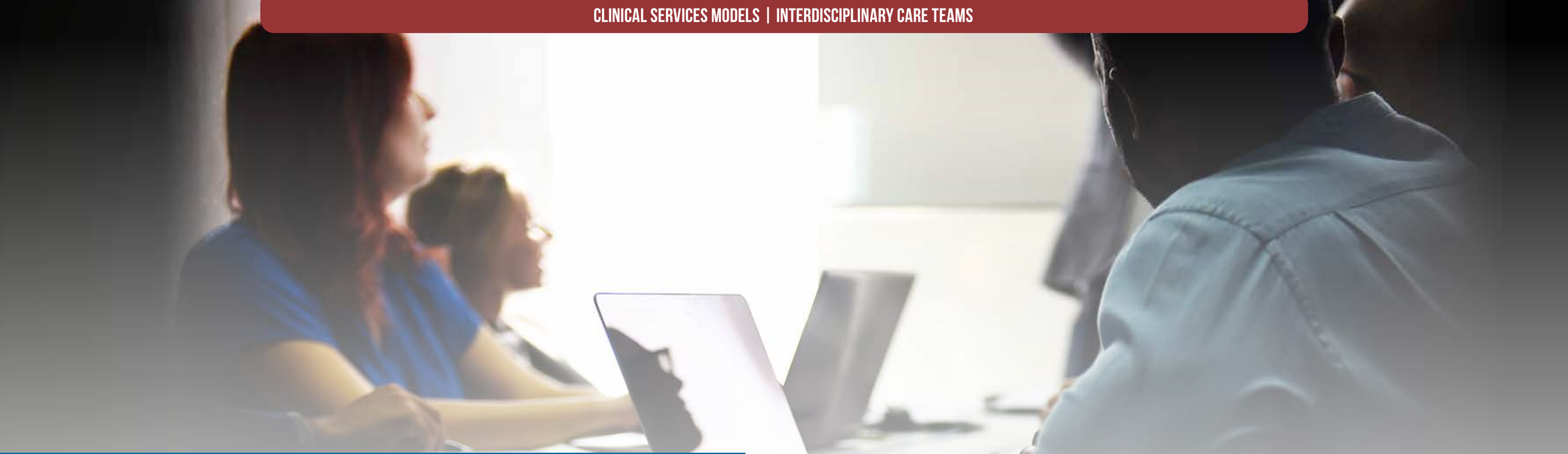
5. DEVELOP A "REINTEGRATION" STRATEGY:

Providers may need to develop strategies to reintegrate YLWH back into their clinics as they age into adulthood, especially if they were referred to a provider that solely focuses on YLWH. This may include "warm handoffs," a period during which case managers accompany YLWH to their appointments at the adult clinic, as well as follow up to ensure a smooth transition.

REFERRALS: PROFILES FROM THE FIELD

- *Support for transgender YLWH:* An urban clinic recognized that transgender youth require special services and supports that another nearby provider was better equipped to provide. The providers established a formal partnership and now transgender YLWH receive care at the second provider location, where they can access hormone therapy and engage with staff who are trained to work with transgender YLWH.

- *University-based system with children's, YLWH, and adult clinics:* A large urban university-based system operates three separate clinics, which target different age populations. The providers work closely together to ensure that clients are referred appropriately. When it's time for a client to move from one clinic to another, the provider uses a "three appointment policy," in which a case manager accompanies the client to the new clinic for three appointments. A nurse practitioner also practices at both the YLWH and adult clinics, so youth clients see a familiar face when they transition out of youth care.



TOPIC 1.2 INTERDISCIPLINARY CARE TEAMS

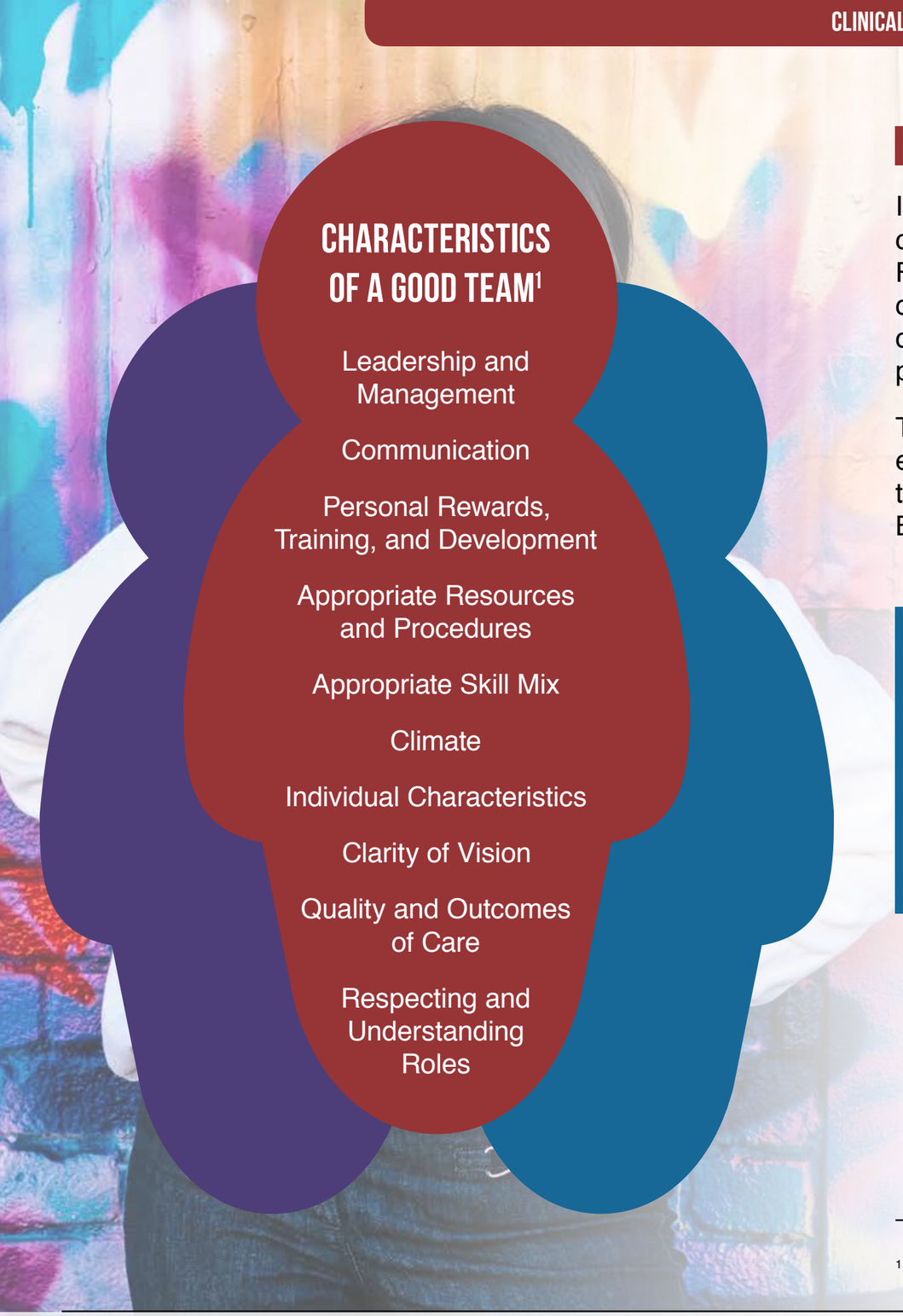
Continuity of care is often difficult for youth living with HIV (YLWH) because they receive care at multiple locations, or from many staff members within the same organization. Co-location of services improves YLWH follow-up on tests and procedures, as well as health outcomes. Many Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) Ryan White HIV/AIDS Program (RWHAP)-funded providers are part of larger health systems that offer a wide range of services. Thus, sometimes important information is lost between providers, case managers, support staff, and others involved in care delivery and coordination.

Interdisciplinary care teams can reduce this fragmentation by addressing YLWH care needs through both delivery and coordination of care. This topic walks providers through the steps for establishing interdisciplinary care teams by assembling professionals across specialties.

Step 1: Identify Care Team Members

Step 2: Identify Data Sources and Sharing Strategies

Step 3: Establish Regular Communication



STEP 1: IDENTIFY CARE TEAM MEMBERS

Interdisciplinary care teams consist of a wide range of professionals working together to plan client care. Each staff member brings unique expertise and perspectives on YLWH's health and well-being. For example, some YLWH may feel more comfortable talking about sexual health with a case manager or mental health professional than with their primary care provider (PCP). A pharmacist, on the other hand, has clinical expertise on drug side effects. Bringing in these varying viewpoints can help providers consider the whole client when planning for and rendering care.

The first step in developing an interdisciplinary model is to determine which staff members are best-equipped to be involved in the care team. The team will vary in size and composition depending on the scope of services delivered by a provider. Care teams in clinics that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project commonly included:

- PCPs, such as physicians, physician assistants, and nurse practitioners
- Other clinicians, such as infectious disease doctors, dentists, psychiatrists, and clinical pharmacists
- Nursing staff, such as registered nurses
- Mental health staff, such as psychologists, licensed social workers, and counselors
- Case managers
- Support staff, such as treatment adherence specialists, outreach/linkage workers, and medical assistants (MAs).

[1] Nancarrow et al. Human Resources for Health 2013, 11:19. http://www.human-resources-health.com/content/11/1/19

STEP 1: IDENTIFY CARE TEAM MEMBERS (CONTINUED)

The right mix of clinical, support, and administrative staff depends on the context of the provider site. At a minimum, the care team might include staff responsible for HIV care delivery and care coordination and a staff member to act as the central point-of-contact for client care. Not all members of the care team need to be involved in every meeting. Clinics might find that having a PCP and a social worker at every meeting is sufficient and other staff can be invited in as needed.

Additionally, clinics reported that buy-in involving all levels of staff, including those at an organizational level, as well as among care team members, is integral to the success of interdisciplinary care teams. This means there is greater success when provider administrators decisively support the model, communicate why the incorporation of care teams is a priority, and support care team members throughout the implementation process. Affording members the opportunity to give regular feedback on the structure and operation of the team also will help build a culture that supports this approach.

Other topics in this toolkit can serve as guides to train staff to be effective members of a care team, such as Staff Recruitment and Retention and Staff Training. More information about interventions funded by the HRSA HAB RWHAP Part F Special Programs of National Significance (SPNS) program related to care teams is available on the TargetHIV, formerly known as the TARGET Center and HRSA HAB websites. In particular, the SPNS initiative Building a Medical Home for Multiply Diagnosed HIV-positive Homeless Populations and resources on patient-centered medical homes may be helpful in developing training approaches.

[1] Nancarrow et al. Human Resources for Health 2013, 11:19. http://www.human-resources-health.com/content/11/1/19

STEP 2: IDENTIFY DATA SOURCES AND SHARING STRATEGIES

Once a clinic has decided who to include in the care team, the next step is to develop a strategy for sharing important data among team members. Data that may be shared include lab data, appointment dates, support services, case management notes, and pharmacy records. Many clinics have multiple systems in place that capture data on the care provided to YLWH. For example, case managers may have one system, clinical data may be housed in another, and observations from mental health visits may be contained in yet another. Clarifying how team members manage and access data is essential to successful implementation of a care team.

DATA COMMUNICATION STRATEGIES

At a minimum, staff will need to be able to communicate about relevant case notes, clinical data, and/or pharmacy data as they develop care plans and collaborate to meet client needs. This exchange of information should occur before the team meets.

Staff can prepare their own notes to report to other care team members during the meeting. Providers may consider developing a template that includes relevant data for team members and may identify staff to populate pieces or the entire template as appropriate.

INTERDISCIPLINARY CARE TEAMS: PROFILES FROM THE FIELD

At one clinic visited during the HRSA HAB Building Futures: Supporting Youth Living with HIV project, medical assistants prepare printed profiles on each youth client who has an appointment before each of their dedicated youth clinic days (see Strategy 1 in Youth-Centered Services for more detail on this model). The profiles provide clinical data, medications, visit history, case notes from the last visit, and indicators that will inform the youth client's care for the day. Another clinic has a similar strategy in which nurses add to an existing case history form at each visit, which is later entered in CAREWare.

IDENTIFY CURRENT DATA MANAGEMENT STRATEGIES

Providers also may wish to investigate electronic data-sharing among team members. This involves integrating the organization's current data handling processes. Departments often have different systems in place to capture data, particularly for providers that are part of a larger organization. For example, one provider reported having a social work-specific system that houses case notes across all social workers employed by the hospital system – not just those working with people living with HIV. This means that case notes for YLWH are entered into the social work system, along with notes for all other clients, and must be extracted for review by the HIV care team.

Providers might consider these questions for each member of the care team:

- Where (in what system) are data for their department housed?
- How do care team members enter and maintain data?
- What other data systems do they have access to?
- What other data systems should they have access to, if any?

If care team members do not have access to data they need, clinics may consider consolidating data systems or facilitating communication between systems. For example, if mental health staff provide treatment adherence counseling in sessions, they might benefit from having access to viral load test data to determine if YLWH have been adherent between medical visits. Interdisciplinary care teams work best when team members have access to all relevant data, such as pharmacy pick-ups, labs, and case notes in order to develop comprehensive care plans.

EXPLORE OPPORTUNITIES FOR ADDITIONAL DATA COMMUNICATION STRATEGIES

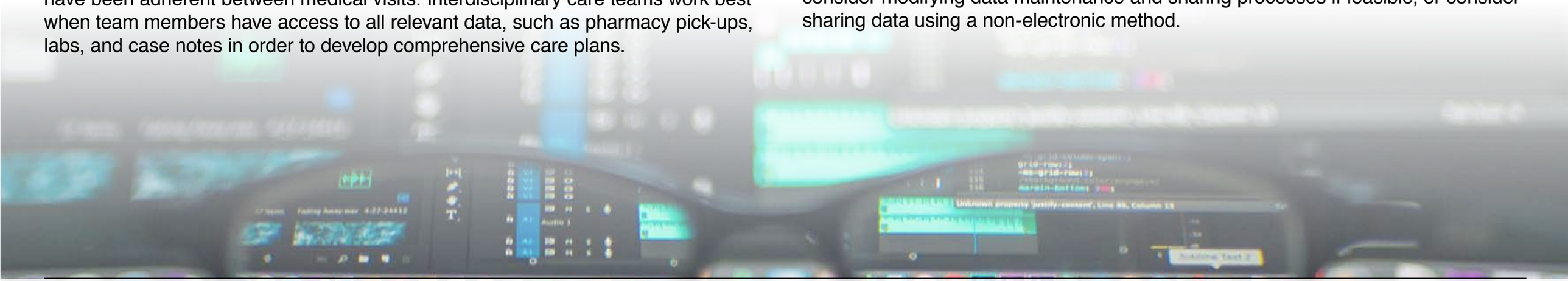
Interoperability between systems will reduce burden in efforts to share information across the team. By having systems that exchange information automatically, trained users will have access to real-time data whenever it becomes available.

However, many providers prefer to complete routine data cleaning and upload across systems. For example, one provider regularly uploads clinical data from an electronic health record (EHR) into CAREWare so that case managers can review lab results before setting up appointments. This process helps ensure that clinical data are clean and accurate by introducing an intermediary opportunity for quality improvement.

Keep in mind that the success of data upload is highly dependent on data being entered in the right place. Providers often struggle to export data entered into case notes or in narrative form. In some instances, these notes may not be the best method for communicating information about the client to other care team members.

If importing data between systems is not feasible, clinics can still establish a central location for all data on YLWH through manual data entry from one system into another. This also allows users to be selective regarding what information to share – for example, a mental health professional could decide to include high-level information about clinical status without divulging specifics from counseling sessions.

Providers may wish to consider whether existing systems are conducive to sharing data across the team. If there is not an appropriate way to share data, they should consider modifying data maintenance and sharing processes if feasible, or consider sharing data using a non-electronic method.



STEP 3: ESTABLISH REGULAR COMMUNICATION

The interdisciplinary care team approach requires regular and consistent communication. This can be achieved through use of data systems, as discussed in the previous section, but also requires regular meetings so the team can discuss difficult cases and coordinate efforts. Some strategies identified by providers incorporate the practices listed below into clinic hours.

1. **Informal conversation.** Many providers indicated that communication frequently occurs in informal settings, such as through an open door policy between staff, or electronically, through email or chat programs such as Skype. Quick, informal communication between members of the care team is an efficient way to communicate in real time about clients and can be particularly useful for determining when staff members should be brought in to see a client. When taking informal approaches to communication, clinics must be cognizant of client confidentiality and not divulge sensitive information in front of other clients.

2. **Informal huddles.** Many providers also indicated that they regularly huddle during clinic hours to discuss issues as clients come in. For example, a social worker, physician, and psychologist may meet briefly in an informal huddle to determine whether a client needs a counseling session before being referred for lab work. Sites also reported that these informal huddles helped staff trade strategies and best practices. If these meetings occur in client-accessible areas, client confidentiality is an important issue to be aware of when discussing cases.

3. **Pre-clinic meetings.** Several providers also instituted formal case conference meetings before clinic hours. For example, one provider with a weekly youth clinic meets in the morning with all staff who potentially see clients, including case managers, PCPs, clinical pharmacists, psychiatrists, and Medical Assistants. Staff are provided a print-out on each client who has an appointment, discuss each case, and decide who will see the client during the visit. While these formal meetings are more resource-intensive than huddles, they offer an opportunity to dig deeply into care planning. When implementing a Youth Program, as outlined in the Youth-Centered Services topic, pre-clinic meetings may be the best method of communication.

4. **Regular check-in meetings.** Finally, providers reported that they have regular meetings to discuss quality of care and care coordination more broadly. These check-ins often occur monthly, quarterly, or biannually, and offer staff a venue in which to report on successes and challenges. The regular check-ins also help to develop a sense of collaboration and solidarity among members of the team.

