HRSA HAB Building Futures: Supporting Youth Living with HIV

Good afternoon. Thank you for joining. We will begin the webinar shortly.

Improving Services to Youth Living with HIV

Infrastructure Development

Thank you for joining the HRSA HAB Building Futures: Supporting Youth living with HIV webinar series. This series focuses on Improving Services to Youth Living with HIV and is a four part webinar series designed to share findings from the Building Futures: Supporting Youth Living with HIV Project a project funded by the Health Resources & Services Administration, HIV/AIDS Bureau (HRSA HAB).

The webinar will include an overview of the technical assistance toolkit developed at the culmination of this project. Each of the webinars will cover one of the 4 major themes of the toolkit and will include presentation from the project team and providers who have tested some aspects of the toolkit and who will share real world application and implementation strategies to help improve services for youth living with HIV.

Housekeeping

» This webinar is being recorded

» Methods for asking questions

– Submit a question through the Chat feature

– Raise your virtual hand to ask your question verbally

» Input your audio pin, so we can unmute your line
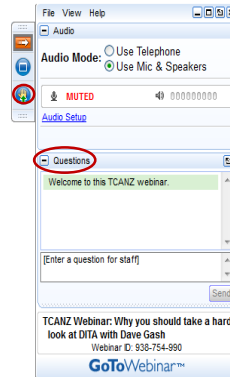
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During this webinar, we will have a Q and A section at the end. Please use the raise hand function found on the webinar control panel screen or type in your question using the chat function also found on your webinar control panel.

If you are asking a question verbally, please enter your audio pin and we will unmute your line so that you can ask your question.

Logistics

» Please answer the evaluation questions at the end of the webinar!

» Certificates of completion will be sent via email to attendees

» The webinar recording and slides will be posted on the TARGET Center after the webinar

» The Toolkit is under final review: look out for an email announcing its release

» https://targethiv.org/news/building-futures

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At the conclusion of this webinar, there will also be a survey. Please take the time to complete this brief survey.

You will receive a certificate of completion for this webinar. This certificate will be sent to the e-mail provided during registration.

The toolkit that we will be discussing throughout this webinar is under final review. Please look out for an e-mail announcement regarding its release. When it is released, it will be posted on the TARGET Center website located at the URL on your screen. This will also be the same web address that will host the webinars once they have been archived.

Objectives

At the end of this webinar, participants will be able to:

» Discuss the HRSA HAB Building Futures: Supporting Youth Living with HIV project's background and goal

» Describe the strategies and resources associated with the technical assistance toolkit

» Explain the lessons learned and implementation strategies from the youth-serving providers utilizing the toolkit

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Meet the Presenters

» Project Team:
  – AJ Jones, Debbie Isenberg, Echo Wang, Emily Rebella
» Provider Participants
  – Kristi Langshaw, LISW-S from MetroHealth
  – Jen McMillen Smith, LISW-S from MetroHealth

Today's webinar will include presentations from the Project Team including youth consultants - AJ Jones, Debbie Isenberg, Echo Wang, Emily Rebella - as well as representatives from MetroHeath in Cleveland, OH. Team members and provider participants will all be available to answer your questions at the end of the webinar.

Defining Terms

» HRSA HAB - Health Resources and Services Administration, HIV/AIDS Bureau

» YLWH – Youth living with HIV

» RWHAP - Ryan White HIV/AIDS Program

» LGBTQ – Lesbian, Gay, Bisexual, Transgender and Questioning

» HIPAA - Health Insurance Portability and Accountability Act of 1996

» PHI – Protected Health Information

» CAB – Consumer Advisory Board

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To get started we would like to first define terms we will be using through out the webinar:

- HRSA HAB - Health Resources and Services Administration, HIV/AIDS Bureau.
- YLWH – Youth living with HIV.
- RWHAP - Ryan White HIV/AIDS Program. Please note that the RWHAP is a HRSA HAB program.
- LGBTQ – Lesbian, Gay, Bisexual, Transgender, Queer.
- HIPAA - Health Insurance Portability and Accountability Act of 1996.
- PHI – Protected Health Information.
- CAB – Consumer Advisory Board.

**HRSA HAB Building Futures:
Supporting Youth Living
with HIV
Project Background**

We want to provide you with some project background so that you are able to understand how the toolkit was developed and the source of the recommendations we will be sharing.

Project Team

» **Project Team**:

– DSFederal, Inc., Mission Analytics, CAI, Positive Outcomes, Inc., and Debbie Isenberg

» **HRSA HAB**:

– Antigone Dempsey, CAPT Tracy Matthews, CDR Holly Berilla, R. Chris Redwood, Jhetari Carney

» **Subject Matter Experts**:

– Jeffrey Birnbaum and Adam Thompson

» **Youth Consultants**:

– D. D'Ontace Keyes, Jontraye Davis, Kahlib Barton, DaShawn Usher, Antoine Crosby, AJ Jones

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The team included staff from DSFederal, Inc., Mission Analytics, CAI, Positive Outcomes, Inc., and consultant Debbie Isenberg.

Staff from HRSA HAB include Antigone Dempsey, Tracy Matthews, Holly Berilla, Chris Redwood, and JT Carney.
Subject Matter Experts include Jeffrey Birnbaum and Adam Thompson.
Youth Consultants include D'Ontace Keyes, Jontraye Davis, Kahlib Barton, DaShawn Usher, Antoine Crosby, and AJ Jones.

We would like extend a special thanks to all the staff and consultants to contributed to this project.
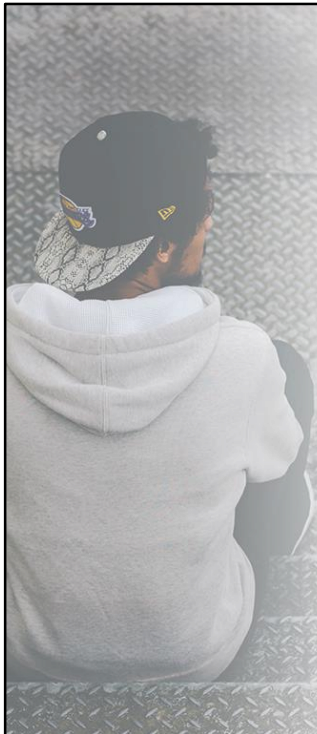
Understanding the Need

» 551,567 clients received services from RWHAP-funded providers in 2016

- 23,144 RWHAP clients living with HIV were youth aged 13-24
- Retention in care (76.6%) was lower than the national RWHAP average (81.7%)
- Viral suppression (71.1%) was much lower than the average (84.9%)

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There are 23,144 youth living with HIV aged 13-24 in the Ryan White HIV/AIDS Program. While improvements in both retention and viral load suppression have been made, disparities still exist. Retention in care for these youth is about 76.6% which was lower than the national Ryan white program average of 81.7%. Viral suppression for this population is at 71.1% which was much lower than the national average of 84.9%.

Goal

To improve outcomes among RWHAP-funded providers serving youth living with HIV aged 13-24

So the Building Futures: Supporting Youth Living with HIV project was working to improve outcomes among Ryan White Program funded providers with the goal of improving outcomes along the HIV care continuum in both retention and viral load suppression. The project was divided into two phases. Phase 1 was the collecting of information and phase 2 was the translating those findings into an actionable toolkit. The resulting Technical Assistance Toolkit presents many experiences and lessons from Ryan white providers like you to help improve outcomes with youth clients.