5. **Other meetings not specific to the care team.** Many providers also reported that they had semi-regular group meetings that were not specific to the care team as a unit. For example, several sites reported to have participated in Project ECHO to bring providers together virtually to discuss cases and topics of interest. One site also regularly facilitated meetings for the HRSA HAB RWHAP Part F AIDS Education and Training Centers (AETC) Program, which includes regular presentations by staff members involved in their care teams.

TIPS FOR ESTABLISHING REGULAR COMMUNICATION

Finding the right balance between too few and too many meetings is a challenge, especially given tight schedules. Consider the following strategies suggested by clinics that participated in the Building Futures: Supporting Youth Living with HIV project:

- Replace an administrative meeting with a care team meeting.
- Start with a monthly meeting and scale up the frequency over time.
- Carve out a regular time with no client appointments. Many providers suggested meeting right before clinic hours.
- Designate a staff member to be responsible for creating agendas and managing the meeting.

THEME 2
INFRASTRUCTURE DEVELOPMENT

HRSA HAB BUILDING FUTURES:

SUPPORTING YOUTH LIVING WITH HIV TECHNICAL ASSISTANCE TOOLKIT

TOPIC 2.1 STAFF RECRUITMENT AND RETENTION

Providers have overwhelmingly attributed high viral suppression rates among youth living with HIV (YLWH) to strong relationships between clients and staff members, including clinicians, case managers, social workers, mental health providers, and front desk staff. Youth clients also stress the importance of seeing the same clinic staff members over time, which demonstrates the importance of staff retention. Staff continuity allows YLWH to develop strong bonds with clinic staff and also encourages them to view the clinic as a safe place where they will receive consistent care. This topic offers suggestions for recruitment and retention strategies to ensure that providers employ staff who meet their youth clients' needs and to assist providers with efforts to improve staff retention.

STEP 1: STAFF RECRUITMENT

Providers identified staff characteristics they seek during the recruitment process and highlighted the importance of strong relationships between YLWH and clinical staff to improve retention in care and achieve viral suppression. The following are brief descriptions of recruitment strategies that providers have successfully employed.

ESTABLISH ROLE AND JOB DESCRIPTION

To successfully recruit the right candidate for a job, it is essential to identify the role, clarify what the position will do, and create an accurate job description. Working with management and human resources personnel, identify the skills, knowledge, and attitudes that candidates will need to succeed in the job. A simple task analysis can help recruiters clarify responsibilities for the new position and identify the corresponding knowledge, skills, and attitudes. Then develop a formal job description that reflects these responsibilities, clearly lists the necessary skills and experience, and incorporates internal policies.

The formal job description can be used to develop interview questions that will help agencies find candidates with the necessary qualifications.

RECRUITING FROM WITHIN

Recruiting from within is a common recruitment strategy among many providers, who have reported using either peer volunteers or Community Advisory Board (CAB) members to establish a resource of full-time employment candidates. A number of providers interviewed through the HRSA HAB Building Futures: Supporting Youth Living with HIV project reported that recruitment from an internal pipeline allows them to spend time with potential candidates to determine whether they might be a good fit for a full-time role working with youth clients. By considering peer volunteers or CAB members as candidates for full-time roles, a provider can assess whether a candidate understands the specific benefits and challenges of working with YLWH. This firsthand observation offers knowledge and insight into individuals' work habits and interactions with youth clients.

Providers reported notable success with internal volunteer-to-staff pipelines. Some providers created these pipelines by recruiting peer volunteers who worked for a period of time before being considered for staff openings. Over time, as volunteers demonstrated attributes that the provider considered valuable, and new positions opened, volunteers had the opportunity to apply on a competitive basis. This process helped providers identify strong internal candidates with background and knowledge of the youth client population. Not only did this strategy help to recruit individuals who had a passion for the work, it also provided greater stability to clients who had developed relationships with the volunteers, allowing those relationships to strengthen and grow. Additionally, volunteers who participated in CABs often had access to community resources, such as support groups or local agencies.

RECRUITMENT FROM THE COMMUNITY: PROFILE FROM THE FIELD

One provider offered use of its clinic meeting rooms to a Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) organization that meets monthly. The clinic and this organization have developed strong partnerships. When the provider identified a need to reach youth clients of color who are men who have sex with men (MSM), it worked with this organization to recruit potential applicants who had extensive knowledge of MSM YLWH. By building this partnership, the provider was able to support a community-based organization (CBO), as well as increase their recruitment reach within the community.

STEP 1: STAFF RECRUITMENT (CONTINUED)

RECRUITING FROM THE COMMUNITY:

Another successful strategy is based on targeted outreach to recruit staff from the community; working with community agencies such as local Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) agencies, community-based organizations (CBOs) serving minority populations in the same community where they work; or promoting jobs on multicultural networks. Providers report the need to build relationships with these key resources and to maintain open communication with them during periods of hiring and recruitment. Through these collaborations, providers can partner with organizations with similar missions to identify staff members who reflect the community they serve and possess the necessary skills and experience.

RECRUITMENT FROM WITHIN: PROFILE FROM THE FIELD

A community health center reported that an internal candidate pipeline allowed them to find personnel who were both a good fit for the organization and who reflected the community the clinic served. The clinic hired a CAB volunteer who helped plan and run events and who also was a visible member of the community. Before becoming a full-time employee, she helped conduct support groups, participated in speaking engagements in the community, and helped plan community events. It was reported that many participants at these events were influenced by the personal stories shared by this individual, and the clinic attributed much of their testing success to the involvement of this staff member. During her time on the advisory board, she demonstrated passion for the community, as well as dedication to serving people living with HIV. When the organization received funding to hire a full-time outreach worker, they were able to hire this individual, based on her extensive experience in the community and the strong relationships she had built with clients.

STEP 2: STAFFING CONSIDERATIONS

RECRUITMENT POLICIES

Many providers reported that it is important to clarify recruitment and hiring policies before beginning the hiring process, particularly for providers housed within larger healthcare systems that have established certain guidelines or universal hiring policies. For example, one provider reported that they had identified a youth CAB member who they felt would be a good fit for an open position. During the recruitment process, they discovered that the larger funding agency required candidates for the position to have at least a bachelor's degree. The candidate did not have a degree; thus, the provider was not able to proceed with the hire. To ensure a seamless recruitment process, providers must not only understand their own needs, but must also pay close attention to high-level recruitment and hiring policies.

IMPORTANT CONSIDERATIONS WHEN WORKING WITH YOUTH

Many providers expressed the importance of hiring staff who reflect or represent the community served – from front desk staff to clinicians. This fosters the clinic's image as a safe and affirming place where staff members are understanding, non-judgmental, and can relate to the youth clients. YLWH report that they build better connections with a clinic and are more likely to adhere to their treatment if they have strong relationships with staff. YLWH note that they feel more connected with staff who understand the unique challenges that a young person might face and are willing to "meet them where they are." Providers reported that staff members who acknowledge successes and provide affirmations while being open and honest with youth clients were most successful, as were those who positioned themselves as allies with YLWH clients. Staff characteristics youth clients are looking for, based on interviews conducted during the Building Futures project:

- *Dedication*. Staff are willing to go above and beyond to serve clients.
- *Patience*. Staff help YLWH feel accepted by taking the time to get to know them and their needs and allowing them to ask questions.
- *Balance between hand-holding and accountability*. Staff should position themselves as allies who help YLWH make decisions about their health by tactfully describing consequences of various actions.
- *Include youth in the planning*. By providing YLWH with options, staff help youth clients feel that they have some control over their treatment and care.
- *Coachable*. Staff should be able to listen and adjust to the requests of the clients.
- *Non-judgmental*. Stigma is a large barrier for YLWH engagement and retention in care. Clinical staff help YLWH accept their diagnoses through a supportive and non-judgmental attitude.
- *Emphasis on non-medical issues*. Clinicians focus on medical intervention, but also are mindful of clients' environments. They attempt to address the social determinants of health that may hinder clients' ability to archieve viral suppression.

STEP 3: STAFF RETENTION

Staff retention is a vital component of client satisfaction and retention in care. Youth clients in HRSA HAB's Ryan White HIV/AIDS Program (RWHAP)-funded provider sites reported that they were more engaged in care when they felt connected to their clinic team and there was a sense of consistency among staff. With the goal of improving client outcomes, providers should pay attention to how clinical teams are supported and receive ongoing training, supervision, and enrichment to boost job satisfaction. Retention can be a difficult challenge in many service fields. To address this, providers reported that they focused on procedures, protocols, and a culture to facilitate support not only from supervisor to employee, but also among colleagues and throughout the organization. It is important to develop systems of support for staff, to establish protocols that ensure supportive supervision, and to create a culture of self care.

CLEARLY DEFINE STAFF ROLES

Providers noted the importance of clear information about staff roles and responsibilities and the objectives of each role. This begins in the pre-hiring process, when the leadership identifies the key responsibilities of a role and carefully articulates those responsibilities in job descriptions. It is essential to clearly communicate responsibilities throughout the recruitment process, as well as after hiring. Roles and responsibilities can be further clarified and defined during regular communication between staff members and supervisors. Special attention also should be paid to development and implementation of capacity-building initiatives to prevent burnout, including training and ongoing professional development.

SCHEDULE REGULAR SUPERVISION

Provide all staff members with regularly scheduled, structured, strength-based supervision from someone who is trained in the area in which they are working. During regular interaction with their supervisors, staff members will review their roles, assess progress and challenges, and outline program goals for their youth clients. Regular supervision is essential to ensure that staff members have an opportunity to ask questions, voice concerns, and offer feedback regarding their roles and responsibilities. Supervisors should recognize how an employee's work impacts their health and their work with youth clients.

CARE TEAM TRAINING: PROFILE FROM THE FIELD

One provider reported that they established a formal training process for their care coordination staff, which included completing online webinars, sharing resources and referral lists, and observing a colleague or supervisor in client meetings; followed by a two-week observed practicum in which the staff member was observed by the supervisor at each client visit. Once the supervisor felt that the staff member was sufficiently trained, the staff member met with clients alone.

STEP 3: STAFF RETENTION (CONTINUED)

STAFF TRAINING

Providers that offer quality, targeted training to staff strengthen service delivery to their youth clients. Ongoing training supports the capacity of the workforce to optimally plan, implement, and sustain HIV treatment interventions for YLWH and address HIV-related morbidity, mortality, and health disparities. To ensure continued staff growth, providers report that it is important to establish a culture of educational opportunities to ensure that all staff are sufficiently trained to perform their job responsibilities.

Some providers interviewed reported engaging all new and current staff in in-service training, as well as external opportunities (e.g., conferences, workshops, online training) designed to increase staff skills and knowledge. They provide ongoing training for staff, ranging from updated clinical practices to engaging YLWH populations. Some providers also developed more informal "lunch and learn" opportunities.

Providers reported participating in the HRSA HAB RWHAP-focused webinars and trainings offered by the HRSA HAB RWHAP Part F AIDS Education and Training Centers (AETC) Program and HRSA HAB RWHAP-funded recipients (state or city funders); trainings with a clinical focus; webinars that include case conferencing for staff; and training provided through national conferences (e.g., National Ryan White Conferences, Conference on Retroviruses and Opportunistic Infections, Conference on HIV Treatment and Prevention Adherence, and the American Conference for the Treatment of HIV). Many of these training opportunities also provided continuing education units (CEUs) for participants.

TIPS FOR DEVELOPING STAFF TRAINING

- Identify the training topics that are most relevant to staff growth and development for new and existing staff working with YLWH.
- If necessary, conduct an internal assessment to identify training needs for staff and supervisors.
- Determine which staff members should attend particular trainings by role and set an internal policy for this process for all new employees.
- Identify training opportunities that are available within the organization and the community.
- Note whether trainings are internal or online (such as webinars or e-learning modules).
- Establish a training budget to cover training costs.
- Create an ongoing assessment of training needs and an evaluation of staff skills and knowledge.
- Allow staff members to share information from trainings and to provide input regarding additional training they might need.
- Document training completed by all staff.
- Establish internal protocols to ensure knowledge transfer between exiting staff members and new employees.

STAFF INPUT PROCESSES

Providers reported that establishing regular check-ins with staff and creating opportunities to report issues and air grievances helped to reduce staff burnout. It is essential to maintain formal mechanisms (e.g., policies and regular supervision) for staff to provide meaningful input and feedback on factors affecting their work. This can include areas such as shifting caseloads, hours, flex time, time off, continued staff training, and approaches to clinical care. Formal processes can include regularly scheduled meetings with supervisors, as well as regular all-staff meetings, team meetings, or mechanisms for internal communication that solicit staff feedback.

STAFF WELLNESS

Many providers reported offering venues for self-care to help counteract burnout. Providers emphasized the importance of creating policies and procedures to address staff wellness, including providing staff education on compassion fatigue, vicarious traumatization, and burnout prevention. Many programs provide regular opportunities for staff to engage in self-care and peer support. Additionally, it is important to provide appropriate supports to staff who have experienced vicarious trauma and crisis (e.g., sudden death of a client), and who need additional supports.

ACTIVITIES TO IMPROVE STAFF MORALE: PROFILES FROM THE FIELD

A provider reported utilizing their quarterly staff meetings to provide opportunities for camaraderie and fun. The quarterly staff meetings, scheduled on Friday afternoons when the clinics are closed, typically take 20 minutes. The rest of the afternoon is spent on fun activities, such as trips to a bowling alley with interested staff.

STAFF RECRUITMENT AND RETENTION RESOURCES

- https://careacttarget.org/library/spns-initiative-system-level-workforce-capacity-building-integrating-hiv-primary-care
  - ◊ Resources on system-level workforce capacity building for integrating HIV primary care in community healthcare settings.
- https://careacttarget.org/library/spns-initiative-system-level-workforce-capacity-building-integrating-hiv-primary-care
  - ◊ A multi-site demonstration and evaluation of system-level changes in staffing structures to improve health outcomes along the HIV care continuum.
- https://careacttarget.org/library/succession-planning-and-organizational-sustainability
  - ◊ On-demand webinar that details ways to maintain organizational sustainability through succession planning to accommodate staffing and agency change through planning, training, recruitment, and adjustments.
- https://careacttarget.org/library/talent-management-key-achieving-organizational-success-and-sustainability
  - ◊ On-demand webinar focused on methods for achieving organizational success and sustainability through talent management.
- https://careacttarget.org/library/organization-assessment
  - ◊ Tool to help assess organizational leadership strengths.

DISCLAIMER:

The referenced resources in this toolkit do not constitute or imply endorsement or recommendation by the federal government.

STAFF TRAINING RESOURCES*

- https://careacttarget.org/library/aetc-national-coordinating-resource-center
  - ◊ The AETC National Coordinating Resource Center coordinates the development and dissemination of national HIV curricula for health professionals, including webinars, online learning curriculums, and trainings.
- Direct link: https://www.aidsetc.org/training
- https://www.cbaproviders.org
  - ◊ The CDC Capacity Building Assistance (CBA) initiative strengthens community-based organizations, health departments, and healthcare organizations in their high-impact HIV prevention initiatives through free capacity-building assistance in the form of information, trainings, and technical assistance. Note that HRSA HAB RWHAP-funded agencies are not eligible for CBA funding unless they are also funded by CDC.
- Direct link: https://wwwn.cdc.gov/Cris2009/pages/main/e1.aspx
  - ◊ This link provides peer workforce supervision resources.
- https://careacttarget.org/library/strategies-supervising-hiv-peers
  - ◊ This on-demand webinar provides strategies for supportive and clinical approaches for supervising peers in the workplace. It includes topics such as managing peer-client relationships, working with peers as part of a multidisciplinary team, and supporting peer development.
- https://careacttarget.org/library/supervising-peers-who-support-clients-hiv-care-and-treatment-part-1
  - ◊ This on-demand webinar is the first of a two-part session and is designed as an introduction to approaches for supervising peers. It includes case examples of common issues, such as boundaries, confidentiality, and integrating peers into the healthcare team.
- https://careacttarget.org/library/supervising-peers-who-support-clients-hiv-care-and-treatment-part-2
  - ◊ This is the second of a two-part webinar discussing supportive and clinical approaches for supervising peers in the workplace. Case examples address issues such as managing peer-client relationships and transference/countertransference.

TOPIC 2.2 IMPROVING COMMUNICATION WITH YOUTH

According to providers that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV Technical Assistance Toolkit, informal, frequent communication can remind youth living with HIV (YLWH) to adhere to medication regimens and attend upcoming appointments. It allows providers to answer questions related to care or services and to provide emotional support. YLWH are frequent users of text messaging and social media, including Facebook, Instagram, Twitter, Snapchat, YouTube, mobile apps, and other online platforms.

YLWH say they prefer to communicate with a person, either face-to-face, via text, or using chat apps, rather than through telephone calls or voice messages. Communication with youth was cited by providers as one of their greatest challenges, because youth report less frequent use of telephones, they sometimes do not have cell phones or plans with sufficient minutes, their phones get disconnected, or their phone numbers change. Because YLWH often rely on free Wi-Fi hot spots, text messaging and social media are more effective than phone calls. Providers expressed interest in communicating through social media, but they reported finding these technologies hard to use, were concerned about privacy issues, or didn't know where to start.

STRATEGY 1: TEXT MESSAGING

Text messaging is a preferred communication method among youth because it helps them connect with clinic staff at their convenience when they need a quick and timely conversation. Texting can offer providers numerous advantages; it may be the fastest and most efficient means of sending information, especially considering factors such as background noise, spotty network coverage, or lack of access to a computer. Texting also prevents clogged email in-boxes full of unanswered messages. Despite the benefits of text messaging, providers noted that legal restrictions from their larger healthcare systems are sometimes a barrier to adopting this practice. They also expressed concerns that texting may violate Health Insurance Portability and Accountability Act (HIPAA) requirements and client confidentiality guidelines.

OPTION 1: HIPAA-COMPLIANT TEXT MESSAGING USING A CELL PHONE

Currently, HIPAA does not restrict any specific mode of communication, including texting. **However, it is best to check with an organization's HIPAA office or legal counsel to determine what is permissible and what is restricted**. In some cases, providers may allow a few clinic staff members to use text messaging, as long as messages do not include protected health information (PHI). Providers can consider the following precautions to make sure that the use of text messaging does not violate HIPAA requirements:[1]

- **Message content:** Text messages must not contain PHI. Do not store first and last names in the text messaging address book. Develop safe, yet creative ways to identify clients, such as storing first name plus last initial only, or first initial/first name and four digits of a birth date or other identifier. Never use a client's first and last name in a text message. Providers also may establish administrative policies prohibiting inclusion of PHI in text messages or limiting the type of information that may be shared via text (e.g., condition-specific information).
- **Consent:** Do not text youth clients or others without written consent. Consent is typically obtained by requiring clients to sign a consent form that clearly describes the types of information that may be shared and the mode of transmission, and that clearly identifies the benefits and risks. Obtaining consent from minors may differ by state; providers can consult their organization's HIPAA office or legal counsel for guidance.

SECURE TEXTING SAMPLE POLICY STATEMENT[2]

- Do not send text messages containing electronic protected health information (ePHI) unless the text message is encrypted using an appropriate application, both in transit and at rest. This applies to text messages sent between employees.
- Individuals who wish to send or receive text messages containing ePHI can ensure that the secure text application is approved by their organization's IT department and that it follows organizational policy.
- Ideally, phones and applications used to transmit ePHI via text message are password protected.
- Consider including only the minimum allowable information necessary when text messages contain ePHI.
- Information transmitted via text message is safest when it is accurate and properly documented.

[1] Storck, L. (Feb. 2017). Policy Statement: Texting in Healthcare. Online Journal of Nursing Informatics (OJNI), 21(1), Available at http://www.himss.org/ojni
[2] ecfirst (2013). The CIO's Guide to HIPPA Compliant Text Messaging. Available at: http://anha.org/uploads/CIOsGuidetoSecureTextMessaging.pdf

STRATEGY 1: TEXT MESSAGING (CONTINUED)

- **Security:** Password-protect the phone used to send text messages. Confirm that the youth client's cell phone number is recorded correctly. Confirm that all mobile devices used to send messages are secure at all times, including at home and work.
- **Storing and deleting messages:** Delete text messages after communication is completed and store information securely. Additionally, it is a good idea to set a timeline for deleting messages from the devices used.
- **Client-generated messages that include PHI:** Do not respond to the original text that contains PHI; instead, send a new message asking the youth client to call you. Immediately delete the initial message.
- **Best practice reminders:** Be aware of tone. Be professional at all times and do not use abbreviations. Text messages are best kept short and concise; messages longer than 160 characters will break into two messages. Check whether text message content is professional and clear and avoids using abbreviations that may not be familiar to clients or subject to different interpretations. Text messaging is a rapid means of communication, so set clear expectations with youth clients about whether you will continue a dialogue and how quickly you expect to reply.

OPTION 2: SECURE TEXT MESSAGING

If PHI is to be communicated electronically, providers should consider using encrypted messages or a secure text application, rather than an unsecured cell phone. It is important to first establish HIPAA text message policies or to address text messaging policies in the agency's security/privacy compliance program. Secure text messaging often requires implementation of a third-party application if one is not already included in the existing electronic health records (EHRs) system. Some case management systems or EHRs offer secure text messaging that is connected to medical charts, but additional fees may be required to use these services. Vendor selection can be based on an organization's existing infrastructure, budget, HIPAA security compliance requirements, and other needs.

STRATEGY 1: TEXT MESSAGING (CONTINUED)

SECURE TEXTING POLICY STATEMENT[5]

- Do not send text messages containing electronic protected health information (ePHI) unless the text message is encrypted using an appropriate application, both in transit and at rest. This applies to text messages sent between employees.

- Individuals who wish to send or receive text messages containing ePHI can ensure that the secure text application is approved by their organization's IT department and that it follows organizational policy.

- Ideally, phones and applications used to transmit ePHI via text message are password protected.

- Consider including only the minimum allowable information necessary when text messages contain ePHI.

- Information transmitted via text message is safest when it is accurate and properly documented.

EXAMPLES OF COMPLIANCE REQUIREMENTS AND CONSIDERATIONS

- Access control – limit access only to staff who require it for work activities
- Password management – implement strong passwords (generally 12+ characters with symbols and numbers)
- Automatic logoff – implement logoff control after transmitting messages
- Account termination – deactivate accounts after a period of non-use
- Audit capabilities – logs users' authentication and access actions and administrative access with a time stamp
- Transmission security – transmit encrypted messages only
- Secure photo sharing – document a policy regarding use of personal photos
- Callback requests – enable recipients to call back with a single tab
- Backup processes – implement a policy that clearly defines storage location and capacity and allows encryption for stored messages.

The full policy statements and the compliance requirements checklist were developed by ecfirst (Home of The HIPAA Academy), and can be found at http://anha.org/uploads/CIOsGuidetoSecureTextMessaging.pdf.

[5] ecfirst (2013). The CIO's Guide to HIPPA Compliant Text Messaging. Available at: http://anha.org/uploads/CIOsGuidetoSecureTextMessaging.pdf

STRATEGY 2: SOCIAL MEDIA PLATFORMS

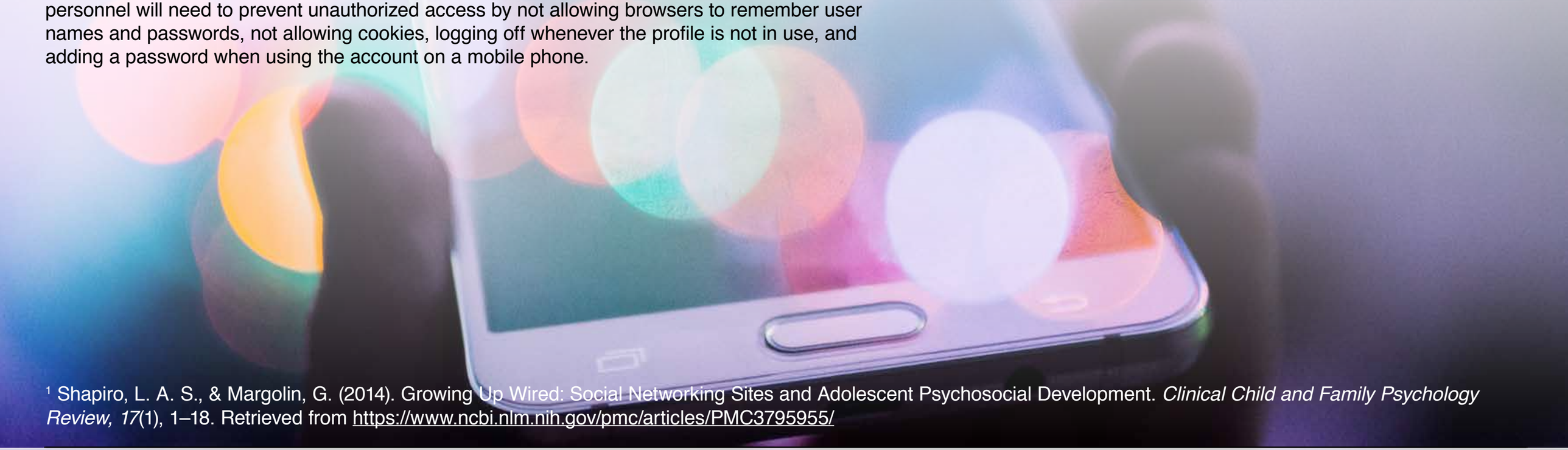
Most teenagers and adults in the U.S. access Facebook or other commonly used social media sites (e.g., Instagram, Snapchat, YouTube) multiple times each day. Many providers have official social media accounts, but YLWH might be hesitant to "friend" or "follow" these pages for fear of undesired disclosure of their HIV status.

OPTION 1: USE SOCIAL MEDIA MESSAGING FOR BETTER COMMUNICATION

For ongoing communication, providers may consider using a separate social media account or application that is not associated with the clinic; for example, private messaging via a social media site. It is recommended that social media accounts be managed and monitored by a few designated provider personnel, such as a case manager or the outreach/linkage/peer coordinator. Designated personnel need to be mindful about discussing confidential or private topics via messenger or social media communication, need to have the ability to respond to messages in a timely manner, and need to provide information consistent with communication delivered through other channels. Messenger accounts are best used to communicate appointment/activity logistics, conduct regular check-ins, and provide emotional and social support. Lab results, disease status, or medications are not appropriate topics to discuss via text message. In addition, the designated personnel will need to prevent unauthorized access by not allowing browsers to remember user names and passwords, not allowing cookies, logging off whenever the profile is not in use, and adding a password when using the account on a mobile phone.

SOCIAL MEDIA FOR COMMUNICATION: PROFILE FROM THE FIELD

One clinic created and set up a Facebook account using a virtual "person" as a spokesperson for the clinic, with a realistic name, address, and other information, such as hobbies. This virtual person behaves like an ordinary teenager who loves to share posts about health and wellness, as well as information on local activities/events. Clinic staff mainly use this account to message youth clients, promote activities organized by the clinic, and post articles on health and wellness (not limited to HIV). Facebook messaging does not require message recipients to be "friends" with the sender; rather, users can exchange messages with anyone on Facebook, regardless of friendship status. This serves as a convenient communication channel between the clinic and youth clients.



[1] Shapiro, L. A. S., & Margolin, G. (2014). Growing Up Wired: Social Networking Sites and Adolescent Psychosocial Development. *Clinical Child and Family Psychology Review, 17*(1), 1–18. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3795955/

STRATEGY 2: SOCIAL MEDIA PLATFORMS (CONTINUED)

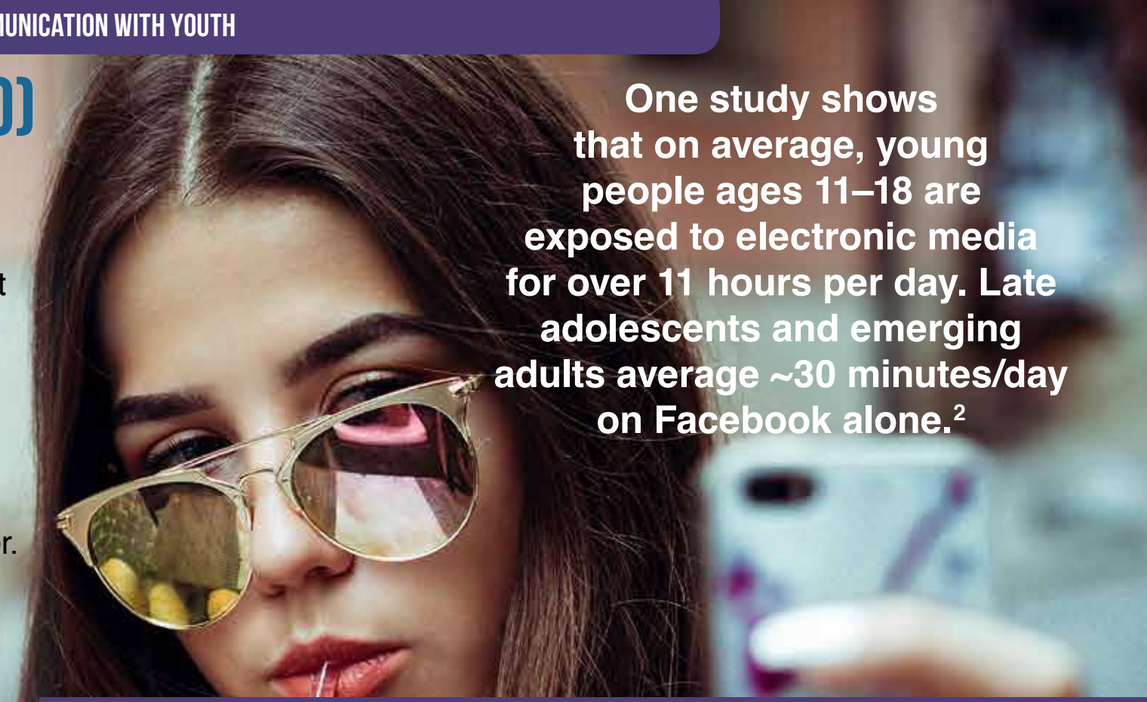
OPTION 2: USE SOCIAL MEDIA TO PUSH RELEVANT CONTENT

A separate social media account can be used to share posts and articles about health, life skills, mental well-being, support services, and other topics that may be useful. Providers may not want to limit the content shared to HIV information, as this may prevent youth clients from associating themselves with the account (e.g., "following," "liking," or "friending"). This strategy is intended to offer an informal platform for communication with youth. However, providers can check with their organizations concerning communication rules and HIPAA guidelines regarding the use of social media, especially related to content posting and sharing.

Other social media platforms suitable for content posting include Instagram, YouTube, and Twitter. One provider found that youth clients prefer Instagram; the provider's Instagram account, which was built for a research project, attracted youth beyond the research participants.

There are several considerations applicable to service providers regarding the context of social media posts recommended by the National Institutes of Health:[1]

- When publishing a research study, ensure that it is peer-reviewed. Research results presented at a scientific meeting may be preliminary and not yet subjected to peer review. Be mindful of live tweeting or streaming unpublished research findings and include appropriate caveats.
- Make sure to convey whether a research study shows causation or association and be clear about the strength of the evidence.
- When highlighting positive results, avoid words that overstate the findings or give false hope, such as "miracle" and "breakthrough." Acknowledge any negative findings, side effects, or caveats.
- Avoid jargon, acronyms, and words that have several meanings, such as morbidity, rare, numerous, low risk, burden, exposure, and host.



One study shows that on average, young people ages 11–18 are exposed to electronic media for over 11 hours per day. Late adolescents and emerging adults average ~30 minutes/day on Facebook alone.[2]

MAINTAIN UPDATED CONTACT INFORMATION

- Ask for a Facebook or Instagram username during check-in (e.g., in kiosks), as these are less likely to change than phone numbers (consent may be required to connect on social media)
- Ask for alternative contact numbers or email addresses
- Ask specific questions, such as "This is the number we have on file; is it still the best number to reach you?" instead of "Is there any change to your contact information?"
- Make frequent updates (i.e., each visit)
- Utilize a kiosk to allow clients to update their own contact information

[1] National Institutes of Health. (Dec 2017). Magnifying Your Messaging. Social Media as Part of A Communication Strategy. Available at https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/perspectives/magnifying-your-messaging

[2] Shapiro, L. A. S., & Margolin, G. (2014). Growing Up Wired: Social Networking Sites and Adolescent Psychosocial Development. Clinical Child and Family Psychology Review, 17(1), 1–18. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3795955/

STRATEGY 2: SOCIAL MEDIA PLATFORMS (CONTINUED)

OPTION 3: USE SOCIAL MEDIA GROUPS TO ESTABLISH SUPPORT COMMUNITIES FOR YOUTH

Providers also may consider creating a private Facebook page or group to support communication between the clinic and its clients and to facilitate communication among the youth clients. This strategy may be most beneficial for providers with sizeable youth populations. A social media group can be used as a discussion forum to allow curated or free discussion or can function as a virtual support group. Discussion topics may include life skills, social skills, school/work, and health and wellness; they need not be limited to topics related to the clinic or HIV. The following are practical considerations recommended by HRSA HAB Ryan White HIV/AIDS Program (RWHAP) providers:

- Who will be managing and monitoring the group and how much time is needed?
- Will this forum be used to share contents, post discussion questions, or both?
- Is the support group offered to all youth clients, or only some clients, based on certain criteria?
- How will youth be recruited for the group?
- Will there be separate communities for different demographic groups (e.g., age, gender)?
- What is the incident management plan (e.g., when to send warnings, remove a member, or delete content)?

Protection of and respect for youth clients' privacy is key to this strategy. Group pages are best kept private and invitation-only, so that no one outside the group will know who is in it. It may be advisable to begin with clients who have participated in an in-person support group, so that group members won't feel they are sharing with strangers. If the organization does not have an active in-person support group, it may be helpful to suggest such a group to youth clients to assess feasibility and level of interest. Although the virtual group can be available for sharing thoughts anytime, it is important to let clients know that it may not be monitored all the time and should not be used for urgent or emergency needs.

For information on support groups, please review the Youth Support Groups topic.

Tip from the field:
"The only way social media can create networks is when it is married with an interpersonal interaction. Social media should not be used as a replacement, but instead, as an enhancement of the interactions."

VIRTUAL SUPPORT GROUP: PROFILE FROM THE FIELD

One clinic created a private Facebook group as a virtual support group for youth clients. The group is used to provide remote social support as a supplement to the in-person support group. Group members are encouraged to talk about life, school, work, experiences, or other topics not limited to HIV. Many virtual support group participants have become Facebook friends or have exchanged phone numbers to stay connected offline. The Facebook group is closely monitored by a social worker at the clinic who also is responsible for inviting and approving new members.

ADDITIONAL RESOURCES

- Information on other social media options for education and intervention, including mobile applications, is available from the Health Resources and Services Administration-sponsored Special Programs of National Significance (SNPS) initiative. Consider this resource: Use of Social Media to Improve Engagement, Retention, and Health Outcomes Along the HIV Care Continuum, 2015-2019.
  https://hab.hrsa.gov/about-ryan-white-hivaids-program/spns-social-media
- This resource offers a library of text messages for multiple situations (general adherence, daily reminders, basic HIV health literacy, retention in care, appointment reminders, risk reduction, etc.). Messages are provided in English and in Spanish.
  https://careacttarget.org/library/ucare4life-client-text-message-inventory
- These materials can help providers understand whether HIPAA does or does not apply, and under what circumstances staff may share protected health information.
  https://careacttarget.org/library/hipaa-and-data-sharing
- The CDC Social Media Tools, Guidelines & Best Practices site provides a social media toolkit, as well as information on writing for social media and platform-specific guidelines for Facebook and Twitter.
  https://www.cdc.gov/socialmedia/tools/guidelines/index.html

TOPIC 2.3 LGBTQ-FRIENDLY POLICIES, ENVIRONMENT, AND CULTURE

Youth living with HIV (YLWH) face significant challenges to retention in care and achieving viral suppression. Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) youth face additional challenges.