Project Roll-out

Phase 1:

» Purpose: Learn different approaches for retaining youth in care and achieving viral suppression

» Two-day site visits conducted with 20 RWHAP-funded providers nationwide
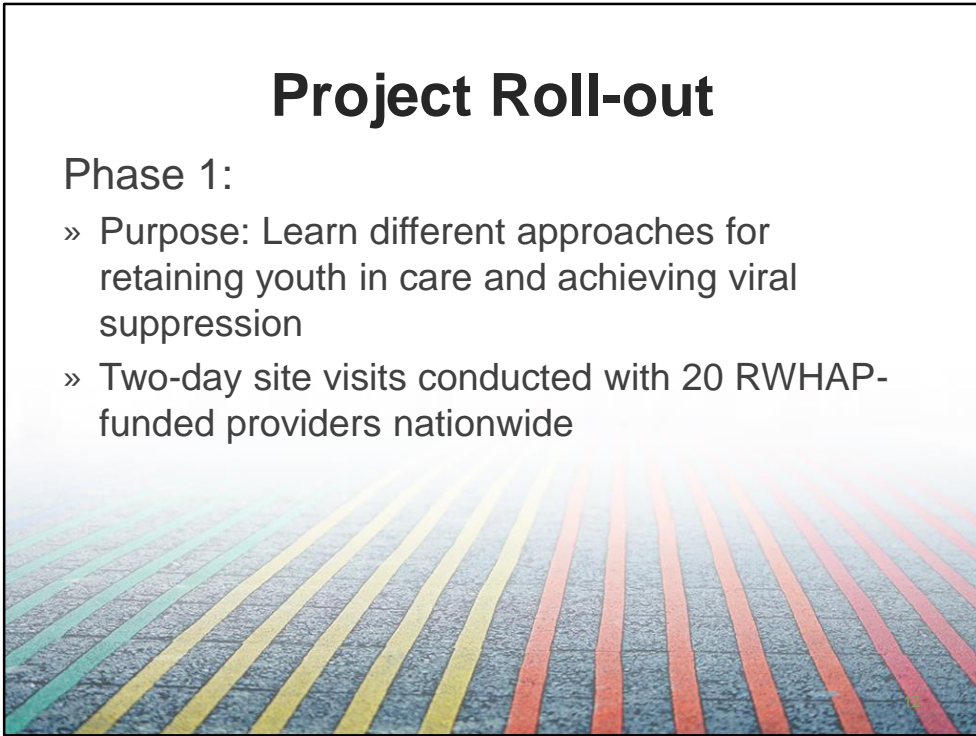
The purpose of phase 1 of the project was to learn different approaches for retaining youth in care and achieving viral suppression.

The project team wanted to understand what challenges and successes agencies face when working with youth clients. In order to do this the project team conducted 2-day site visits. During those site visits, the project team heard what works with youth and what does not work so well. We will present many of these findings during this webinar series, and they can be found in the technical assistance toolkit.

The site visit included interview with staff and youth clients as well as walk throughs of the clinic and pre-site visit survey.

Each site visit was conducted by a three-person team that included a project team lead, a clinical expert, and a youth consultant.

Location of Site Visits
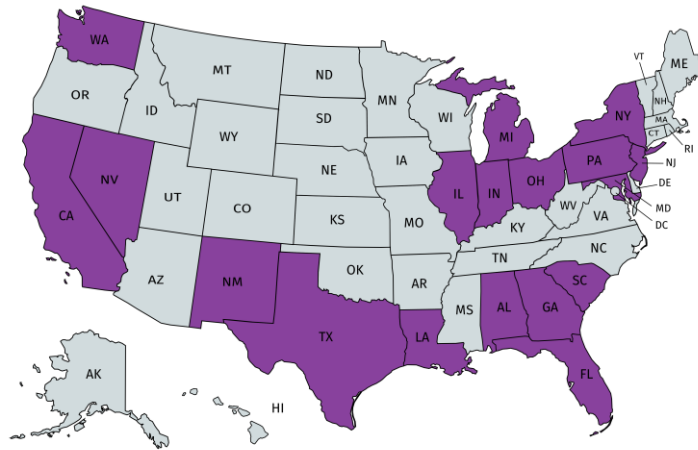
Using 2014 and 2015 RSR data, a sample of providers was selected from Ryan White funded programs. A number of criteria were used when selecting the sites including the number of youth served client population demographics, geographic location, and provider type.

Provider type included health department, hospital/university based clinics, and community health centers and community-based service organizations.

This variety was very important to the project because it allowed the project team to consider applicability in different contexts (e.g. engagement strategies in rural vs. urban context, or among different client populations).
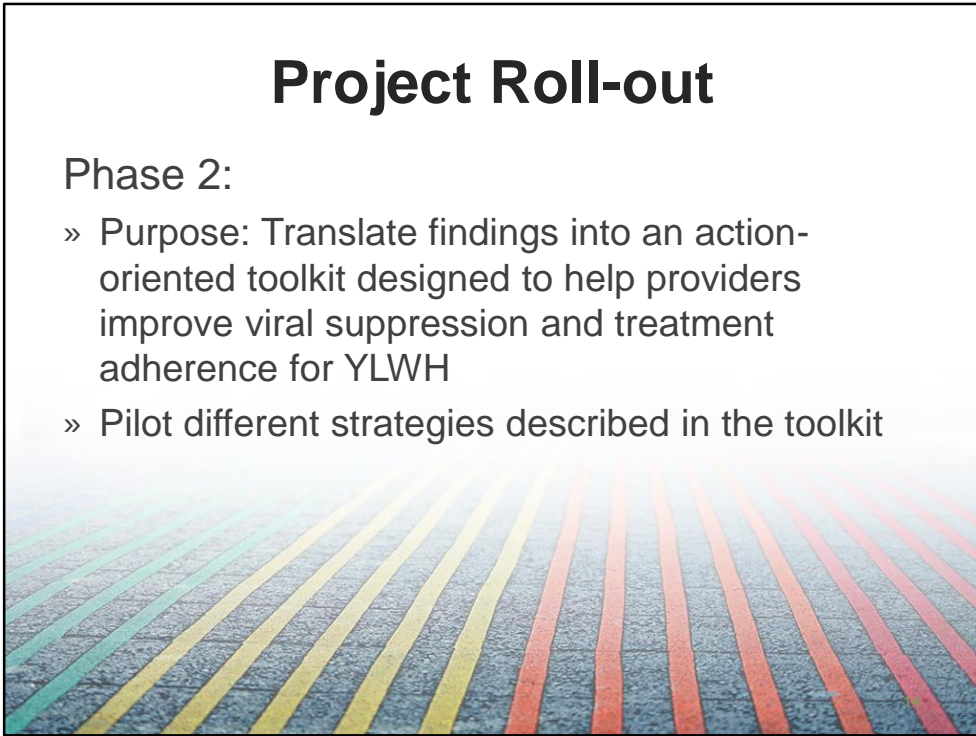
Participation in this project was voluntary.

The map shows the location of the providers by state.

Project Roll-out

Phase 2:

» Purpose: Translate findings into an action-oriented toolkit designed to help providers improve viral suppression and treatment adherence for YLWH

» Pilot different strategies described in the toolkit

The result of phase 1 activities was the development of the technical assistance toolkit which integrates the feedback and lessons learned from the 20 sites that were visited. The toolkit focuses on best practices for improving outcomes for youth living with HIV. After the development of the toolkit, each of the original 20 agencies were contacted and asked if they would like to pilot some aspect of the toolkit that might be useful for their clinic. The agencies who piloted elements of the toolkit participated in 4 check-in webinars and 1 in-person site visit. Their feedback was incorporated into the toolkit.

These providers are also participating in this webinar series, so you will be able to hear what they found during this process and some of the strategies they implemented.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
HIV/AIDS BUREAU

BUILDING FUTURES: SUPPORTING YOUTH LIVING WITH HIV

TECHNICAL ASSISTANCE TOOLKIT

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This toolkit is a unique resource as it captures the lessons and experiences of providers working with youth clients. The resource is designed as an actionable tool and has been tested in field.