Ensuring an LGBTQ-friendly environment is critical to addressing these challenges. LGBTQ-friendly means there is a culturally competent setting in which to receive services that is welcoming, safe, and non-judgmental. This topic is intended to help youth-serving providers establish an LGBTQ-friendly setting in which to provide HIV care and treatment services. Through an organizational culture with appropriate policies for this population and the integration of culturally competent care delivery, providers can better meet the needs of LGBTQ youth.

"The specific and often unaddressed needs of HIV positive lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth further complicate this issue. The multitude of psychosocial and structural barriers that they face due to their sexual orientation or gender identity – mental health problems, homelessness, substance use, and stigma – within a society that often misunderstands and mistreats them, makes coping and living with an HIV diagnosis particularly complex"[1]

[1] Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV – A Guide for Adult HIV Healthcare Providers, May 2012, page 1.

ORGANIZATIONAL CULTURE

Establishing policies, protocols, and an organizational culture that are LGBTQ-friendly demonstrates a commitment by leadership to meet the needs of LGBTQ youth clients. A provider who is sensitive to the needs of LGBTQ youth clients and able to address their specific health needs can help them remain in care, improve medication adherence, and ultimately achieve viral suppression.

The Joint Commission, a national accreditation organization of healthcare organizations and programs, outlined some important considerations for ensuring that policies address the needs of LGBTQ clients, including a broad organizational culture that demonstrates this commitment.[2] Recommendations include:

- Integrate LGBTQ client needs into new/existing policies
  - ◊ Outline nondiscrimination policies that include sexual orientation and gender identity
  - ◊ Develop/adopt a policy identifying clients' right to choose their support person
  - ◊ Utilize a broad definition of family
- Demonstrate ongoing commitment by agency leadership to inclusivity for LGBTQ clients and their families
  - ◊ Evaluate agency activities to ensure the provision of culturally competent client- and family-centered care to LGBTQ clients
  - ◊ Outline the process for reporting discrimination or disrespectful treatment
  - ◊ Develop disciplinary processes for intimidating, disrespectful, or discriminatory behavior toward LGBTQ clients or staff
  - ◊ Identify a specific employee who is directly accountable to leadership for overseeing agency activities to provide more culturally competent and client-centered care to LGBTQ clients and families
  - ◊ Identify and support champions who have expertise/experience with LGBTQ issues
  - ◊ Appoint an advisory group to assess and make recommendations for improving the climate for LGBTQ clients

Providers can work with human resource professionals (their own or outside professionals), senior leadership, and front-line staff to ensure that appropriate policies and procedures are implemented throughout their programs. One provider that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project underscored the importance of emphasizing the inclusivity of their clinic and their organizational culture in supporting LGBTQ clients when hiring new staff. Another provider has a committee of social workers, nursing staff, and medical assistants that meets monthly to discuss ways to become more transgender-friendly and holds a quarterly Community Advisory Board (CAB) meeting on the topic.

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[2] The Joint Commission: Advancing Effective Communication, Cultural Competence, and Patient- and Family Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide. Oak Brook, IL, Oct. 2011. LGBTFieldGuide.pdf.

CHECKLIST: AREAS FOR CONSIDERATION

- Mission statement and/or a vision statement, clearly posted, that includes LGBTQ-friendly language
- Physical environment with inclusive signage and educational materials
- Gender-neutral restrooms
- Inclusive materials and resources
- Training plan for all staff, from front desk staff to clinical providers
- Intake forms and electronic medical records that incorporate appropriate language and policies, such as preferred name and gender identity
- Individualized disclosure process based on client needs

CULTURALLY COMPETENT CARE AND TREATMENT SERVICES

There are many aspects of settings and services that must be addressed to provide culturally competent care and treatment. These include the organizational environment, disclosure process, inclusivity, data systems, staff training and resources, and LGBTQ-focused activities and services. The checklist on this page provides examples of culturally competent care and treatment services in clinical settings.

Environment

The physical space of the clinical setting is critical to ensuring that LGBTQ youth clients feel welcome and safe. For example, it is important that the nondiscrimination policy is inclusive of both sexual orientation and gender identity and is clearly posted in the waiting areas and exam rooms. In addition, ensuring that materials and brochures include the LGBTQ community is essential. Insignia or other items worn by staff, such as “my pronoun is” buttons or stickers, rainbow flags, or a pink triangle also can demonstrate inclusivity. Gender-neutral or single-stall bathrooms demonstrate a commitment to an inclusive environment.

Many providers utilize free resources that are available online, such as rainbow “safe zone” signage to indicate that the clinic welcomes all individuals. Organizations such as The Trevor Project; GLAAD; the Human Rights Campaign; Gay, Lesbian & Straight Education Network (GLSEN); and the Centers for Disease Control and Prevention (CDC) offer materials and information that are representative of LGBTQ populations.

Disclosure and Inclusivity

Another important consideration is disclosure. For LGBTQ youth clients, disclosing HIV status to their partners, families, and friends often means disclosing sexual orientation or gender identity as well. HRSA HAB RWHAP-funded providers reported that LGBTQ youth felt that disclosing their sexual orientation or gender identity was often more difficult than disclosing their HIV status. Given that many LGBTQ youth are still on their parent’s insurance, engaging in medical care can lead to disclosure, as use of the insurance may result in parents receiving an Explanation of Benefits (EOB) that discloses HIV status. An effective provider approach to disclosure is to support each youth client in their own process and timeline for “coming out.” Lack of disclosure should not be a barrier to care, particularly if a client declines to use their parent(s)’ health insurance.
In some cases, LGBTQ youth clients may not wish to disclose their sexual orientation or gender

identity to clinic staff. Therefore, providers may need to help their youth clients feel comfortable in disclosing their sexual orientation or gender identity. One approach is to use clinic forms that are inclusive, such as providing choices for gender other than male or female.

Training

Staff training contributes to the successful integration of an LGBTQ-friendly culture in provider settings. Providers offered several examples explaining how they currently address staff training needs in this area. These included:

- Training all new staff on LGBTQ cultural competency, with a focus on transgender issues, such as welcoming gender expression and using the preferred pronouns
- Incorporating LGBTQ issues in bimonthly cultural competency trainings
- Purchasing training that includes LGBTQ cultural competence through an online company. Staff members also can complete voluntary modules and receive continuing education units. One provider found it beneficial to have staff view a video on LGBTQ issues and then facilitate a discussion among staff members.

It is critical that staff have access to LGBTQ-specific training; there are several resources available to providers. The HRSA HAB RWHAP Part F AIDS Education and Training Centers (AETCs) Program are a national network of training centers funded by HRSA. Also funded by HRSA is the National LGBT Health Education Center that provides training and technical assistance on LGBTQ health needs and services for community health centers, inclusive of youth-specific needs. The Gay and Lesbian Medical Association (GLMA) provides access to archived webinars on a range of LGBTQ topics. Additional resources are listed at the end of this topic, as well as in the Staff Recruitment and Retention topic.

Data Management Systems

Providers can ensure that the data management systems they use for client care capture inclusive information on gender, preferred names, and pronouns. One provider indicated that their case management database has comprehensive fields, but the electronic health record (EHR) does not; staff are working with their IT department to align the systems. Another provider noted that their EHRs cannot be modified at this time, but they are using unstructured (open-ended) fields in the data system to capture the necessary information. They use “preferred name” and “preferred pronoun” fields and all forms collecting information are similarly inclusive.

LGBTQ-FRIENDLY SETTING: PROFILE FROM THE FIELD

A community health center clinician shared her experience of working with gender-fluid youth. She asks clients how they would like to be referenced (he, she, or they) and uses those pronouns throughout their sessions.

> ***“A transgender client may not come back if they are mis-gendered by the front desk staff.”***
> - HRSA HAB RWHAP-funded provider

LGBTQ- Focused Activites and Services

Providers can organize activities and provide services that specifically target LGBTQ youth clients or refer to other agencies that provide these services. Agencies may establish a Memorandum of Understanding (MOUs) to clarify referral processes with LGBTQ agencies (i.e., referrals to or from other agencies). Many providers reported that they conducted testing and outreach at venues frequented by LGBTQ clients; several received referrals from LGBTQ agencies with clients who tested positive. Partnerships with LGBTQ agencies are especially important if providers do not have the staffing or capability to treat all the health needs of their LGBTQ youth clients. Examples of specialized services include hormone therapy for transgender clients or support groups for LGBTQ youth clients.

When referring an LGBTQ youth client to an outside agency, providers may need to identify the client's point-of-contact and should take additional steps to ensure a smooth transition. This type of warm hand-off was reported to be particularly important for LGBTQ youth clients. particularly important for their youth clients.

RESOURCES

The TargetHIV, formerly known as the TARGET Center website has specific resources for youth, men who have sex with men (MSM), and transgender clients. Some resources include:

- The National LGBT Health Education Center
- The Center of Excellence for Transgender Health
- San Francisco Department of Public Health
- His Health: Engaging Black MSM in HIV Care

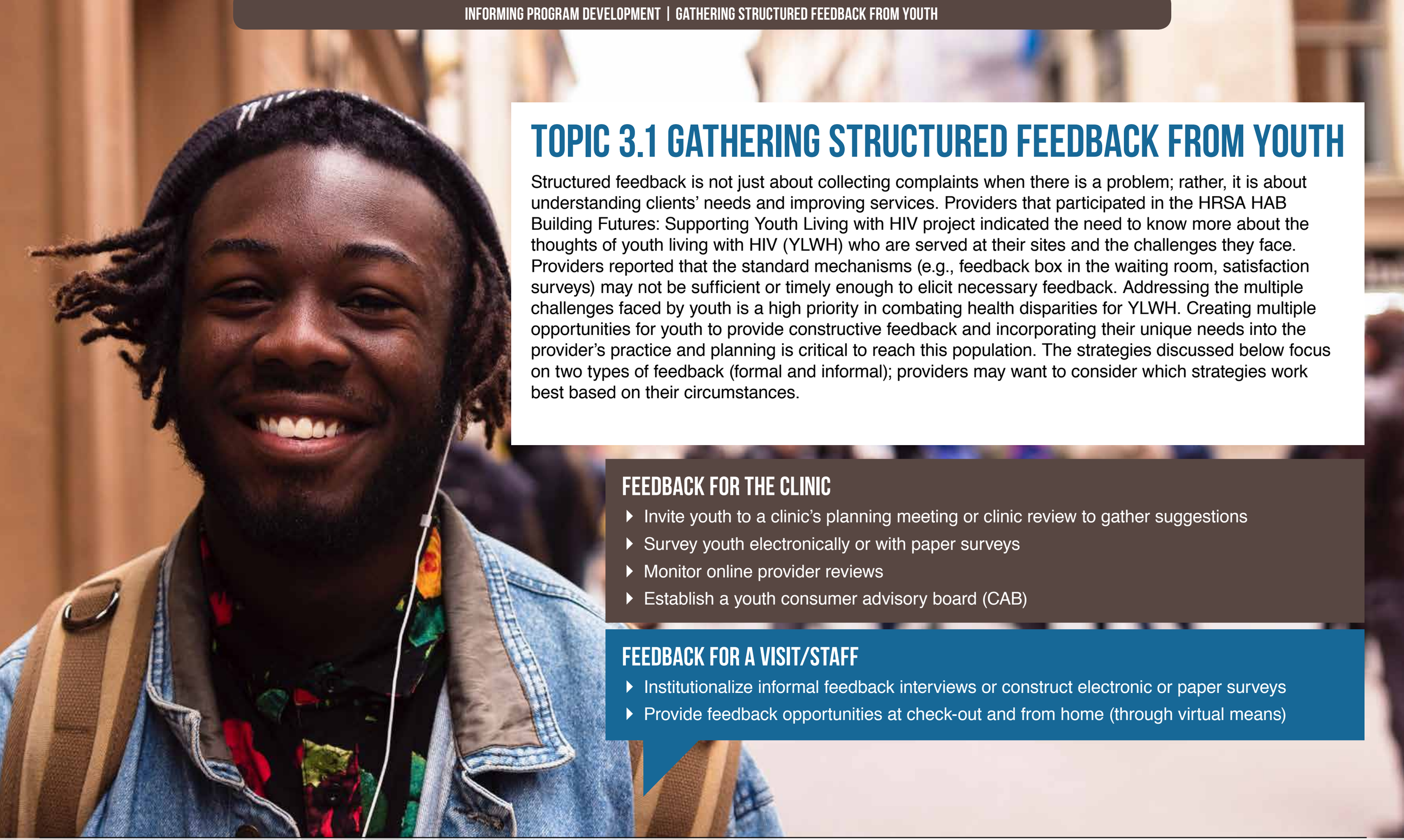
Additional resources beyond the TargetHIV below:*

- Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide
- HHS Culturally Competency Training Resources
- Gay and Lesbian Medical Association (GLMA)
- ACT for Youth
- Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV – A Guide for Adult HIV Healthcare Providers

DISCLAIMER:

The referenced resources in this toolkit do not constitute or imply endorsement or recommendation by the federal government.

THEME 3
INFORMING PROGRAM DEVELOPMENT



TOPIC 3.1 GATHERING STRUCTURED FEEDBACK FROM YOUTH

Structured feedback is not just about collecting complaints when there is a problem; rather, it is about understanding clients' needs and improving services. Providers that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project indicated the need to know more about the thoughts of youth living with HIV (YLWH) who are served at their sites and the challenges they face. Providers reported that the standard mechanisms (e.g., feedback box in the waiting room, satisfaction surveys) may not be sufficient or timely enough to elicit necessary feedback. Addressing the multiple challenges faced by youth is a high priority in combating health disparities for YLWH. Creating multiple opportunities for youth to provide constructive feedback and incorporating their unique needs into the provider's practice and planning is critical to reach this population. The strategies discussed below focus on two types of feedback (formal and informal); providers may want to consider which strategies work best based on their circumstances.

FEEDBACK FOR THE CLINIC

- Invite youth to a clinic's planning meeting or clinic review to gather suggestions
- Survey youth electronically or with paper surveys
- Monitor online provider reviews
- Establish a youth consumer advisory board (CAB)

FEEDBACK FOR A VISIT/STAFF

- Institutionalize informal feedback interviews or construct electronic or paper surveys
- Provide feedback opportunities at check-out and from home (through virtual means)

STRATEGY 1. PROVIDE FORMAL FEEDBACK OPPORTUNITIES AT CHECK-OUT AND OFF-SITE (VIRTUALLY)

PROVIDER-INITIATED FEEDBACK OPPORTUNITIES

Maintaining an open connection beyond the exam rooms is vital to the feedback process. A one-time survey is often offered, but its timing may make it difficult to collect contructive feedback. For example, in some instances, youth clients do not have time to complete the survey, or have not had time to gather their thoughts. Thus, such surveys may miss recommendations at point of service. By establishing an opportunity to provide feedback post-visit, providers can elicit timely suggestions, complaints, or compliments; and allow issues to be addressed quickly. Some providers may insert a few survey questions into the kiosk's check-out process (if applicable), or hand out short surveys to complete while checking out (on paper or tablet). Alternatively, providers may send out short online questionnaires from either the clinic's online portal or a survey platform, to gather feedback after each visit. The second approach, however, may not reach those who do not have Internet or email access.

It is important to keep these "mini-surveys" short, limiting the number of questions to five or fewer straightforward questions including scale ratings or check boxes, with one optional open-ended question at the end. The post-visit feedback questions could be associated with a youth client's account or a specific visit (e.g., through the kiosk); however, they can also be made anonymous. Anonymity may depend on what questions are included and how the organization plans to use the results. The post-visit survey differs from a client satisfaction survey, as it focuses on a specific visit or specific staff members who served the youth client, and is much shorter.

It is also critical for providers to monitor survey results and take action on issues identified by the surveys. Analyzing the survey results can take time, and time-consuming analysis may delay action. Since these post-visit surveys are short, routine monitoring (e.g., once a month) could focus on low ratings and responses to the open-ended question and identify specific issues. Providers should also review aggregate results to identify trends and gauge overall performance and client satisfaction. Findings from these surveys could be reasons to conduct feedback interviews (see Strategy 2).

SAMPLE QUESTIONS FOR POST-VISIT MINI-SURVEYS

- How satisfied am I with this visit (rate on a scale of 1 to 5, with 1 indicating "not satisfied" and 5 indicating "very satisfied")? 1 2 3 4 5
- My clinician answered all of my questions clearly.
  Yes ☐ No ☐ Other: ____
- My case manager was able to answer my questions, address my concerns, and provide necessary resources.
  Yes ☐ No ☐ Other: _____
- What comments do you have regarding this visit and any staff members you interacted with?

MONITOR ONLINE PROVIDER REVIEWS

An increasing number of healthcare providers are being rated online, even when providers are not soliciting it (usually anonymously). Youth clients are more likely to search online for health information and to rely on online physician ratings before seeing a doctor.[1] Youth clients also are more likely to submit feedback online rather than communicate directly with the provider, as online reviews often do not require verification of client identity or authenticity of visit details. Although online healthcare reviews are controversial, providers suggest monitoring them and acting when appropriate.