This toolkit contains 10 topic areas divided into 4 themes. Each of the 10 topics includes strategies to address the specific topic, with resources provided to support the implementation. Providers can use some or all information in the toolkit to enhance their programs to better meet the needs of YLWH.

Themes and Topics

Infrastructure Development **August 9th**	• Staff recruitment and retention • Improving communication with youth • LGBTQ-friendly policies, environment, and culture
Informing Program Development **August 16th**	• Gathering structured feedback from youth • Data-driven programming for youth
Wraparound Services **August 23th**	• Youth support groups • Identifying and addressing support service needs • Re-engaging youth lost to care
Clinical Service Models **August 30th**	• Youth-centered services • Interdisciplinary care teams

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The 10 topics within each theme are hyperlinked, so users can move easily from one topic area to the next. While topic areas predominantly summarize information gathered through the Building Futures project, they also contain links to other relevant resources on the TARGET Center site.

You can see a list of topics found under each theme.

Staff Recruitment and Retention

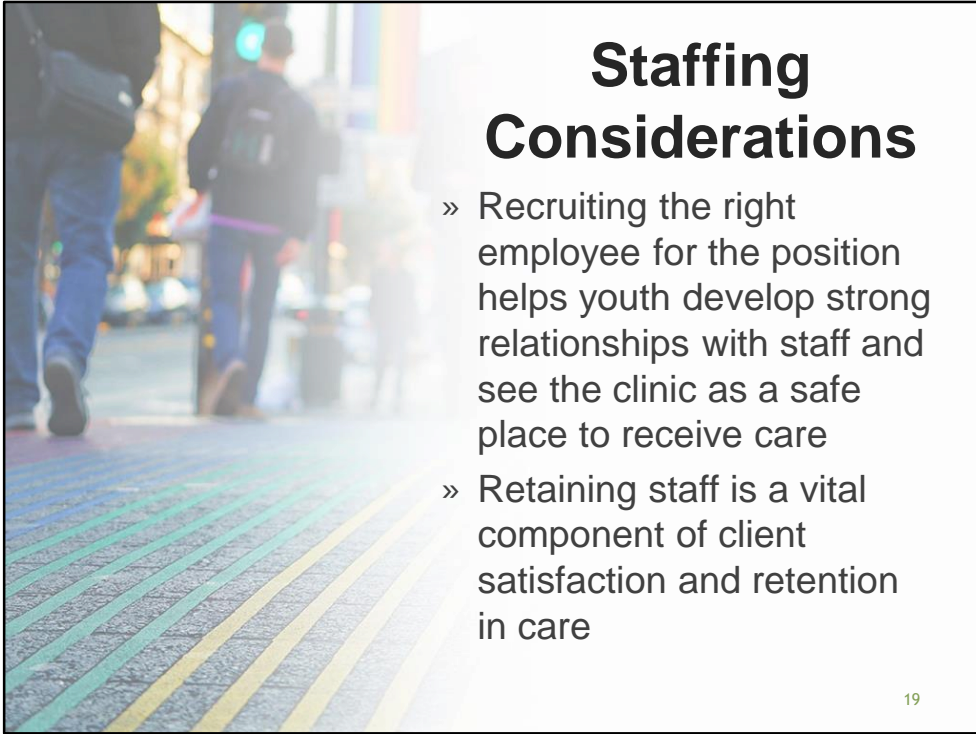Staff recruitment and retention will be the first topic discussed.

Background

Youth Need:
» Safe place to receive care
» Consistency of clinic staff
» Strong bonds with staff

From all of the 20 providers visited, both the staff interviewed as well as youth interviewed overwhelmingly attributed high viral suppression rates among YLWH to strong relationships between clients and staff members.

The youth interviewed stressed the importance of these relationships and often identified one or two clinic staff members with whom they have strong connections. These connections did not have to be with the clinicians. In fact, one youth mentioned in an interview that they see the woman at the front desk as a mother figure. This front desk staff member had been with the clinic for 25 years and was clearly the a hub for the clinic. The youth client knows that the staff member will always be there to greet her and to offer a kind word, but also will "tell it like it is" when the young person is "messing up" (e.g. missing appointments).

The youth interviewed in the project also acknowledged that the ability to see the same staff members over time was greatly appreciated as this let them established strong bonds with staff and help the youth develop a sense of safety at the clinic.

Staffing Considerations

» Recruiting the right employee for the position helps youth develop strong relationships with staff and see the clinic as a safe place to receive care

» Retaining staff is a vital component of client satisfaction and retention in care

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As there is such a strong emphasis placed on the bonds between the staff and the youth clients, it is really important to recruit the right people for job openings and retain the staff already in place.

Recruiting the right employee for the position has many elements to it.

Staff Recruitment

» It is important to identify the role, clarify what the position will do and create an accurate job description when recruiting

Recruitment Strategies

» Recruiting from within is a common recruitment strategy among many providers

 – Use peer volunteers or CAB members to establish a resource of full-time employees

» Recruiting using targeted outreach to local community agencies ensures the hiring staff of who reflect and/or represent the community served

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It is important to first understand the recruitment and hiring policies your agency has before beginning the hiring process. Providers interviewed shared that this is especially important for providers who are part of larger healthcare systems. Many of these systems have guidelines and universal hiring policies that must be adhered to. For example, a job might have educational level requirement associated with it. It is necessary to understand all of these guidelines and hiring policies before beginning the recruitment process.

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. A simple task analysis can be done where you identify the job responsibilities and the corresponding knowledge skills and attitudes needed to complete those responsibilities. This task analysis help the recruiters and interviewers meet the staffing needs. If it is possible, have clinic representation in the interviewing process as this will help ensure that the new hires meet the needs of the clinic.

A strategy for recruitment that we heard from the field was that agencies regularly recruited peer volunteers or CAB members for full-time positions as they were posted. Recruiting from within allowed continuity as often the CAB members or peer-volunteers have been with the agencies and have developed relationships with the staff and clients. One agency, who had hired a CAB member recently as their Outreach Coordinator found great success with this as this member was very active in the community as well as very active in the CAB. This really helped the agency situate themselves within the community they serve.

Youth want staff who:

» Show dedication

» Have patience

» Practice a balance between hand-holding and accountability

» Include them in their care planning

» Are coachable

» Demonstrate a non-judgmental attitude

» Spend time on non-medical issues

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One important finding from the interviews conducted was the identification of the characteristics that youth wanted from clinic staff. Youth didn't just look for these characteristics in clinicians but all clinic staff.

The youth wanted staff who:
- *Show dedication.* Staff are willing to go above and beyond to serve clients.
- *Have patience*. Staff take the time to get to know them and their needs and allow them to ask questions.
- *Practice a balance between hand-holding and accountability*. Youth liked staff who are allies but who also describe consequences of various actions.
- *Include them in the planning of their care.*
- *Are coachable.* In other words, staff should be able to listen and adjust to the requests of the clients.
- *Demonstrate a non-judgmental attitude.* Stigma is a huge barrier for youth. Having staff who listen to the youth and do not pass judgment on the youth and their lifestyle and choices is very important.
- *Spend time on non-medical issues in the youth's life as well.*

Staff Retention

» Clearly define staff roles

» Schedule regular supervision

» Provide staff training

» Allow staff input in clinic process

» Provide opportunities for staff wellness

So not only is recruiting the right staff important but so is keeping the staff you have.

A few tips we heard during site visits is that staff need clearly defined roles so that they know what they are supposed to do and are then supported by their supervisors in their roles. Staff want to receive ongoing training and have education opportunities. Staff want to have input into the clinic process. And finally, the agency should provide opportunities for staff wellness.

The agencies interviewed had different ways of working on wellness with their staff. One agency gathered together for what they called "family meals." Another agency would get together monthly for a fun activity such as bowling and karaoke where they would get together and not talk about work. This wellness time allowed for staff to bond as a team develop a sense of community.