[1] Ellimoottil C et al. (2013). Online physician reviews: The good, the bad, and the ugly. Bulletin of the American College of Surgeons. http://bulletin.facs.org/2013/09/online-physician-reviews/#.WhiPiVWnHIU

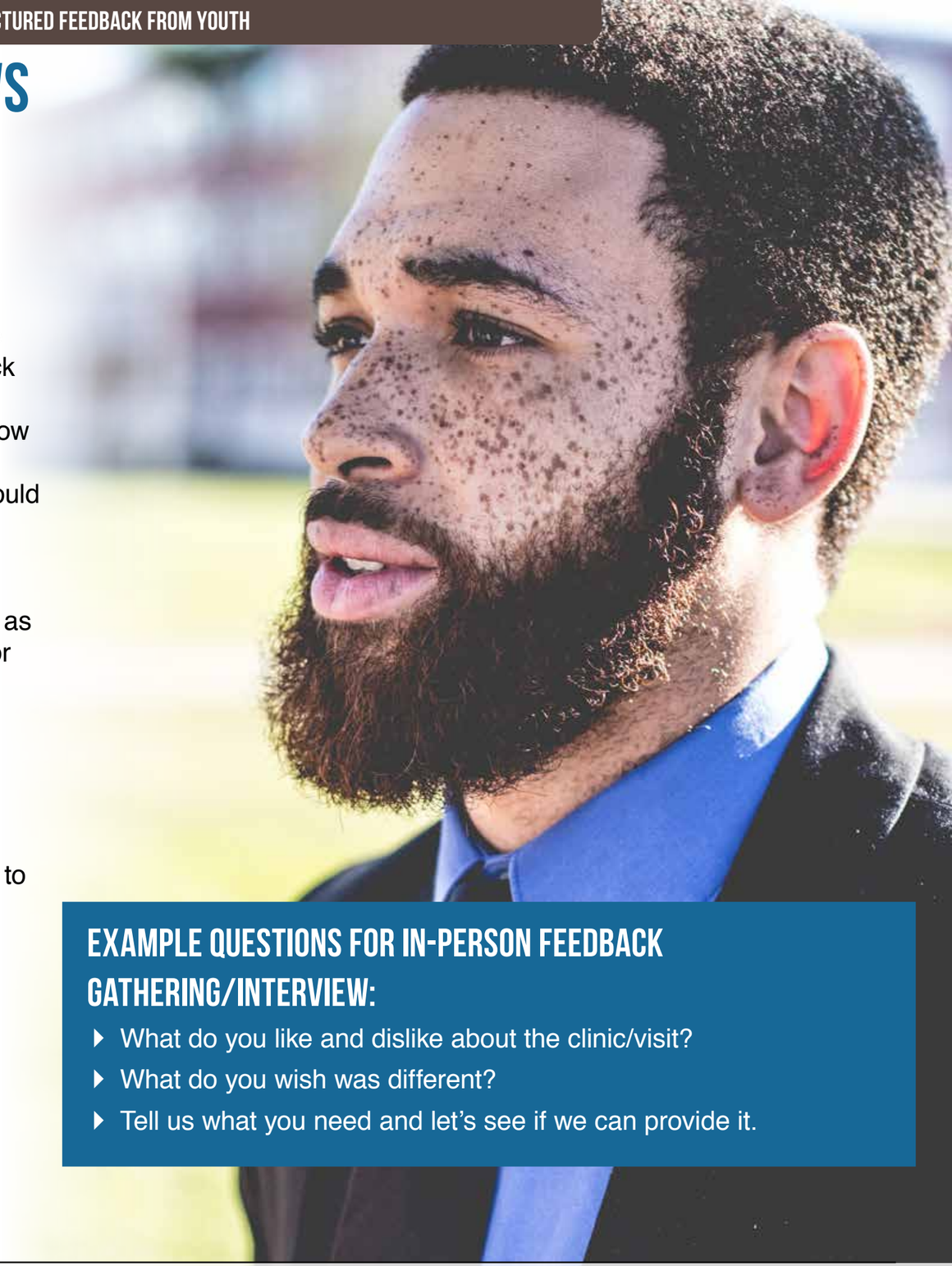
STRATEGY 2. INCORPORATING FEEDBACK INTERVIEWS AS PART OF THE ROUTINE/WORKFLOW

INFORMAL FEEDBACK INTERVIEWS

According to YLWH, their case managers are often the first persons they would approach with a complaint, suggestion, or concern. Rather than waiting for clients to speak first when an issue arises, case managers may consider routinely asking youth clients for suggestions and feedback at least twice a year. These informal interviews can be used to inquire about youth clients' relationships with their clinician/key staff to gather feedback about the clinic in general, or to follow up on low ratings or specific feedback from the previous post-visit survey. Depending on the situation, a case manager, nurse, peer navigator, or someone who is close to the youth client could proactively ask for feedback during an appointment (perhaps during the last five minutes of the meeting).

The informal feedback interview also can be embedded in a support group. It can be organized as a quick group discussion (with less than three questions) or a paper-and-pencil short survey. For tips on organizing a support group, please see the topic Youth Support Groups.

A set of three to five questions may work best, with answers documented; a plan to respond to feedback also may be outlined. The provider could consider allocating time in a staff meeting to discuss collected feedback, identify follow-up actions, and address them accordingly. It is important to implement changes as fast as possible to show clients that the agency is serious about their feedback. If there are barriers for implementing youth client suggestions, circle back to the client to demonstrate that the provider has considered the feedback.



EXAMPLE QUESTIONS FOR IN-PERSON FEEDBACK GATHERING/INTERVIEW:

- What do you like and dislike about the clinic/visit?
- What do you wish was different?
- Tell us what you need and let's see if we can provide it.

STRATEGY 2. INCORPORATING FEEDBACK INTERVIEWS AS PART OF THE ROUTINE/WORKFLOW (CONTINUED)

GAIN INSIGHTS INTO THE YOUTH CLIENTS - EMPATHY MAP

Empathy mapping is a quick and easy visual tool to help understand a person's experience and communicate that experience to others. Such mapping could be conducted as part of the psychosocial assessment or part of the eligibility recertification. Empathy mapping also could help staff gain insight into the youth clients' unique perspectives when they are in confronted with unfamiliar or difficult situations, assisting the staff in prioritizing client needs.

Empathy mapping is typically done using a pen and paper with individuals or with markers and large paper when conducted in a group. It normally includes these steps :

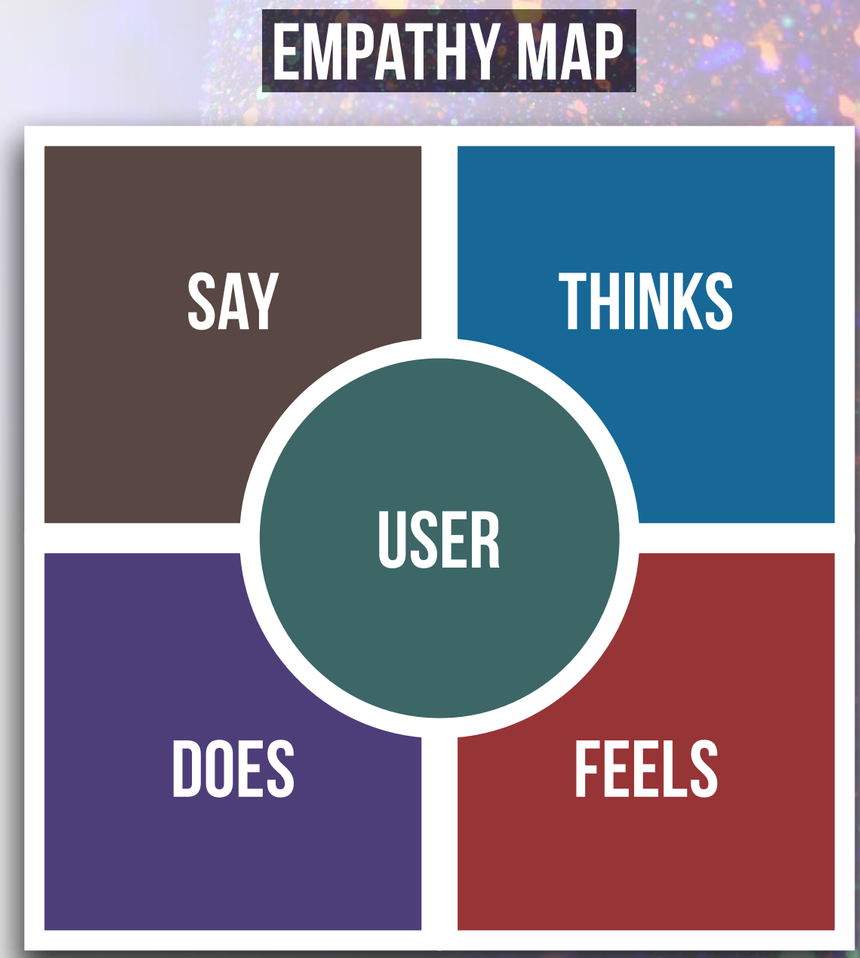
1. **Identify what experience you are trying to understand.** An example might be: "What is it like for youth to keep their HIV status a secret from their family?" or simply "What does your day look like?"

2. **Tell people what you are trying to understand and get their consent before you start asking questions.** Make sure clients are comfortable discussing the experience with you.

3. **Ask a question from each quadrant on the empathy map and listen to the answers.**
   - **A. Says.** The quotes and defining words the client said.
   - **B. Thinks.** What might the client be thinking? What does this tell you about his or her beliefs?
   - **C. Does.** What actions and behaviors did you notice?
   - **D. Feels.** What emotions might your client be feeling?

4. **Write down what people say in the relevant quadrant of the map.** Try to use their exact words whenever possible.

5. **Repeat the process until you keep hearing the same things.** This means that you likely have a good representation of the experiences of the youth clients. In a group setting, everyone can be asked the same question; the same process can be used to record the answers. This can be an effective way to get people thinking differently about a problem or to share their different perspectives.



STRATEGY 3. INVITING YOUTH TO CLINIC PLANNING MEETINGS/REVIEWS TO GATHER OVERALL SUGGESTIONS

Providers may consider inviting youth client representatives to participate in clinic-wide planning or review meetings. These meetings differ from weekly or monthly staff meetings, which often focus on care coordination, issue resolution, and short-term planning. They also differ from Consumer Advisory Board (CAB) meetings, as the scope and list of attendees are often broader, and clients' attendance can be optional. Instead, these planning or review meetings often take place once or twice a year and are attended by clinic staff, internal and external stakeholders, and clients, who discuss new initiatives, accomplishments, challenges, and plans for the upcoming year. Inviting youth clients to these meetings could help them understand the clinic's current state, future direction, and limitations, which could enable them to provide constructive feedback that is informed by this increased knowledge.

STRATEGY 4. YOUTH CONSUMER ADVISORY BOARDS

CABs offer another way to gather constructive feedback and engage youth clients in clinic planning activities. Providers may use CABs in different ways or may call them by other names. For clinics that serve a mixture of adult and youth populations, it is important to have a dedicated youth CAB if possible, or at least include youth clients on the adult CAB. A CAB can take many forms, dependent on the client population. For example, some CABs may include members who are and who are not living with HIV; clients served by the clinic and community stakeholders; and may inform both clinic operations and research activities.

Regardless of the composition of the CAB, it is important to keep the group engaged and active. Several measures may be employed, such as appointing an organizer to whom members can relate or are likely to respond to. CABs can be used to advertise to the target population, leverage other resources (e.g., research, other funding) to provide incentives, and address specific discussion topics that are interesting and meaningful to the target population. To learn more about establishing and operating CABs, read Getting Started: A Consumer Advisory Board Manual for Title IV Programs and A Self-Assessment Tool for Consumer Advisory Boards.

YOUTH CAB: PROFILES FROM THE FIELD

One provider in Florida has a youth CAB with a diverse group of members that includes YLWH served at the clinic, youth from local high schools, coordinators from local organizations focused on youth well-being, and students working on research projects related to the clinic. The CAB informs the clinic's operations, outreach, and education efforts. Because of its diverse focus, the CAB is very active, and has come up with creative ideas for community engagement, such as handing out educational materials and HIV/STD testing brochures on Halloween night. Additionally, incentives such as food (provided through a non-Ryan White HIV/AIDS Program [RWHAP] funding source), fun activities, and a chance to make a difference in the community attract youth to the CAB and encourage their continued participation.

TOPIC 3.2 DATA-DRIVEN PROGRAMMING FOR YOUTH

Most providers understand the importance of data analysis in quality improvement efforts. Data analysis also can help providers justify the financing of a program or staff member (e.g., peer navigator who re-engages clients in care). These providers have relatively easy access to outcomes data through their clinical and reporting practices. This access allows providers to regularly calculate viral suppression rates for various populations. However, providers may not drill down sufficiently to understand differences within the youth living with HIV (YLWH) population. Retention in care and adherence issues affect different YLWH subpopulations differently. Therefore, providers must identify the groups that face the greatest challenges (e.g., older YLWH, black/African American YLWH, or those who are perinatally infected) through more sophisticated data analysis. Providers can then channel resources and modify outreach efforts to meet the unique needs of these groups.

This topic presents five high-level steps that providers can use to develop more data-driven YLWH programming. This resource focuses on using healthcare service and outcomes data. A separate topic discusses processes for gaining feedback from YLWH – another essential data source.

FIVE STEPS TO ACHIEVING DATA-DRIVEN YLWH PROGRAMMING

STEP 1: SELECT PERFORMANCE MEASURES

STEP 2: IDENTIFY YLWH TARGET POPULATIONS

STEP 3: IDENTIFY THE DATA SOURCE

STEP 4: BUILD ANALYTICAL TOOLS

STEP 5: DEVELOP QUALITY IMPROVEMENT EFFORTS BASED ON FINDINGS

STEP 1: SELECT PERFORMANCE MEASURES

Performance measurement helps program staff determine whether a program is achieving its intended results. Measures should meaningfully capture the provider's objectives. They also should be actionable, reasonable to calculate, and easy to interpret. One of the hardest tasks of data-driven programming is defining performance measures. The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has done much of this work for providers.

HRSA HAB has identified five core performance measures to support the HRSA HAB Ryan White HIV/AIDS Program (RWHAP)-funded providers in measuring client service utilization and clinical outcomes. These performance measures were endorsed by the National Quality Forum (NQF), an organization that develops and rigorously tests measures to improve healthcare quality. The table below presents each measure's numerator and denominator, and provides comments on measurement implications and recommendations for use.

In addition to these core performance measures, providers also may want to assess utilization of primary and preventive care services for YLWH populations. For example, providers may be concerned with a recent syphilis outbreak, or may worry that they are not screening enough young women clients for cervical cancer. HRSA HAB has a more comprehensive list of measures that range from hepatitis C screenings to oral health exams.

FIVE CORE PERFORMANCE MEASURES

MEASURE	COMMENTS	DENOMINATOR	NUMERATOR
Viral suppression (Highly recommended for use)	Providers use viral suppression most frequently because it represents the primary health outcome for people living with HIV. When individuals are virally suppressed, the virus cannot be detected in their blood (or a very low level is detected). Providers may also want to assess "durable viral suppression," which requires at least two (or all) tests to indicate suppression. This measure may be used to detect YLWH who "rebound" due to lack of adherence.	Number of patients with a diagnosis of HIV, with at least one medical visit during the measurement year (and viral load reported).	Number of patients in the denominator with an HIV viral load less than 200 copies/ml at last HIV viral load test during the measurement year.
Prescription of antiretroviral therapy (ART) (Not necessarily recommended for use)	Individuals achieve viral suppression by taking ART. However, an individual prescribed ART may not adhere to the medication regimen, and thus may not achieve viral load suppression. Therefore, ART prescription is better used as a measure of appropriate healthcare than as a measure of a client health outcome.	Number of patients with a diagnosis of HIV with at least one medical visit during the measurement year.	Number of patients from the denominator prescribed ART during the measurement year.
HIV medical visit frequency (Recommended for use)	HIV medical visit frequency is an indicator of engagement in care, and thus is an indicator of individuals' adherence to ART. This measure assesses whether or not individuals are attending appointments at least every six months over a two-year period. HAB uses a slightly different measure for monitoring purposes, because Ryan White Services Report (RSR) data reporting periods are just one year. The "retention in care measure" assesses whether an individual had at least two appointments at least 90 days apart during a given year. While the "HIV medical visit frequency" measure is better for assessing longer-term engagement, it may not be effective for transient or recently diagnosed YLWH. Note that individuals may not regularly attend appointments, but may still pick up their prescriptions and continue to adhere to ART. On the opposite end of the spectrum, individuals might meet with their doctors, but remain unsuppressed due to lack of adherence. Therefore, once again, viral load is the true measure of quality health outcomes.	Number of patients with a diagnosis of HIV, with at least one medical visit during the first six months of the 24-month measurement period.	Number of patients in the denominator who had at least one medical visit during each six-month interval of the 24-month measurement period, with a minimum of 60 days between the first medical visit in the prior six month period and the last medical visit in the subsequent six-month period.

FIVE CORE PERFORMANCE MEASURES (CONTINUED)

MEASURE	COMMENTS	DENOMINATOR	NUMERATOR
Gap in HIV medical visits (Recommended for use)	Also a measure of engagement in care, a gap in HIV care is highly correlated with HIV medical visit frequency. However, studies also show that a gap in HIV medical visits might be slightly better at predicting viral suppression than the retention in care measure. This measure might be more appropriate to identify clients who have recently fallen out of care and need to be re-engaged.	Number of patients with a diagnosis of HIV who had at least one medical visit in the first six months of the measurement year. Providers may want to shorten the six-month duration for YLWH to better identify those at risk of falling out of care (See Retention in Care topic).	Number of patients in the denominator who did not have a medical visit in the last six months of the measurement year.
Prescription of PCP prophylaxis (Not necessarily recommended for use)	This measure assesses whether individuals with low CD4 counts are being prescribed Pneumocystis jiroveci pneumonia (PCP) prophylaxis. This is not necessarily recommended as a measure, because the calculation is complicated and it is primarily an indication of appropriate healthcare provision, not of health outcomes.	See HAB's performance measure document for specifications.	