Staff Training

» Establish a training budget

» Identify the training topics relevant to staff growth

» Identify training opportunities in the field

» Create an ongoing assessment of training needs

» Evaluate staff skills and knowledge

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Staff training was an important element of staff retention. Each provider interviewed had different ways they provided ongoing training and education. But in order to make training a realistic and sustainable option at your agency, it is necessary to:

- Establish a training budget.
- Identify the training topics relevant to staff growth.
- Identify training opportunities in the field. These training can be internal, online, or offsite options such as through your local AETC or at a conference.
- Create an ongoing assessment of training needs with your staff.
- Evaluate staff skills and knowledge to know what gaps need to be filled.

It is necessary to determine which staff members should attend which training and to keep abreast of what training new hires need versus ongoing education for existing staff.

Sharing What You've Learned

» Allow staff members to share information from trainings and provide input regarding additional training they might need

» Establish internal protocols to ensure knowledge transfer between exiting staff members and new employees
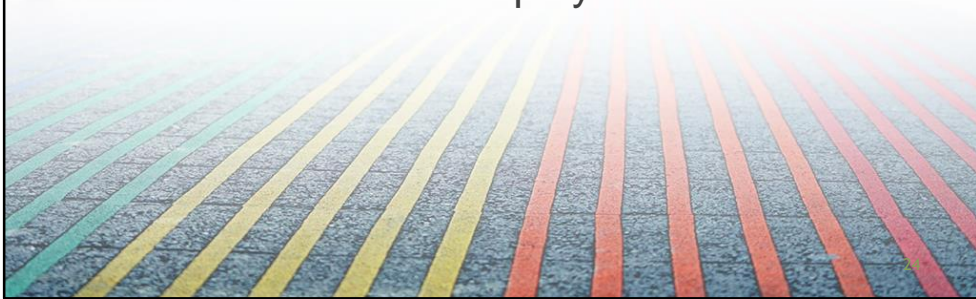
Then once staff are trained, allow for opportunities for staff to share the information they learned at trainings or conferences. This not only allows other staff who might not have been able to attend receive the information, but also helps further build a sense of community and allows for information to be shared when one staff leaves and when another gets hired.
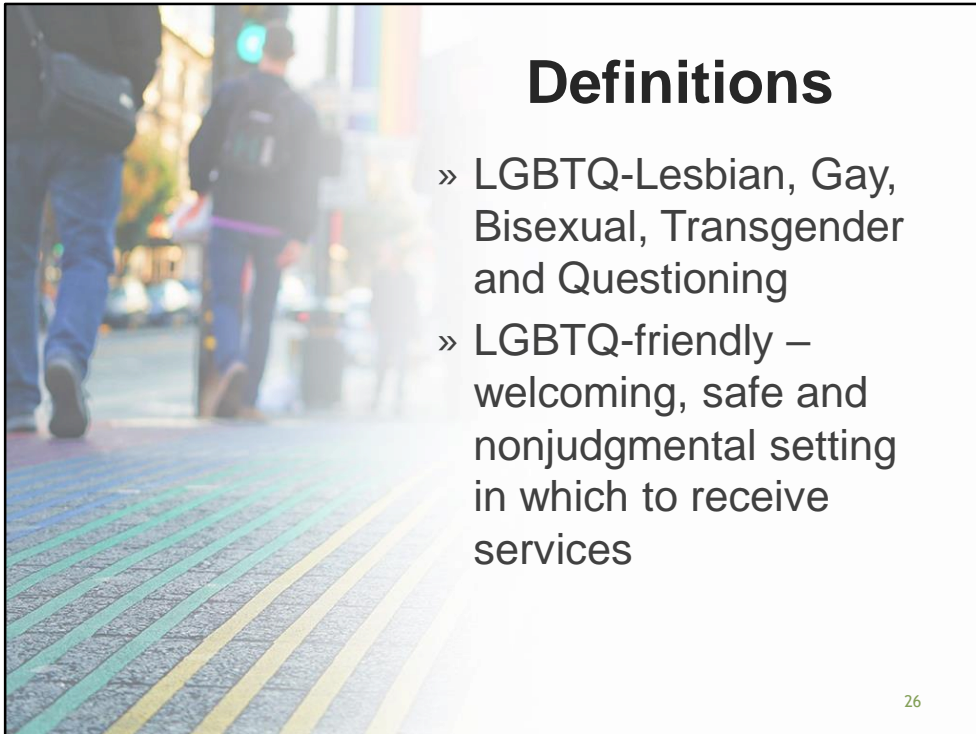
Next up Debbie will be speaking on the topic, LGBTQ-friendly policies, environment, and culture.

LGBTQ-Friendly Policies, Environment, and Culture

Definitions

» LGBTQ-Lesbian, Gay, Bisexual, Transgender and Questioning
» LGBTQ-friendly – welcoming, safe and nonjudgmental setting in which to receive services

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Thanks Emily! Before we get started, let's review some terms to make sure that we're all on the same page. First is LGBTQ. This stands for lesbian, gay, bisexual, transgender and questioning. For an agency to be LGBTQ friendly, they should be providing a welcoming, safe, and non-judgmental setting in which to receive services.

Background

» LGBTQ youth face psychosocial and structural challenges including:
  – Mental health issues
  – Trauma
  – Homelessness
  – Substance use
  – Stigma and discrimination
» Challenges make coping and living with HIV diagnosis more complex

I think it is also helpful to provide some important context for this topic. The National Alliance for State and Territorial AIDS Directors (or NASTAD) actually published a guide in 2012 for Improving Engagement and Retention in Adult Care Settings for LGBTQ Youth Living with HIV that nicely outlined the key challenges that we heard providers say are facing LGBTQ youth because of their sexual orientation or gender identity. These include mental health and substance use issues, trauma, homelessness, and stigma and discrimination. These additional challenges have implications for both coping and living with their HIV diagnosis. So how to address these challenges? Hence, the topic for the toolkit - LGBTQ-Friendly Policies, Environment, and Culture!

Source: 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.

Poll

How LGBTQ-friendly is your agency?

a. Not very – There aren't any specific activities but we support LGBTQ YLWH if they ask for assistance

b. Somewhat – Making some changes in policies and procedures or clinic practices but still work to be done

c. Very – Both policies and procedures and/or specific clinic practices have been developed to ensure LGBTQ-friendly experience

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Before we jump into the content, I'd like to a poll to get you 'virtually' up and moving. I'm going to ask you to rate how LGBTQ friendly your agency is-not very, somewhat, or very. Ellie, can you launch the poll?

Great. Thanks for participating. It appears that most of you marked somewhat. Hopefully you'll be able to find some useful information from the toolkit to help you agency move to "very" LGBTQ friendly.

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

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

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Thanks again for providing your input on the poll. This topic in the toolkit provides areas for review to ensure that your agency is LGBTQ-friendly. There are two main areas in the toolkit. First, organizational culture focuses on leadership engagement and policies and procedures. The second section is culturally competent care and treatment services which is further broken down into five areas: environment, disclosure and inclusivity, training, data management systems, and LGBTQ-Focused Activities and Services. The Joint Commission, an agency that accredits more than 21,000 US health care organizations and programs, provided some great recommendations on areas for consideration in their 2011 field guide that is highlighted in the toolkit. I'll review each of these sections in more detail.

Source: 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.

Organizational Culture

» Areas for consideration to assess your organizational culture include:

- Do your non-discrimination policies include sexual orientation and gender identity? Are they followed?
- Is your leadership committed to inclusivity? How do you know this?
- Do disciplinary processes address intimidating, disrespectful or discriminatory behavior to both LGBTQ staff and clients?

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Let's start with organizational culture. The toolkit includes areas of consideration to review your organizational culture. Some examples include if your non-discrimination policies include sexual orientation and gender identity, if your leadership is committed to inclusivity, and if you have disciplinary processes that address behavior that is intimidating, disrespectful, or discriminatory to LGBTQ clients as well as staff.

Source: 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.

Culturally Competent Care and Treatment Services

» Ensure culturally competent care and treatment services
  - Environment
  - Disclosure and inclusivity
  - Training
  - Data Management
  - LGBTQ-Focused Activities and Services

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Let's move on to culturally competent care and treatment services. As I mentioned previously, there are five areas on which I'm going to focus. Let's start with environment.

Cultural competency is the ability to understand, communicate with, and effectively interact with people across cultures.

Culturally Competent Care and Treatment Services

» Environment=Physical setting
  - Nondiscrimination policy posted
  - Inclusive print materials (brochures and posters)
  - Providers establish safe space which could include:
    - Wearing insignia such as "my pronoun is," rainbow flag, and/or pink triangle

By environment, I mean the physical clinical setting in which services are provided. Some activities that you can implement include having the nondiscrimination policy that incorporates sexual orientation and gender identity posted. You also want to ensure that your print materials are inclusive, displaying examples of LGBTQ youth. Finally, clinic staff can wear insignia to show that they are culturally competent. Some examples include "my pronoun is," a rainbow flag, or pink triangle.

Culturally Competent Care and Treatment Services

» Disclosure and Inclusivity

- Recognize that disclosure can be two-fold for LGBTQ youth-HIV status and sexual orientation or gender identity
- Meet youth where they are in the disclosure process
  - Provide opportunities for youth to disclose their sexual orientation or gender identity to staff
  - Lack of disclosure should not be a barrier to care

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Disclosure and inclusivity is next. One of the things that we heard from several providers during our site visits is that for LGBTQ youth, disclosure of their HIV status is more challenging because it often involves disclosure of their sexual orientation or gender identity as well. They underscored that it is important to meet youth where they are in the disclosure process. You can provide opportunities for youth to disclose their sexual orientation or gender identity; for example, you can ensure that your clinic forms provide inclusive options such as non-binary choices for gender. It is important that lack of disclosure should not be a barrier to care.

Culturally Competent Care and Treatment Services

» Training
  - Ensure all staff are LGBTQ culturally competent
    - Gender Expression
    - Use of pronouns
    - Care and treatment needs for transgender YLWH
  - Consider having your LGBTQ clients come to a staff training to share their experiences

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Another way to support culturally competent care and treatment services is by providing training for your staff on LGBTQ cultural competency. Suggestions from providers we visited including ensuring that training content encompasses gender expression, use of pronouns, and care and treatment needs for transgender YLWH. One provider shared that they had some of their LGBTQ clients come to a training to share their experiences with staff. The toolkit outlines training and technical assistance resources, including the HRSA-funded National LGBT Health Education Center. While the center specifically targets community health centers, the on demand webinars and publications are available for use by any agency. The Gay and Lesbian Medical Association was also mentioned by one of the providers as a useful resource.

Culturally Competent Care and Treatment Services

» Data Management
  • Critical that forms are inclusive, whether on paper, in an electronic health record (EHR) or another data management system
    ▪ Non-binary gender options
    ▪ Preferred Name
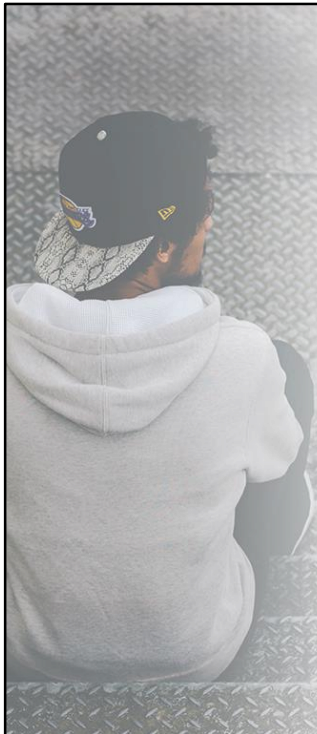   ▪ Pronouns
    ▪ Inclusive definition of family

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Data management systems are also very important. You'll want to be sure that your clinic forms are inclusive whether they are paper forms, part of an EHR, or another data management system. Examples include non-binary gender options, a space for preferred name, preferred pronoun, and an inclusive definition of family. We heard examples from providers where EHRs were modified to address these needs and where that was not feasible, providers used open text fields in the EHR. One provider underscored the importance of ensuring that transgender clients are referenced by their preferred name and pronoun, so they include this information in their EHR so that the client can be greeted appropriately by front office staff.

Culturally Competent Care and Treatment Services

» LGBTQ-Focused Activities and Services
- Partnerships with LGBTQ agencies to ensure comprehensive services
  - Hormone therapy for transgender clients
  - LGBTQ-specific support group
- Establish memorandum of understanding (MOU) when feasible
- Ensure warm handoff or attend with client

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Finally, an important area identified was LGBTQ-focused activities and services. One provider we visited had a partnership with another agency to provide hormone therapy for transgender clients. Another wasn't able to sustain their own support group, so they referred LGBTQ clients to another provider in the community. When working with other agencies, try to establish a formal memorandum of understanding (or MOU) with each agency when feasible. When providing referrals, providers noted the importance of a warm handoff such as attending the first appointment with the client or accompanying them to the first support group and introducing them to the support group leader.
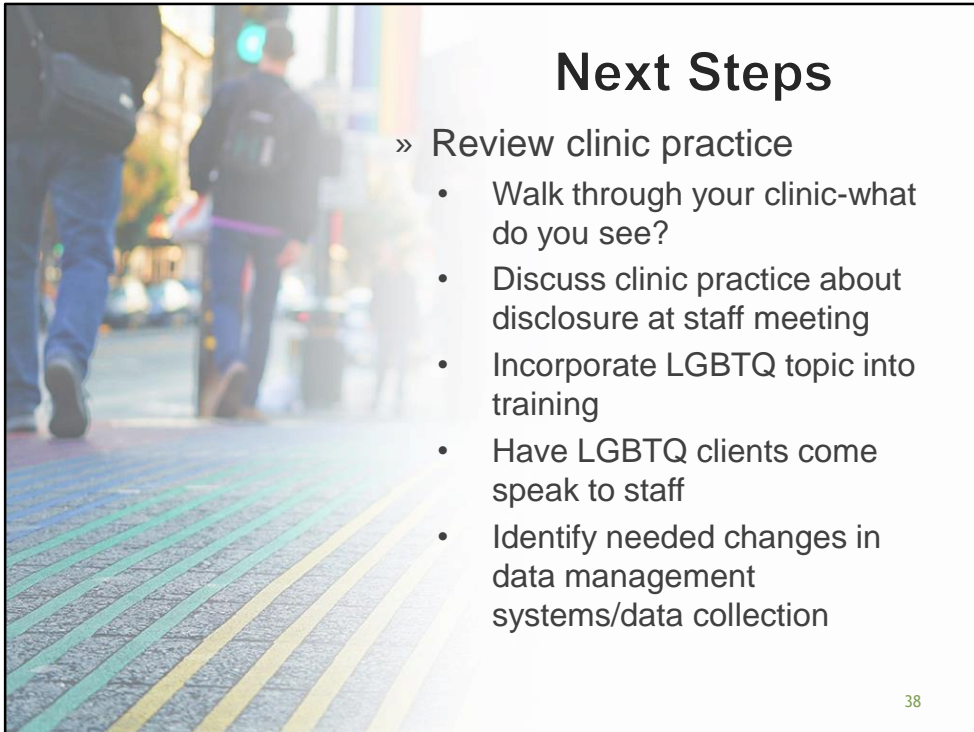
Next Steps

» Review your policies and procedures to see to what extent they are LGBTQ-friendly and identify areas for improvement:

- Be sure that your leadership is engaged and supportive
- Develop committee (can just be a few people) to help
- Use resources from toolkit to identify needed changes

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So we've reviewed a lot of activities that you may be able to do and they are outlined in greater detail in the toolkit. Of course, we also know that HRSA HAB makes a lot of great technical assistance (TA) materials available for providers. How can you make the ideas in this toolkit actionable? One way to start is by reviewing your existing policies. To do this, maybe you can enlist the help of some of your colleagues. Remember there are also resources in the toolkit to help you identify needed policy and procedure changes.