STEP 2: IDENTIFY TARGET POPULATIONS

YLWH face different barriers to engaging in care. For example, young men who have sex with men (MSM) and transgender YLWH may face stigma or disapproval from their families, friends, and communities. Disclosing HIV status often means disclosing sexual orientation or gender identity, which can conflict with family and community values. Therefore, YLWH may carry the burden of their HIV status alone, receiving no emotional or logistical support for their treatment. YLWH who do disclose their status may lose their housing or may be ostracized by family, friends, and faith communities.

Perinatally-infected YLWH may struggle in different ways. Some may be resigned to their illness, may be tired of taking medications, or may have parents who do not serve as good role models because they do not adhere to their own HIV treatment regimens.

The 2016 Ryan White HIV/AIDS Program Annual Client-Level Data Report, which documents viral suppression rates for various YLWH populations, indicates that YLWH populations with the greatest challenges are transgender YLWH, young MSM, black/ African American, and YLWH who are uninsured, unstably housed, and at income levels at or below 100% of the federal poverty level.

Providers should understand different challenges faced by YLWH at their clinics by calculating performance measures not only for all YLWH, but for subpopulations.

SUBPOPULATIONS TO CONSIDER:

Gender identity
HIV risk factor
Age (13-17 versus 18-24)
Race
Ethnicity
Housing status
Medical insurance type
Poverty level

STEP 3: IDENTIFY THE DATA SOURCE

HRSA HAB RWHAP providers commonly use multiple data management systems for care management, billing, and reporting purposes. In addition to electronic health record (EHR) systems, which are primary sources for clinical and service utilization data, providers often use systems that allow their recipients to monitor grant activities. While CAREWare is the most common non-EHR system (used by about half of providers for reporting the Ryan White HIV/AIDS Program Services Report [RSR] data) many cities and states have developed their own systems to manage provider data. (Visit the TargetHIV website, formerly known as the TARGET Center for a list of these systems.)

The table below presents the pros and cons of each of these sources, in terms of data comprehensiveness, data timeliness, and availability of analytical tools.

Providers will need to carefully weigh their options and base decisions on their unique data management environments. For example, assume that a provider operates a HRSA HAB RWHAP data management system with user-friendly analytics tools. However, viral load test data are more complete and accurate in the provider's EHR. The provider might still choose to use the HRSA HAB RWHAP data management system for performance measurement to generate reports more quickly and more frequently.

ISSUE	EHR	HRSA HAB RWHAP DATA MANAGEMENT SYSTEM
What characteristics of the client population will be analyzed?	EHRs are often used across an entire healthcare system or community-based clinic and therefore contain data for all patients, regardless of their HIV status.	These systems only contain data on people living with HIV and therefore require less data manipulation.
How comprehensive are the data?	Providers primarily use EHRs to track and manage clinical care, so EHRs contain comprehensive medication, service, and lab data. However, they may not contain HIV-specific fields if they have been selected and customized by large healthcare systems and not by the HIV service provider.	Because recipients and private vendors develop these systems for HIV care providers, they contain all necessary HIV-related fields. However, they are not the provider's primary data system; therefore, data may not be complete. Time-consuming double data entry or faulty electronic bridges connecting the EHR to the HRSA HAB RWHAP data management system often mean that key clinical data, such as most recent viral load value, are lacking.
How up-to-date are the data?	Providers input data in real time, so they are typically very up-to-date.	Providers typically input or import data in alignment with recipient or HRSA HAB reporting requirements, which can require monthly or in some cases annual reporting. This means that data may not always reflect a client's current health status.
What analytical tools are available?	While EHRs offer analytical tools for providers, many of these tools require sophisticated data management skills. Providers often complain of the difficulty in extracting and using their EHR data. While large healthcare systems might have the analytical capacity, HIV clinics might not have easy access to these resources.	"Off-the-shelf" reporting tools such as performance measurement reports are often made available to providers through these systems. In addition, recipients may offer providers technical assistance resources on using these tools.

STEP 4: BUILD ANALYTICAL TOOLS

The analytical tools that providers use depend on their selected data management systems. In the following section, tools for HRSA HAB data management systems versus EHRs are described.

HRSA HAB DATA MANAGEMENT SYSTEMS

As previously discussed, HRSA HAB data management systems often have standard and customizable reports that allow providers to generate performance measures for specific populations. CAREWare users can begin with the following resources:

- Performance measure wiki
- CAREWare files for performance measures
- Webinar on CAREWare performance measures

Contact the CAREWare help desk to learn more. For non-CAREWare users, providers can contact their recipient or data management system vendor to learn about available tools. If recipients or vendors do not offer tools or support, providers may wish to encourage them to do so.

ELETRONIC HEALTH RECORDS

Providers often customize EHRs to suit local needs. They create their own workflow processes and data entry screens to capture key data elements. This means that while reporting tools are similar across providers that use the same EHR, the programming code that creates actual reports often must be created in house. Providers can take steps to ensure that they understand the purpose of each measure, the subpopulations for which they are calculating the measure, the definitions of the numerator and denominator, and the location of the related fields in the EHR. Providers need to keep the following in mind:

- Data mapping is likely necessary because provider's EHR data might be captured in a slightly different format than is required by the performance report.
- Services, labs, and medications are particularly tricky, because codes change regularly. If one code is replaced with another, the information linked to the previous code may not be pulled into the mapping process.
- Providers are encouraged to have their clinicians and intake staff use a limited number of service and lab codes to ensure that the majority of data are mapped and extracted. Providers will benefit from staying informed about any new codes that may be used, so they can incorporate them into their mapping processes.
- Once the report tool is programmed, provider staff need to know how to use it so they can periodically run reports without the assistance of IT support staff.

STEP 5: DEVELOP QUALITY IMPROVEMENT EFFORTS BASED ON FINDINGS

Once providers have developed reports, findings are helpful only if they are used. Providers can use findings to change clinical care provision or develop supplemental initiatives that target specific YLWH subpopulations. As a first step, providers should meet with their quality improvement teams (comprising clinicians, case managers, social workers, data analysts, and consumers) to discuss underlying reasons for disparities and potential strategies to address them. When developing strategies, providers also may consult directly with YLWH. Learn more through the topic on Gathering Structured Feedback from Youth. Other related topics that may be of interest include:

- Re-engaging Youth Lost to Care
- YLWH-Centered Services
- Improving Communication with Youth
- Youth Support Groups

The Plan, Do, Study, Act (PDSA) cycle, developed by Associates in Process Improvement (API),and promoted by the Institute for Healthcare Improvement, is a method for testing initiatives to address service needs. Additionally, providers often generate lists of YLWH who are not virally suppressed or engaged in care to distribute to clinicians, case managers, and social workers, so they can provide targeted care. These lists can be made available during monthly staff meetings or daily huddles in which providers cross-reference individuals on the list with clients scheduled to be seen that day. (See the topic on Interdisciplinary Care Teams for more on that approach.)

USING DATA TO MONITOR SUCCESS: PROFILE FROM THE FIELD

Maricopa County received a 2017 Quality Award from the National Quality Center (NQC) for increasing viral suppression rates across the jurisdiction by 7 percent. One of their subrecipients, which primarily serves Native Americans, implemented a PDSA cycle involving intensive case management; 95 percent of clients participating in this initiative achieved viral suppression.

One provider conducted an in-depth analysis on no-show rates and found that the same individuals tended to miss their appointments and many of them were very low income. The provider developed more intensive reminder and support efforts to encourage these individuals to come to their appointments. This organization also posts data snapshots in their lobby, highlighting the types of services PLWH receive, so their clients are more aware of and take advantage of the services offered.

An epidemiologist at another provider location sat with the clinic's patient navigator while she input data into their EHR so she would understand exactly how EHR fields were being used and to identify additional data collection needs for future analyses. This provider also emphasized the importance of supplementing canned reports from the EHR with a manual review of the data. This process allows the epidemiologist to understand the unique challenges faced by the small subset of clients that struggle with medication adherence.

THEME 4
WRAPAROUND SERVICES

HRSA HAB BUILDING FUTURES:

SUPPORTING YOUTH LIVING WITH HIV TECHNICAL ASSISTANCE TOOLKIT

TOPIC 4.1 YOUTH SUPPORT GROUPS

This topic provides suggestions and resources from the field for conducting support groups for youth living with HIV (YLWH), a review of lessons learned from the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB) Ryan White HIV/AIDS Program (RWHAP)-funded providers, and brief descriptions of different models for support groups. It also addresses important considerations for sustaining a support group and discusses resources and ideas for group facilitation.

The providers that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project noted that a strong support group is key in helping youth clients achieve viral suppression and stay in care. Support groups also can help YLWH build social networks, increase knowledge and skills, and decrease social isolation. Support groups provide a community for youth to discuss issues related to their HIV treatment and care, as well as life and social issues. Groups also work to build camaraderie among the participants and help to address issues that might impact a youth client's treatment, such as medication adherence, side effects, and disclosure. It was noted that support groups can be general or target specific populations, such as newly diagnosed YLWH, women, men who have sex with men (MSM), people of color, or youth who were perinatally infected.

Support groups have a long history in HIV care and treatment. Studies have shown that support groups impact morbidity, retention in care, mortality, and quality of life for people living with HIV. Involvement in support groups also has been shown to improve the disclosure rate in clients.[1]

Many of the YLWH interviewed in the Building Futures project expressed the importance and value of formalized youth groups offered by providers.

[1] Bateganya M, Amanyeiwe U, Roxo U, Dong M. The Impact of Support Groups for People Living with HIV on Clinical Outcomes: a systematic review of the literature. Journal of acquired immune deficiency syndromes (1999). 2015;68(0 3):S368-S374. doi:10.1097/QAI.0000000000000519.

STEP 1: DEVELOPING YOUTH SUPPORT GROUPS

Many providers reported that having a separate support group for youth based on needs that are unique to YLWH was critical. Therefore, the first step in developing a support group is identifying the needs of youth clients to determine the type of group that would be most beneficial. The next step is to establish goals for the support group and identify the population it will serve. This information is crucial in deciding who will lead the group and who will be invited to participate. From the outset, the goals of the group need to be clearly defined and communicated to staff and participants. As group dynamics develop and client needs change, goals may need to be adjusted accordingly.

ESTABLISH THE GOALS OF THE GROUP

After identifying client needs, the next step is to establish goals for the support group and identify the population it will serve. This information is crucial in deciding who will lead the group and who will be invited to participate. Group goals may be very structured, but also may be very simple, such as: 1.) Help the youth feel less isolated, 2.) Help fight the stigma they face, and 3.) Provide a safe place to talk about anything. One of the main goals of any group should be to create an environment of trust between the facilitator and youth participants.

IDENTIFY THE STRUCTURE OF THE GROUP

After determining the type of support group that is needed and establishing its goals, it is necessary to identify a structure for the group. While providers expressed the importance of how a support group is implemented, the actual structure of the group can be very flexible. Traditional support groups usually meet at a set time and specific day. In making this decision, it is important to solicit client and staff feedback on group structure and utilize it to build the structure that will be most responsive to youth clients' needs. Considerations include support group type, such as utilizing a structured curriculum versus allowing discussions to be free-form, open versus closed, timing and frequency of meetings, and location.

REFINE LOGISTICS

After establishing the group's goals and structure, it is then possible to refine logistical considerations, such as who will lead the group, where it will meet, and for how long. When selecting a location, it is important to choose a space that is private enough so that participants feel comfortable sharing and will consider the location a safe place. Organizers also may wish to consider whether the group will be ongoing or will have a specific number of meetings and an end date. Another consideration is whether to provide meals and snacks (if there is a budget for food) or transportation support for the youth clients. Lastly, determine how participants will be identified and selected. For example, will the group be open only to newly diagnosed clients?

MARKET TO THE DESIRED AUDIENCE

After the goals and logistics of the support group have been finalized, providers can begin to develop marketing materials that will help engage youth. Recruitment should be based on the established goals. To ensure continued participation, outreach efforts must be ongoing. Providers may consider identifying a dedicated staff member to work on recruitment and retention efforts.

Important considerations that contribute to the ongoing success of a support group include establishing staff support and having protocols for supervision of the facilitator(s). From the outset, organizers must convey clear information about what will take place within the support groups, who will be responsible for running the group, timelines, and goals for implementation. It also is important to outline a feedback loop for facilitators and youth clients that will provide regular input into the process and help providers gauge success based on the support group's established goals.

STEP 2: SUPPORT GROUP FACILITATION

After clearly outlining the goals and focus of the support group, providers can then decide who will lead the group, based on level of experience and expertise. Once a staff member (or two) have been identified to lead the group, it is recommended by providers that organizers meet with them to discuss the established goals. As logistics are refined, the staff facilitator should remain engaged in the process. Ideally, the staff facilitator should lead the logistical process to ensure the facilitator's understanding and buy-in. It is necessary to clearly define processes for regular supervision of the facilitators so they have an avenue to voice concerns, ask questions, or provide feedback. Organizers also should decide how the staff facilitator(s) will be trained, if necessary, before the group begins, and how they will receive ongoing training in group facilitation and working with youth.

It is recommended that the staff facilitator develop an outline of the support group plan that will allow opportunities for ongoing feedback from clients. Many clinical staff who run support groups identify general facilitation topics for the group, but they also remain flexible, letting the conversation flow based on the topics group members would like to discuss.

Support Groups: Things to note when running a group:

- It is often useful to have an open-door policy for a support group, allowing participants to come and go as needed. While this might help increase attendance, it may slightly disrupt the flow of the group, so it will be necessary to develop a curriculum or group structure that allows for these disturbances.
- Being flexible to address the immediate needs of youth is necessary to maintain attendance. Providers should work with the youth and agency to identify creative solutions to issues that might decrease attendance.
- Facilitating a support group can be challenging. Identifying the right staff member to conduct a group can be crucial to its success. (See the Staff Recruitment and Retention topic to help identify the staff.)
- When beginning a new support group, it is useful to identify a staff member who has a strong rapport with the youth and who has experience facilitating support groups. Before introducing new staff as facilitators, it is recommended to first allow them to shadow a strong group facilitator to ensure that they feel comfortable conducting support groups. They also will need sufficient support from supervisors and colleagues to debrief after the sessions.

Sample Support Group Session:

- **Start with a check-in or icebreaker to begin the session.**
  - ◊ Examples of check-ins/icebreakers from programs interviewed: Have everyone share a story about or the background of their name or play Two Truths and a Lie. Two Truths and a Lie asks each participant to share with the group two truths and one lie about themselves. The group then guesses which statement is untrue.
- **Move into the content of the session.**
  - ◊ Depending on the structure and goals of the group, this may be a formal curriculum that is facilitated during each session, or it could be an informal topic to be discussed. Instead of proposing a topic, ask the group what they would like to talk about during the session. However, it might be necessary to have topics ready to discuss in case the participants do not propose topics.
  - ◊ Examples of discussion topics could include: living with HIV since birth, strategies for keeping appointments, disclosing your status to loved ones, ways to remember to take medication, or a news article of interest for the group to respond to. Providers interviewed also recommended websites such as TherapistAid.com, PostivePeers.org, and hazeldenbettyford.org as resources for identifying topics.
- **End the session with a check-out.**
  - ◊ Examples for check-outs may include reading a poem, asking a question about how the youth are feeling, or reading a daily meditation.

SUPPORT GROUPS: PROFILES FROM THE FIELD

A support group for newly diagnosed youth clients started by one provider set specific topics for each week, since the support group lasted for six weeks. This group addressed HIV treatment, the importance of medication adherence, and side effects of medication.

STEP 3: TYPES OF SUPPORT GROUPS

There can be various types of support groups within different provider settings, depending on the needs of the youth client populations served. As previously discussed, some groups may be organized with specific educational topics for each session, while others may be more open, or may cover topics other than HIV care.

Each of the support groups described in this toolkit has the capacity to work independently from each other. For example, an agency can decide to implement a group that only focuses on enrichment activities or is a substance use treatment group, or they can choose elements from each and create a multi-focused group. It is also possible to adopt elements from several types of groups described to create a hybrid model. For example, some providers have opted for a hybrid of the more traditional weekly support group, supplemented with a fun activity every month or every other month. This facilitates HIV care, education, and support, while also engaging YLWH in fun activities that build social support.

Providers reported participating in community enrichment activities. These activities included volunteering at soup kitchens, food drives, or other community service events. Through these enrichment activities, the youth clients developed camaraderie with fellow participants, as well as with their larger community. One benefit of such activities is that they are not limited to a structured time, and are often available on weekends throughout the year, which might work better for youth clients' schedules. Since providers reported that many YLWH face challenges with transportation, it is important to identify ways to support youth clients who want to participate, such as organizing transportation or offering transportation reimbursements.

Some providers reported creating support groups that address topics other than HIV treatment and care. Instead, these support groups address topics related to education, work, and housing. Although these topics do not relate directly to retention in HIV care and treatment adherence, providers reported that it is helpful to have a support group addressing life issues that might impede clinical outcomes. The groups helped participants build a sense of community and support, and provided them with resources and education on relevant topics. It is important to identify the needs of each specific group to determine whether topics should be covered in a life skills support group, or in tandem with a more traditional support group.

STEP 3: TYPES OF SUPPORT GROUPS (CONTINUED)

ENRICHMENT ACTIVITIES

Providers reported participation in community enrichment activities. These included volunteering at soup kitchens, food drives, or other community service events. Through these enrichment activities, the youth clients developed camaraderie with fellow participants, as well as with the larger community. One benefit of such activities is that they are not limited to a structured time, and are often available on weekends throughout the year, which might work well for youth clients' schedules. Since providers reported that many YLWH face challenges with transportation, it is important to identify ways to support youth clients who want to participate, such as organizing transportation or offering transportation reimbursements.