Next Steps

» Review clinic practice
- Walk through your clinic-what do you see?
- Discuss clinic practice about disclosure at staff meeting
- Incorporate LGBTQ topic into training
- Have LGBTQ clients come speak to staff
- Identify needed changes in data management systems/data collection

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You can also review your clinic practice. One suggestion is to walk through your clinic and using the criteria that we outlined, see if you think the clinic is LGBTQ friendly. Is your nondiscrimination policy posted? Are your print materials inclusive? Do providers establish a safe space by wearing/displaying insignia? What would you change?

Another approach is to raise the topic of disclosure at your routine staff meeting. You can also expand your existing training by adding a topic on LGBTQ cultural competency. To identify needed changes in your forms, EHR, or other data management systems, set aside a few minutes to look things over.

Next Steps

» Review clinic practice
- Identify possible service expansion (support group, hormone therapy)
- Identify agencies in community to whom you can refer
- Request technical assistance
- Contact peers to learn from their experiences
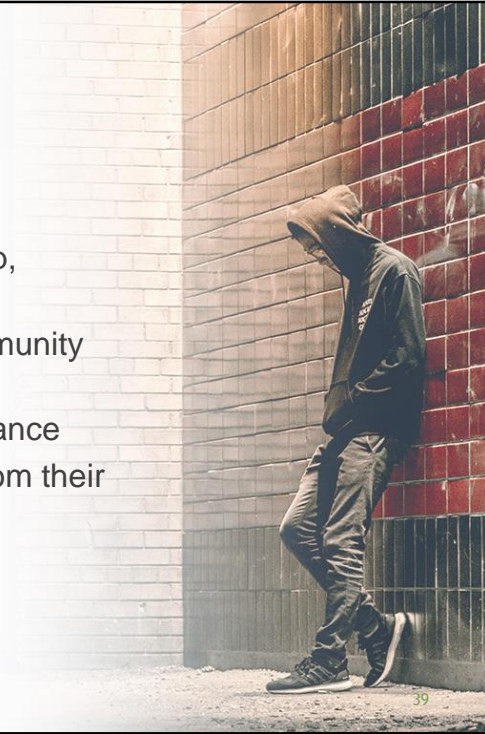
You can also identify places for needed service expansion such as support groups or hormone therapy. Perhaps an agency in the community can offer assistance. Don't forget that the National LGTBQ Health Education Center that I mentioned earlier can provide technical assistance if you are a community health center. If you are not a community health center but are a Ryan White recipient, talk to your HRSA HAB Project Officer about any TA needs that you have. If you are a subrecipient, discuss your training and TA needs with your recipient. Also peers are a great resource. You'll hear from a peer today (MetroHealth) about improving communication with youth.

Poll

What actions you can take to ensure that your agency is LGBTQ friendly? (Check all that apply.)

a. Meet with leadership to discuss
b. Review policies and procedures
c. Add inclusive brochures/print materials
d. Enhance existing staff trainings
e. Modify data systems/clinic forms

Before I wrap up this section, I'm asking everyone to identify what actions you can take to ensure that your agency is LGTBQ friendly. You can check more than one but try to check at least one area. Ellie, can you launch the poll?

Hopefully you heard something today that will help you in making your clinical setting more LGBTQ-friendly. Now I'm going to turn things over to Echo for the final topic - Improving Communication with Youth.

The next topic is improving communication with youth. In this topic, we will cover a variety of youth-preferred communication mechanisms, including text messaging and use of social media. Now let's start with the background.

Background

» Challenges for providers to communicate with youth clients:
  - Phone calls do not work well for youth
  - Difficulty of navigating HIPAA regulations for using text messaging or social media
  - Not sure how social media can help
  - Lack of relevant best practices to properly manage a social media account

HIPAA: Health Insurance Portability and Accountability Act of 1996

According to providers we visited in the Building Futures: Supporting Youth Living with HIV project, communication with youth clients was cited as one of their greatest challenges for several reasons.

Phone calls do not seem to work well for youth. Providers felt like youth are less likely to return phone calls, more likely to change numbers, and sometimes do not have sufficient minutes for their phone plan.

Since YLWH often rely on free Wi-Fi hot spots, text messaging and social media seem to be preferred and more effective than phone calls. Providers were all very interested in using social media, but their major concern is privacy and the difficulty of navigating HIPPA regulations to find out what they can and cannot do.

Additionally, many providers were unsure about how exactly social media can help, what is the right platform for their population, and in general, how to get started. These are all reasons why we wanted to provide you with options and considerations that focuses on the unique needs of Ryan White providers to help you get started with using social media.

Poll

In addition to phone calls, do you use the following platforms regularly for communicating with clients? (Check all that apply.)

a. Text messaging
b. Facebook
c. Instagram
d. Other
e. None

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Strategies

» Text messaging
  • HIPAA-compliant text messaging using a regular cellphone
  • Secure text messaging
» Using social media platforms
  • Social media messaging
  • Pushing content on social media
  • Social media groups
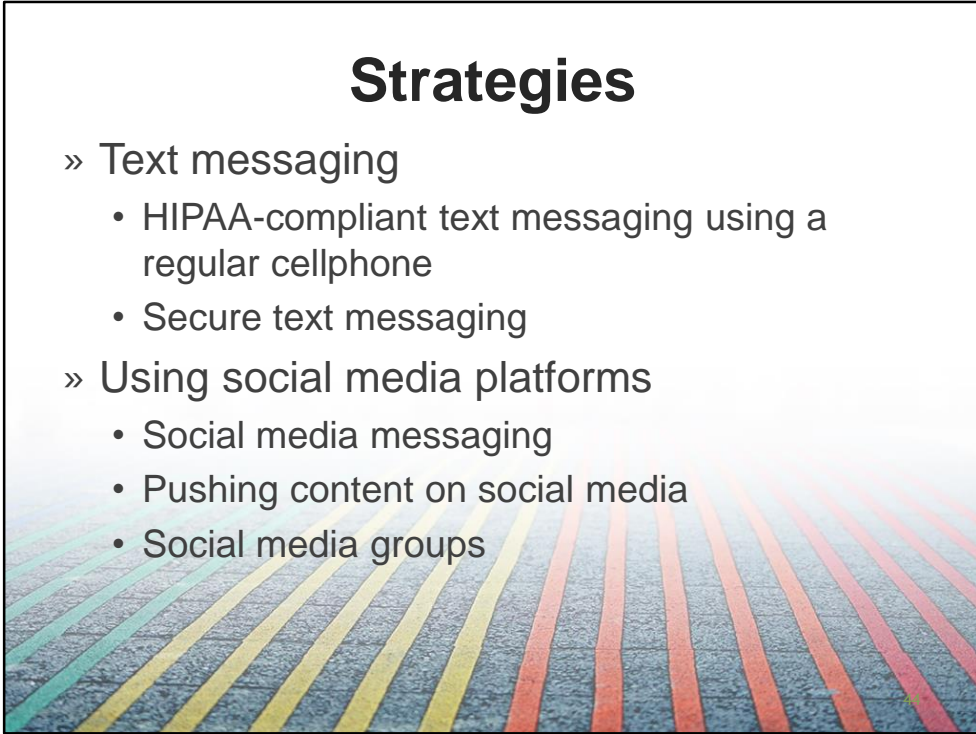
We developed two major strategies based on what providers need, which are text messaging and social media platforms.

For text messaging, we will discuss the considerations and guidelines for using a regular cellphone, and through a secure messaging platform. The major difference is that the former method does not permit you to communicate protected health information (PHI).

For social media platforms, we will cover 3 different approaches and provide examples of how providers are currently using them. You will also hear one of the providers MetroHealth from Cleveland OH to talk about their experience.

Text Messaging-Using a Regular Cellphone

- » **Message content**: Text messages must not contain protected health information (PHI).
- » **Consent**: Do not text youth clients or others without written consent.
- » **Security**: Password-protect the phone used to send text messages.
- » **Storing and deleting messages**: Delete after communication and store securely.
- » **Client-generated messages that include PHI**: Do not respond to the original text that contains PHI and send a new one.
- » **Best practices and professionalism still apply.**

Regular cellphone can be a smart phone, or flip phone, as opposed to a special, secure messaging application.

Currently, HIPAA does not restrict any specific mode of communication, including texting. However, the first thing is still to check with an organization's HIPAA office or legal counsel to determine what is allowed and what is restricted in your organization. In most cases, you may allow a few staff members to use text messaging through a regular cellphone, as long as messages do not include protected health information (PHI). In the tool kit, we listed the guidelines and links to the full policy for texting in healthcare, recommended by Healthcare Information and Management Systems Society (HIMSS). The key points are listed on the slide as well.

First of all, text messages cannot contain PHI. That includes client's full names.

Next, consent is required before texting the clients. Consent is typically obtained by signing a consent form as part of their enrollment or check in process.

Also, the phone used to send text messages should be password-protected and stored securely at all time.

if you need to store messages, they need to be stored securely. And messages should be deleted after communication is completed or having a regular schedule for deleting

all messages.

If a client sends messages that include PHI, do not continue the discussion in the same message chain. You should ask the youth client to call you. You should also immediately delete the initial message containing the PHI.

Lastly, the communication best practices and professionalism should still apply when communicating through text messages.

Secure Text Messaging

» Can be used to communicate PHI
» Offered through electronic health records system or third-party provider
» Security and compliance considerations
  • Access
  • Automatic logoff
  • Password and account management
  • Backup processes
  • Audit capabilities

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If PHI needs to be communicated electronically, providers should consider using encrypted messages or a secure text application, rather than an unsecured cell phone.

Secure text messaging often requires a third-party application that can be either provided through your existing electronic health records (EHRs) system, or a secure texting application provider. This option is apparently more expensive, but it would allow you to communicate protected health information (PHI).

You will probably need to work with your IT department to implement a secure text messaging application that follows your organizational policy and complies with HIPAA regulations. In the tool kit, we provided sample policies for using secure messaging, as well as a long list of compliance requirements. Those requirements typically include user access controls, automatic logoff after a defined period of time, password and account management, backup processes, and audit capabilities which logs all user actions related to authentication and access.

Social Media Messaging

» Social media messaging for better communication

- Private messaging using social media
- Should follow the guidelines for text messaging using a regular cellphone
- Best used to communicate logistics, regular check-ins or provide emotional support
- Should not be used to communicate lab results, disease status or medications
- Should not use a staff's personal social media account
- Seek consent before reaching out to client

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In addition to text messaging, providers may also consider using social media tools' private messaging to communicate with clients, following the same guidelines as text messaging using regular cellphone. Social media tools that can be used for private messaging include Facebook messenger and other chat apps.

Some providers may establish a social media account that is not associated with the clinic for communicating with clients, so clients are more comfortable "friending" or "following" them online without concerning about disclosing the association with the clinic.

Social media is best used to communicate logistics, regular check-ins, or provide emotional support rather than communicate lab results, disease status, or medications - "no PHI."

An example from the field includes one clinic who 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.

Other ways of using social media include posting contents and establishing virtual support groups.

Content posting

Some providers already have social media accounts that are used to share posts and articles about health, life skills, mental well-being, support services, and other topics that may be useful to clients.

Social media platforms that are often used for pushing content include Facebook, Youtube, Instagram, and Twitter.

It is important to follow organizational communication policies when using social media. In the toolkit, we listed several recommendations to best use social media for content posting from providers and NIH.
- Provides found that clients are more likely to follow you or like your post if the shared content does not limit to HIV; so that clients would not be concerned of being associated with HIV.
- NIH also provides a list of recommendation regarding posting research findings. You will find the key message and the link to full guideline in the toolkit; here is a few examples.
  - 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.

Social media groups

Another way of using social media was to create an online community for your clients. We provided various considerations in the toolkit to help you determine whether this approach will work for your organization and client population, and if so, how it should be maintained. MetroHealth in Cleveland had successes in creating a private Facebook page as a virtual support group for their youth clients. You will hear more about it from MetroHealth's Jen in her presentation.

Lessons from the Field

Next you will hear from Jen McMillen from MetroHealth. MetroHealth staff participated in the initial site visits and have also participated in testing some elements of the technical assistance toolkit.

MetroHealth

Kristi Langshaw, LISW-S

Jen McMillen Smith, LISW-S

Infectious disease clinic provides HIV care for about 1,600 people living with HIV, and about 10% patients are age of 13-24.

Our Approach to the Toolkit

» Reviewed the entire document
» Chose topics and parts of topics we felt would be:
  – ***most beneficial*** for our patients
  – conducive to ***streamlined implementation***
  – without added staffing or much expense

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Approach to the toolkit: Reviewed document and chose topics that we felt would be most beneficial for our patients, conducive to streamlined implementation, and without added staffing or much expense, done in a cost effective manner.

Best Practice for
Improving Communication with Youth

Social media Platforms:
Secret Groups on Facebook

We noticed clients aged 18-30 years old living with HIV friending each other on Facebook after support group. In an effort to connect with patients in the same way they connect with each other, we created a safe space on Facebook that focuses on living well with HIV.

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Secret Facebook group: We noticed that after group instead of exchanging phone numbers with each other, they will ask for each other's Facebook names and add each other as a friend. That's about 5 years ago. More often now it is Instagram and Snapchat. We are thinking about those things. But about 5 years ago, everyone was on Facebook, so we thought that's where we needed to be.

What We Did and Lessons Learned

» Hire a social media design firm to create the secret Facebook group

» Utilize Facebook's privacy settings so the group isn't searchable

» Use a "pass-through" friend to identify people to invite into the group

» Limit members to individuals (no organizations, including AIDS Service Organizations, are accepted)

» Develop & post guidelines for participation and policies for what participants can post

» Use a content schedule to plan posts in advance

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We did this by hiring a local social media design firm to help us to create it. We knew we need to be very careful about privacy and making sure our patients could feel safe, so we can communicate with them in a safe way. The firm helped us set the privacy setting, so the group can't be searchable. People friend me on Facebook and I add them into group. I limit members to individuals (no organizations). I only add people into the group if I know they live with HIV. We have guidelines on the kinds of posts people can make in the group. For example, posts need to be made with love and acceptance and are not judgmental. Posts can also be informational. We also have our own staff post in the group to share photos, interesting articles, or event reminders.

Findings

» There are seven main ways the secret Facebook group is used by both the clinician facilitator & patient participants

In the past five years, there are seven main ways that people uses the secret Facebook group. In the following slides, the large circles depict these uses. The small circles are quotes taken from actual Facebook group posts and comments written by people living with HIV/AIDS & the facilitator.

Connect

with patients in a familiar venue they interface with throughout the day, everyday. Facebook is a 24/7 way for patients to reach out to peers.

"You are not alone. It may get lonely, but we can always find an ear to hear on this site and at groups."

"We get through with a little help from these friends. Just keep on doing what you're doing by talking about how you feel."