LIFE SKILLS SUPPORT GROUPS

Some providers reported creating support groups that address topics other than HIV treatment and care. Instead, these support groups address topics related to education, work, and housing. Although these topics do not relate directly to retention in HIV care and treatment adherence, providers stated that it is helpful to have a support group addressing life issues that might impede clinical outcomes. The groups helped participants build a sense of community and support and provided them with resources and education on relevant topics. It is important to identify the needs of each group to determine whether topics should be covered in a life skills support group, or in tandem with a more traditional support group.

ONLINE SUPPORT GROUPS

Some providers have decided to supplement traditional group activities and develop online support groups through social media platforms, such as Facebook. Social media-based groups offer support, but are not restricted to a specific location and time. These groups are closely monitored by provider staff to prevent harassment or disclosure issues. In addition to being a place for peers to lend support, these groups are also a place where resources and other educational materials can be shared. YLWH expressed positive feelings about Facebook support groups, since they allow them to check in with friends without a traditional meeting time. It is important to note that before starting an online support group, providers need to identify protocols that protect client health information covered by the Health Insurance Portability and Accountability Act (HIPAA). Online groups often require internal approval in advance, to ensure that youth clients' information is protected. (See Improving Communication with Youth topic for more information.)

RECREATIONAL ACTIVITIES

Some providers reported planning activities focused on fun rather than education. Such activities included bowling, karaoke, and holiday parties. These events are designed to build social support for youth clients in a fun and engaging environment that builds a sense of community. It is important to note that transportation might be an issue, and organizers will need to consider transportation options during the planning phase, to ensure that youth clients will be able to get to the event. Additionally, there might be a cost involved with such activities, and providers will need to determine if their budgets will cover the costs, or if their youth clients will be required to pay. Other providers have opted for a hybrid of the more traditional weekly support group, supplemented with a fun activity every month or every other month. This facilitates both HIV care education and support, while also engaging YLWH in a fun activity that builds social support.

STEP 3: TYPES OF SUPPORT GROUPS (CONTINUED)

SUBSTANCE USE SUPPORT GROUPS

Providers reported that substance use is one of the greatest areas of concern for the YLWH they serve. In response, agencies reported creating support groups that focus on YLWH with substance use issues and the specific challenges those clients face. If a provider does not have the capacity to address substance use, it is important that they build relationships with community partners for referrals.

YOUTH CAMPS

Some providers reported that camps for YLWH represent another avenue for developing social support. While most providers do not establish or run camps, it may be beneficial to identify any camps designed for YLWH in or near the community. These camps are designed to help youth build relationships and also offer support and education on HIV care and treatment. Other providers reported that some general camps do not focus on or discuss HIV status, so that YLWH can attend without disclosing their status. Some YLWH who participated in these camps reported making friends who provided ongoing support in their lives.

REFERRALS TO OUTSIDE SUPPORT GROUPS

Providers sometimes found it necessary to refer clients to partnering service providers that offered other types of support groups to address specialized needs not addressed in-house. For example, if a provider did not have the internal capacity to conduct a substance use support group, they referred youth clients for support in this area. One clinic teamed up with a local Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) community-based organization (CBO) to send clients to a LGBTQ-specific support group. These partnerships and community referrals allow providers to expand the resources they can offer their youth clients.

ADDITIONAL RESOURCES

RESOURCES FOR ESTABLISHING SUPPORT GROUP

https://careacttarget.org/library/support-group

The Support Group intervention provides a protocol for establishing support groups that provide a confidential space where people can share their experiences of living with HIV and benefit from peer support in coping with and overcoming stigma and fear issues.

https://careacttarget.org/library/support-retreat

The Support Retreat provides a protocol for a group-level intervention to allow people living with HIV to meet with other infected individuals to share experiences, develop a support network, and engage in peer-to-peer education.

https://careacttarget.org/ihip/webinar-out-of-care-women-of-color

This on-demand webinar discusses how to leverage evidence-informed interventions to further engage and retain women of color in care in both urban and rural environments.

https://careacttarget.org/library/woman-woman-support

The Woman-to-Woman Support intervention provides a protocol for health educators to work with women living with HIV or at risk of infection to develop confidence and skills that lead to accessing HIV testing, engaging in care if infected, and coping successfully with HIV.

TOPIC 4.2 IDENTIFYING AND ADDRESSING SUPPORT SERVICE NEEDS

The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Ryan White HIV/AIDS Program (RWHAP) supports a comprehensive array of services to address the needs of uninsured, underinsured, and low-income populations. In addition to core medical services, such as outpatient ambulatory health services (OAHS), treatment for mental health and substance abuse, and medical case management services, HRSA HAB RWHAP also provides critical support services. These services help address the basic needs of people living with HIV (PLWH) and include housing assistance, transportation assistance, food banks/home-delivered meals, and emergency financial assistance. Economic instability often leads to unstable housing, which makes it harder for youth living with HIV (YLWH) to safely store and access their medications. YLWH also may face other barriers to care, such as a lack of healthcare coverage or access to transportation. The challenges to addressing these needs are exacerbated for YLWH.

A majority of YLWH (76%) receiving services from HRSA HAB RWHAP-funded providers in 2016 had incomes below 100% of the federal poverty level.[2] The American Academy of Pediatrics, Committee on Pediatric AIDS noted that factors that impact treatment adherence and viral suppression for YLWH include poverty, food insecurity, unstable housing, and lack of or limited education and employment.

Several essential support services were identified by HRSA HAB RWHAP-funded providers who participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project, including:

- Transportation assistance is a critical need and is most commonly reported across sites. Inadequate public transportation, unreliable Medicaid-supported transportation, and long distances in rural areas present barriers for many youth clients. In addition, many providers noted that for lesbian, gay, bisexual, transgender, and questioning (LGBTQ) YLWH, public transportation often presents safety risks.
- Food insecurity among YLWH was commonly reported. Providers also emphasized the importance of having food available during appointments, support groups, and other clinic services.
- Housing instability was frequently reported, as some YLWH may be "couch surfing," living with friends/partners, or in other transitional housing situations. Others may still live with family members, but may not have disclosed their HIV status, sexual orientation, or gender identity.
- Job training, clothing, and school supplies were noted as needs among YLWH. Addressing these needs can reduce the broad barriers to remaining in HIV care that result from unemployment or a lack of educational attainment
- Economic issues are common among youth, highlighting the need for financial assistance and incentives. In addition, youth often need assistance with budgeting, establishing a bank account, and developing financial literacy.

Addressing these needs can be difficult because reasoning and executive functioning skills are not fully developed in youth. This often impacts their decision-making and prioritization of HIV care appointments, which contributes to the larger challenges of keeping youth in care and virally suppressed. Understanding and effectively addressing these needs is critical. Three key steps that providers can use to assess support service needs among YLWH and leverage HRSA HAB RWHAP funding and other resources to effectively meet these needs are outlined below.

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[1] Health Resources and Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016*. http://hab.hrsa.gov/data/data-reports. Published November 2017. Accessed December 27, 2017.
[2] Martinez, Jaime, Rana Chakraborty, and the Committee on Pediatric AIDS. "Psychosocial Support for Youth Living With HIV." *Pediatrics* 2014;133,558. DOI: 10.1542/peds.2013-4061. Originally published online February 24, 2014.

STEP 1: ASSESS NEEDS

Providers must first gather information to understand the specific needs of the youth clients they serve. Ongoing needs assessment, beginning at intake, and continuing during the provision of care, is critical to ensuring that providers are responsive to the needs of their YLWH clients. Assessments provide not only an opportunity to gather important information, but also to establish rapport with clients and help them feel more engaged in care.

Using both formal and informal assessments and ensuring good communication among the care team were identified as effective strategies among the providers interviewed as part of the Building Futures project

FORMAL ASSESSMENT

As part of care delivery, YLWH receive a formal assessment. In addition to assessing HRSA HAB RWHAP eligibility, the assessment addresses a broad range of socio-demographic topics that need to be incorporated into care delivery. TargetHIV, formerly known as the TARGET Center has several examples of case management assessment forms. Common areas for assessment include:

Areas for Assessment:

- Income
- Transportation Assistance Needs
- Housing Stability
- Food Insecurity/Nutrition Needs
- Job Training Needs
- Intimate Partner Violence
- Mental health and substance use issues

Case management is a critical component of HRSA HAB RWHAP-funded services that can assess and address these needs. Medical and non-medical case management services were the second and third most commonly utilized services at HRSA HAB RWHAP-funded providers in 2016; only outpatient ambulatory health services (OAHS) were more commonly utilized.[1] Medical case management services focus on improving healthcare outcomes, while non-medical case management services focus on improving access to other needed services.[2] Both medical and non-medical case management include initial assessments of service needs and the development of individualized care plans that are re-evaluated at least every six months. Using empathy maps can be a helpful technique for learning more about client needs; more information can be found in the Gathering Structured Feedback from Youth topic.

As the initial assessment is often the youth client's first care experience at a clinic, it is important to ensure that the necessary information is obtained, and that staff conducting the assessment are trained to address the specific needs of YLWH. For more information about staff training, review the Staff Recruitment and Retention topic.

[1] Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2016. Webinar presented on November 29, 2017
[2] Ryan White HIV/AIDS Program Services: Eligible Individuals & Allowable Uses of Funds Policy Clarification Notice (PCN) #16-02 (Revised 12/05/16)

INFORMAL ASSESSMENT

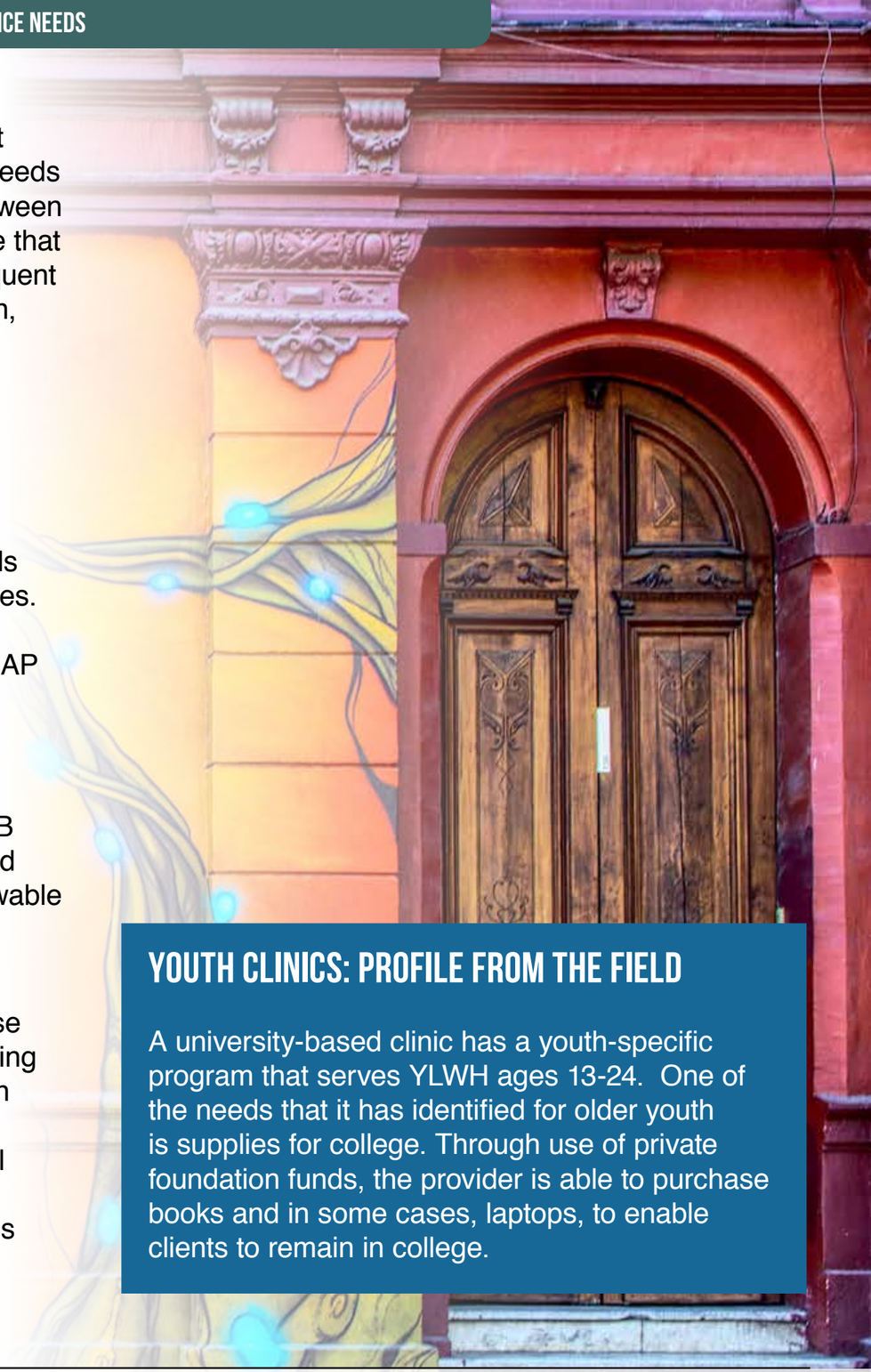
It is critical for case managers, clinicians, and other members of the care team to focus on broad youth client needs, including transportation, food, housing, and job training, among others. Assessment of the ongoing needs of YLWH can be integrated into regular visits so providers can be alerted to any changes in youth needs between formal assessments. In addition, communication among the members of the care team is essential to ensure that the entire team is addressing youth client needs. Informal care team "huddles" can be an integral part of frequent information sharing. For more information on informal huddles and interdisciplinary care team communication, review the Interdisciplinary Care Teams topic.

STEP 2: IDENTIFY AVAILABLE ORGANIZATION RESOURCES

After identifying YLWH needs, each organization will need to identify available resources to meet these needs and link clients to services. As previously noted, HRSA HAB RWHAP funds a range of critical support services. However, the Ryan White HIV/AIDS Treatment Modernization Act of 2006 guides the allowable use of these funds, so it is important to review the latest HRSA HAB RWHAP policies to determine how HRSA HAB RWHAP funds can be used to address the needs of YLWH. The HRSA HAB Policy Clarification Notice (PCN) 16-02 provides a comprehensive review of allowable use of HRSA HAB RWHAP funds.

The table Meeting Support Service Needs (beginning on page 68) for YLWH outlines many of the common support service needs among YLWH and offers guidance on whether they can be provided using HRSA HAB RWHAP funds. These include transportation assistance, housing assistance, and food banks/home-delivered meals. However, costs for clothing and employment or employment-readiness services are typically not allowable under the legislation. Addressing economic issues, also identified by several providers as a need, are not supported by HRSA HAB RWHAP funding.

Providers often use funding sources other than HRSA HAB RWHAP to address support service needs. These include other federal funding sources, such as Department of Housing and Urban Development (HUD)/Housing Opportunities for Persons with AIDS (HOPWA); Substance Abuse and Mental Health Services Administration (SAMHSA) grants for mental health and substance use; and state funding. In addition, some providers participating in research studies have access to non-HRSA HAB RWHAP funding to provide food or financial incentives. Access to private non-profit or local government funding for services that cannot be provided by HRSA HAB RWHAP are other possible resources. One provider noted the importance of collaboration across programs within the organization as an effective way to leverage different funding streams to address the needs of YLWH.



YOUTH CLINICS: PROFILE FROM THE FIELD

A university-based clinic has a youth-specific program that serves YLWH ages 13-24. One of the needs that it has identified for older youth is supplies for college. Through use of private foundation funds, the provider is able to purchase books and in some cases, laptops, to enable clients to remain in college.

HRSA RYAN WHITE HIV/AIDS PROGRAM SERVICES: MEETING SUPPORT SERVICE NEEDS FOR YLWH (SOURCE: PCN 16-02)

SUPPORT SERVICE NEEDS	SUCCESSES FROM THE FIELD	SERVICE CATEGORY	PROGRAM GUIDANCE	WHAT'S NOT ALLOWED WITH HRSA HAB RWHAP FUNDS
Transportation assistance to appointments, support groups, and other clinic services	Agency van without markings, transportation network or rideshare services, such as Uber or Lyft Assistance with taxi vouchers Gas vouchers Bus/mass transit tokens Full-time transportation specialist	Medical transportation	▸ Contracts with providers of transportation services. ▸ Mileage reimbursement (through a non-cash system) that enables clients to travel to needed medical or other support services visits, but should not in any case exceed the established rates for Federal Programs (Federal Joint Travel Regulations provide further guidance on this subject). ▸ Purchase or lease of organizational vehicles for client transportation programs, provided the recipient receives prior approval for the purchase of a vehicle. ▸ Organization and use of volunteer drivers (through programs with insurance and other liability issues specifically addressed). ▸ Voucher or token systems.	▸ Direct cash payments or cash reimbursements to clients. ▸ Direct maintenance expenses (tires, repairs, etc.) of a privately owned vehicle. ▸ Any other costs associated with a privately owned vehicle such as lease, loan payments, insurance, license, or registration fees.
		Emergency financial assistance	▸ Limited one-time or short-term payments to assist the HRSA HAB RWHAP client with an emergent need to pay for essential utilities, housing, food (including groceries and food vouchers), transportation, and medication. Emergency financial assistance can occur as a direct payment to an agency or through a voucher program.	▸ Direct cash payments to clients are not permitted. ▸ All other sources of funding in the community for emergency financial assistance will be effectively used prior to use of HRSA HAB RWHAP funds. ▸ Continuous provision of an allowable service to a client should not be funded through emergency financial assistance.

HRSA RYAN WHITE HIV/AIDS PROGRAM SERVICES: MEETING SUPPORT SERVICE NEEDS FOR YLWH (SOURCE: PCN 16-02) (CONTINUED)

SUPPORT SERVICE NEEDS	SUCCESSES FROM THE FIELD	SERVICE CATEGORY	PROGRAM GUIDANCE	WHAT'S NOT ALLOWED WITH HRSA HAB RWHAP FUNDS
Housing assistance	Rent assistance Emergency housing	Housing	▸ Transitional, short-term, or emergency housing assistance to enable a client or family to gain or maintain outpatient/ambulatory health services and treatment. Housing services include housing referral services and transitional, short-term, or emergency housing assistance. ▸ Must assess every client's housing needs at least annually to determine the need for new or additional services. Must develop an individualized housing plan for each client receiving housing services and update it annually.	▸ Housing services cannot be in the form of direct cash payments to clients, and cannot be used for mortgage payments.
		Emergency financial assistance	▸ Limited one-time or short-term payments to assist the HRSA HAB RWHAP client with an emergent need to pay for essential utilities, housing, food (including groceries and food vouchers), transportation, and medication. Emergency financial assistance can occur as a direct payment to an agency or through a voucher program.	▸ Direct cash payments to clients are not permitted. ▸ All other sources of community funding for emergency financial assistance will be effectively used prior to use of HRSA HAB RWHAP funds. ▸ Continuous provision of an allowable service to a client should not be funded through emergency financial assistance.

HRSA RYAN WHITE HIV/AIDS PROGRAM SERVICES: MEETING SUPPORT SERVICE NEEDS FOR YLWH (SOURCE: PCN 16-02) (CONTINUED)

SUPPORT SERVICE NEEDS	SUCCESSES FROM THE FIELD	SERVICE CATEGORY	PROGRAM GUIDANCE	WHAT'S NOT ALLOWED WITH HRSA HAB RWHAP FUNDS
Food assistance	Food/meals provided in clinic setting and during support groups/youth activities	Food bank/ home-delivered meals	▸ Provision of actual food items, hot meals, or a voucher program to purchase food. Also includes the provision of essential non-food items limited to personal hygiene products, household cleaning supplies, and water filtration/ purification systems in communities where issues of water safety exist.	▸ Unallowable costs include household appliances, pet foods, and other non-essential products.
		Emergency financial assistance	▸ Limited one-time or short-term payments to assist the HRSA HAB RWHAP client with an emergent need for paying for essential utilities, housing, food (including groceries and food vouchers), transportation, and medication.	▸ Direct cash payments to clients are not permitted. ▸ All other sources of funding in the community for emergency financial assistance will be effectively used prior to use of HRSA HAB RWHAP funds. ▸ Continuous provision of an allowable service to a client should not be funded through emergency finacial assistance.

HRSA RYAN WHITE HIV/AIDS PROGRAM SERVICES: MEETING SUPPORT SERVICE NEEDS FOR YLWH (SOURCE: PCN 16-02) (CONTINUED)

SUPPORT SERVICE NEEDS	SUCCESSES FROM THE FIELD	SERVICE CATEGORY	PROGRAM GUIDANCE	WHAT'S NOT ALLOWED WITH HRSA HAB RWHAP FUNDS
Clothing	Encompasses both basic clothing needs, as well as job interview clothing.	None	Not an allowable use of funds.	Not applicable
Education support	Supporting educational materials such as books, backpacks, and laptop computers.	None	Not an allowable use of funds.	Not applicable
Employment training	Preparing youth for job interviews and employment.	None	Not an allowable use of funds.	Not applicable
Financial incentives	Incentives for attending appointments and participating in research.	None	Not an allowable use of funds.	Not applicable

STEP 3: ENHANCE COLLABORATIONS TO ADDRESS REMAINING GAPS

As noted in Step 2, HRSA HAB RWHAP funding alone may not be sufficient to meet the complex support service needs of YLWH, or a provider may not be funded for the necessary services. Providers noted the importance of collaborations with other agencies in their communities to meet the support service needs of YLWH. They emphasized that case managers should be aware of available resources, so clients can be referred as needed.

In addition to collaborating with other HRSA HAB RWHAP-funded agencies and community-based and AIDS service organizations (CBOs/ASOs), it is critical to look beyond HIV-specific organizations. One provider mentioned that they participate in a "cookie swap" with all support service organizations in the community (similar to a community resource fair). They also suggested calling 211 (funded by the United Way) to identify resources in the community.

After identifying other organizations that can provide support services to YLWH, it is helpful to establish a memorandum of understanding (MOU) to formalize agreements. Staff with previous experience at other provider sites can assist in establishing MOUs. For more information about linkages and MOUs, review resources on the TargetHIV, formerly known as the TARGET Center, including the Opening Door Linkages Training Manual. Statewide planning documents, such as the Integrated HIV Prevention and Care Plan and the Statewide Coordinated Statement of Need may be helpful in identifying additional resources. Contact the HRSA HAB RWHAP Part B representative for more information.

YOUTH CLINIC: PROFILE FROM THE FIELD

A community health center identified job/employment needs among YLWH served, and established a collaborative relationship with external agencies to address this need. The staff linked a young, homeless client to community partners to obtain identification and professional attire, and referred the client to additional agencies to receive interviewing and job skills training.

TOPIC 4.3 RE-ENGAGING YOUTH LOST TO CARE

Ensuring that youth living with HIV (YLWH) regularly attend clinic appointments is essential to improving their short-term and long-term health outcomes. YLWH are at risk for dropping out of care, which limits their exposure to treatment adherence messaging and impedes their access to core medical and support services. However, it is not always easy to determine whether clients have fallen out of care or if they may have moved or established care at another provider. Once out-of-care clients are identified, it can be just as hard to figure out how to reach them, re-engage them in care, and keep them engaged. The following steps include strategies and suggestions that providers can incorporate into a program to re-engage YLWH in care.

STEP 1: IDENTIFYING OUT-OF-CARE CLIENTS

Many providers that participated in the HRSA HAB Building Futures: Supporting Youth Living with HIV project have strategies for identifying clients who have fallen out of care. One common approach is to regularly generate out-of-care lists that alert staff when a client has not attended a clinic visit in a set length of time. Providers that lack data analysis capacity may rely on outreach workers, case managers, or other staff to identify clients who have not been in for a visit. According to providers serving YLWH, the process for identifying out-of-care youth may be different than the process for older clients.

ESTABLISH OUT-OF-CARE MEASURES

Many providers noted that younger clients may fall out of care more quickly than older or more stable clients. If providers wait until a YLWH client hasn't attended a clinic visit in six months, it may be too late to reach them. Providers use a variety of strategies to identify YLWH who have fallen out of care; however, what is effective for one provider might not work for another. Clinics should consider the following when selecting measures to identify out-of-care YLWH:

1. **Establish a shorter out-of-care window for YLWH.** The Health Resources and Services Administration, HIV/AIDS Bureau (HRSA HAB) retention in care measures consider two years of data, which is effective in gauging retention among established clients. However, this approach is not as effective at identifying clients who have fallen out of care, particularly those who are younger or newly diagnosed. Failure to attend clinic visits in one, two, or three months may be a better indicator than six months to determine who is out of care. A single missed appointment may also be a strong indicator that a YLWH client is at risk for falling out of care – providers reported that they follow up with YLWH who miss an appointment more aggressively than they would with an adult client.

2. **Consider support services as an indicator.** To attend appointments consistently, many YLWH need significant psychosocial and support services, including help with mental health and substance use issues and transportation services. When YLWH seek access to support services less frequently, it may signal that they are likely to miss a medical appointment.

3. **Consider non-clinical indicators, such as missing a lab draw, to identify out-of-care YLWH.** Clinics should consider establishing other indicators to identify YLWH who are out of care. For example, some providers have co-located lab services available, but find that YLWH leave their medical visits and do not receive lab services. Indicators such as skipping out on a blood draw, missing a lab visit, or failing to pick up a prescription may be appropriate to trigger an immediate re-engagement response.

4. **Providers should review data more frequently to identify out-of-care YLWH clients.** Once out-of-care measure(s) that effectively indicate when YLWH need re-engagement outreach are identified, clinics should consider how often to review data and conduct outreach. Clinics may wish to do so more frequently for YLWH than for older clients. Missed appointment lists for youth clients should be run at least weekly, if not daily. Finally, clinics may wish to frequently review viral suppression rates among YLWH to assess whether they are engaged in care and maintaining adherence to antiretroviral therapy (ART). For more ideas on how to use data, refer to Data Driven YLWH Programming in this toolkit.

STEP 1: IDENTIFYING OUT-OF-CARE CLIENTS (CONTINUED)

DETERMINE WHEN YLWH ARE CONSIDERED OUT OF CARE

Providers interviewed for the HRSA HAB Building Futures: Supporting Youth Living with HIV project reported that YLWH often live more transient lifestyles, which means that these measures may not paint a complete picture of when they have fallen out of care. YLWH may move more frequently, both within a service area and to other jurisdictions; and may also engage in behaviors such as substance use that put them at high risk for incarceration or missed appointments.

Given these challenges, case managers or other staff should cross-check out-of-care lists and/or caseloads against other available resources, such as incarceration and hospital records, to see if enrolled YLWH have been incarcerated or are seeking care at another location. Staff also may check YLWH social media for recent check-ins or posts that indicate that the client has moved to another area.

Finally, providers may wish to establish relationships with HIV Surveillance Data to Care programs to follow up on lists of YLWH identified as out-of-care. Matching provider-level and surveillance data can help further identify clients who have established care elsewhere or who have moved, died, or are incarcerated.

MAINTAINING UP-TO-DATE CONTACT INFORMATION

Being able to reach YLWH requires accurate and up-to-date contact information. YLWH often change contact information, particularly cell phone numbers, more frequently than other clients. Consider the following strategies for YLWH.

- Verify at least three points of contact in each visit, such as parents, partners, and friends.
- Explain to YLWH exactly what you will say to alternate contacts, e.g., “I’m calling from the University…” or “I’m Mary and I’m trying to reach…” rather than “I’m calling from the HIV clinic about your appointment.”
- Maintain multiple means of contact, such as text, email, social media, and mailing address. See the Improving Communication with Youth section for ideas. Obtain consent for each method of communication – some YLWH may not wish to be contacted on social media, for example.

[1] Chassin, Laurie. (2008). Juvenile justice and substance use. The Future of Children, 18(2): 165-183.

STEP 2: INTENSIVE OUTREACH AND LINKAGE

Once clinics have identified YLWH who have fallen out of care and are candidates for re-engagement, they will need to establish outreach policies and procedures to bring clients back into care. It may be feasible to conduct outreach efforts in-house, or clinics may wish to establish partnerships with other organizations to facilitate linkage. A mixture of approaches may best fit the capacity and YLWH population of a clinic.

WHO IS RESPONSIBLE FOR OUTREACH?

Involving case managers, social workers, and other support staff is a great first step in efforts to reach youth clients. These staff members often have developed a rapport with clients and may be familiar with client-specific challenges or strategies for tracking down particular clients. Depending on organizational structure, these staff members may be able to go out into the community to meet with youth clients. For example, nurse case managers at one site traveled to clients' homes to schedule appointments if they were unable to reach them via phone. This may not be feasible for clinics that are part of a larger system that does not allow staff to leave the premises.

If resources are available, clinics should consider hiring an on-site linkage specialist who is dedicated to linking new youth clients to care and re-engaging those who have fallen out of care. Responsibilities of a linkage specialist may include more intensive interaction with YLWH, such as personalized text reminders before appointments (see Improving Communication with Youth), brief intervention sessions when youth clients come in for care, or walking YLWH through their appointments. Linkage specialists may be well-suited to work with hard-to-reach populations.

Another strategy is to hire peer navigators who are from the target youth population. This strategy proved effective in a recent HRSA HAB RWHAP Part F Special Programs of National Significance (SPNS) project designed to improve engagement of young men of color who have sex with men (MSM) in care. More information about the strategies implemented by HRSA HAB RWHAP Part F SPNS recipents is available on the HRSA HAB website.

Other providers are considering using their outreach and testing staff to conduct re-engagement activities, because these staff members are already engaged in the community and know clients. They may be familiar with the locations that YLWH frequent and know who within an identified youth client's social circle could provide information on that client's whereabouts. Several providers reported that they could add re-engagement responsibilities to existing staff member's roles.

Finally, providers that don't have the resources to conduct intensive outreach efforts or hire new staff may wish to consider developing partnerships with local organizations that have the necessary resources. For example, one university-based clinic has a close working relationship with their local health department, who assists in re-engaging YLWH who the provider couldn't reach.

DEVELOP AN OUTREACH AND LINKAGE PROTOCOL

Once clinics identify staff who will be responsible for outreach and linkage, they should develop a protocol for bringing YLWH clients back into care. The protocol will depend largely on the provider's staffing and capacity. For example, clinics with a linkage specialist on staff should consider having case managers attempt contact several times before referring the case to the linkage specialist. The linkage specialist also may try to establish contact via phone before going out into the community or trying to reach YLWH using another platform.

Providers also will need to develop protocols for a YLWH's first visit when returning to care. Protocols for outreach and linkage will serve as guidelines for staff, but development of flexible and creative approaches is encouraged. Some approaches may work for some YLWH, but not others, and a dynamic approach to service delivery will benefit all YLWH clients. Strategies to consider include:

1. **Meet youth clients where they are.** Providers must be understanding of lapses in care and nonjudgmental of youth clients when they return. For example, a youth client who has resumed substance use may not be ready to start substance use treatment, but may be receptive to getting back on HIV medications, or vice versa. Providers should do their best to identify the most pressing needs of YLWH.

2. **Understand what happened.** Understanding why a YLWH client fell out of care can help clinics provide needed supports to ensure successful re-engagement. Talk to youth clients about why they missed their appointments (e.g., issue with clinical provider, depression, housing instability) and build re-engagement strategies from there. At a minimum, a first visit back should include a check in with YLWH to understand the lapse in care and emphasize self-care.

3. **Have a shorter, more focused first visit.** Some providers believe that trying to fit too much into a first visit increases the likelihood that a youth client will fall out of care again. They may focus the first visit on lab work, for example; and wait to prescribe medication until the client is more stable. Clinics that take this approach should consider scheduling more immediate follow-up appointments.

4. **Have a more comprehensive first visit.** Other providers expressed that a youth client's first visit is the most important opportunity to communicate the importance of care and medications. These providers try to fit as much content as possible into the youth client's first visit in case they have a lapse in care afterward. This approach may be more appropriate for youth clients who have a history of gaps in care.

5. **Incorporate counseling and referral to support services into the first visit.** YLWH have often fallen out of care because of barriers such as housing instability or lack of transportation, which may be addressed by linkages to support services. Additionally, competing priorities and other life events are commonly associated with lapses in care. Having a youth client meet with a case manager/care coordinator for an assessment and referral to support services in their first visit may help address these barriers and prevent another lapse. (See Identifying and Addressing Support Service Needs for more information.)

6. **Have an outreach worker/case manager accompany youth clients to their first visit.** Several providers reported success when having an outreach worker, case manager, or other support staff member accompany youth clients on their first visit. This helps clients adjust and feel supported throughout their visit and offers the opportunity for the staff member to coordinate with care providers in case the youth client is overwhelmed and needs additional services.

STEP 3: RETENTION IN CARE

Once YLWH are brought back into care, providers will need to develop strategies for retaining them. Findings on retention in care among providers that participated in the site visit portion of the HRSA HAB Building Futures: Supporting Youth Living with HIV project include:

1. **Enhance essential support services.** YLWH face many barriers in accessing care, especially in terms of housing stability, transportation, financial security, food, and clothing. These concerns are often more urgent to YLWH than medical care. Consider offering more intensive support services to YLWH to stabilize them, rather than focusing solely on medical outcomes.

2. **Encourage YLWH autonomy.** Providers reported that YLWH who felt engaged in their treatment plans were more likely to be retained in care. For example, some providers offered youth clients a choice of clinician, and some actively involved YLWH in selecting medication regimens to improve the likelihood of maintaining medication adherence.

3. **Celebrate victories, no matter how small.** For YLWH who are coming back to care, recognizing incremental progress can be a meaningful and powerful motivator. Responding to a text, attending an appointment, or improving adherence to medications are great opportunities to celebrate progress and support YLWH.

4. **Take missed appointments seriously.** Just one missed appointment might mean that the youth client is falling out of care. Don't just send an automated reminder for them to make another appointment. Instead, ask case management staff to make an immediate connection to schedule another appointment.

5. **Identify support staff who work well with YLWH.** Case managers and social workers play a particularly important role in connecting youth clients to support services and keeping them engaged in care. Clinics may wish to assign newly re-engaged youth clients to a case manager/social worker who has experience working with younger, hard-to-reach clients.

6. **Schedule more frequent clinic visits for newly re-engaged YLWH.** When youth clients are first re-engaged in care, providers may want to schedule them for more frequent medical and non-medical visits before gradually scaling back.

7. **Promote continual contact with youth clients.** Providers reported that contacting YLWH frequently about appointments, medications, medical issues, and general check-ins improved retention in care. Providers are encouraged to consider adopting strategies to keep in contact with youth clients electronically.

8. **Establish programming specific to YLWH who are newly re-engaged in care.** Providers may wish to develop programming that specifically targets YLWH who have recently returned to care. For example, providers should consider allowing drop-in visits for a period of time after re-engagement, even if the clinic does not normally allow drop-ins.

There are also many resources available to help providers choose the right intervention(s) for improving retention among YLWH. More information about interventions funded by the SPNS program for innovative strategies is available on the TargetHIV, formerly known as the TARGET Center and HAB websites. In particular, the SPNS initiatives Dissemination of Evidence-Informed Interventions and Outreach, Care, and Prevention to Engage HIV Seropositive MSM of Color may be helpful in selecting approaches.

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