A comment after a member posted about a missed dose: "Adherence 364 days out of 365 is EXCELLENT. Be proud of that and encourage others to do the same."

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Mostly people use Facebook to connect with each other. We can connect with patients in this familiar venue and give them 24/7 access to each other.

Strengthen Social Networks

By reminding patients about upcoming opportunities for face to face interactions with supportive peers at education events and support groups in the Cleveland HIV community.

"Today is the day I go to my appointment…still kind of nervous…well really nervous lol."

"I really enjoyed myself & met a lot of new people!! Thank you, I don't feel alone! I feel as if in time I could be a good asset to our community."

After a Gentlemen's Quarterly Dinner: "Kudos to all who spoke up and shared. Thank you."

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Facebook group is useful to strengthen social networks. We can remind them about upcoming opportunities for face-to-face interaction, such as picnics at local parks.

Share Wellness Messages

Exercise, healthy diet, the proper amount of sleep & quitting smoking, to name just a few are wellness issues people living with HIV (and everybody else!) need little reminders about and strategies to make healthy lifestyle choices.

"Did you know? You can get Gonorrhea in your through – ask your doctor about a throat swab if you have oral sex."

"Just in time for the weekend! MetroHealth can give you a fresh supply of condoms, lubes, dental dams, & female condoms at your request…. just ask us!"

"A recent study in AIDS showed that people who are able to well-control their HIV through anti-retroviral drugs have no higher risk of dying than people without HIV."

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Share great wellness messages for everyone, not only for people living with HIV.

Ask Questions

Often people living with HIV just want to ask people living with HIV a question. Getting answers from a physician or HIV social worker is one thing - getting answers from another person living with HIV is a valuable tool in a completely different way.

"Honestly I never knew how hard it would be to just take one pill a day! It's hard for me to adjust to it, maybe it's just me or is this something hat happens to other people?"

"Just became a part of the group everyone, I'm scared what can I do to cope wit dis?"

"Could you share your experiences & creative ways to disclose your status to someone you would like to date & possibly build a loving relationship?"

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We found people really want to ask questions to other people living with HIV who can understand them. This group has become a way to get an answer from someone who has experienced it firsthand.

Encourage & Uplift One Another

People living with HIV are uniquely qualified to understand each others' struggles & provide support.

"This is our private confidential place where people understand what you are going thru – because most of us went thru something similar. It's GOOD not to have to do it alone – so this group helps us all get thru all the challenges together."

"It has taken me 5 years to recognize & begin to appreciate how the good outweighs the bad. One reason I love Compass Group is that is has helped me to get to this point."

"Welcome, M, to the Group we are all here to support each other."

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People use Facebook group to encourage and uplift each other. People living with HIV are uniquely qualified to understand each others' struggles & provide support.

Educate

Patients don't always remember everything we tell them in the exam room or during an education group. Facebook provides a way to continuously put educational posts in front of people living with HIV. Facebook users tend to be more attuned to notifications of new posts.

"The first couple wks are the hardest, and perhaps weirdest, but IT GETS BETTER! Make sure to take the meds at bedtime so you will sleep through most of the side-effects."

"The only person you MUST tell you have HIV is your sex partner(s). Anyone else is at your personal discretion."

"There were some questions about the difference between genotype and phenotype resistance testing. Here are some more detailed explanations: (article link)."

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Educate and remind people that what we tell them in the exam room or during an education group.

Stand in Solidarity

Private Facebook Groups provide a safe and confidential space with access to supportive peers that some patients might not otherwise have.

"Acceptance and honesty will see us through this if combined with gratitude & love!!!"

"I have came to the conclusion I am ready to disclose my status with some people that are close to me but I am scared I may be looked at differently or even judged."

"I feel like I can share this here…My partner found out he was HIV+ while he was incarcerated…"

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Stand in solidarity. Provide a safe, supportive, and confidential space. Some things are hard to say, but they can type it into the Facebook group and get some feedback.

Toolkit States:

» YLWH prefer to communicate with a person via text or chat apps than a phone call

» YLWH tend to not have sufficient minutes, get their phones disconnected, or their numbers change

» YLWH rely on free WiFi

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Toolkit states that YLWH prefer to communicate with a person via text or chat apps than a phone call. They tend to not have sufficient minutes, get their phones disconnected, or change their numbers. They always know where the free Wi-Fi is.

Next Steps

» These realities plus positive patient responses to our work on Facebook led us to apply for a HRSA SPNS Social Media grant and develop Positive Peers

Positive Peers

is a web-based, mobile application (app) that aims to engage young people in holistic HIV care while creating a private, stigma-free, supportive community.

Positive Peers is made possible through a U.S. Department of Health and Human Services Health Resources and Services Administration, HIV/AIDS Bureau Special Projects of National Significance (SPNS) Grant to The MetroHealth System. For more information about the SPNS grant initiative, visit: http://hab.hrsa.gov/abouthab/special/socialmedia.html#5

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Positive Peers is a web-based mobile app and it engages young people in holistic HIV care, and it created a private, stigma-free, supportive community. Basically it is Facebook, but only for young people living with HIV and only people that we expected and put into the app.

Avatars & Usernames

zigzag123   ladygoogoo   2legit2qt   imsofansee

People can communicate with each other with Positive Peers by using avatars and usernames instead of their actual name that they are using on Facebook. Now people have the ability to add a personal photo.
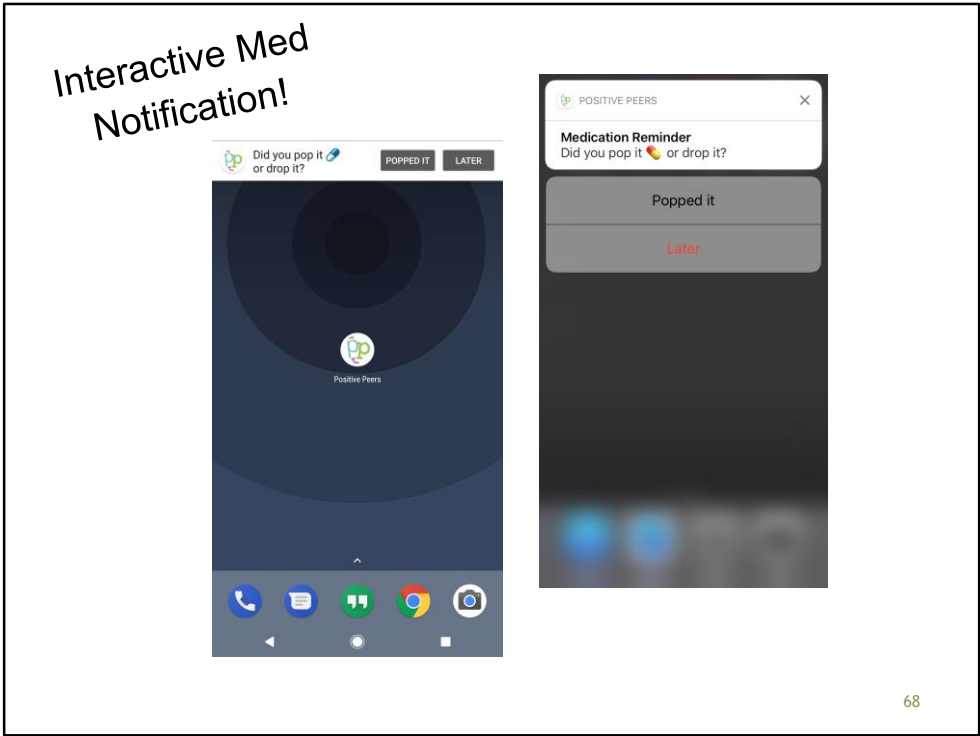
Positive Peers Provides

Health management tools
that chart improvement,
track activities, and set medication
& appointment reminders.

These features are built to have a
game-like feel and are housed
under the My Health (or home)
tab.
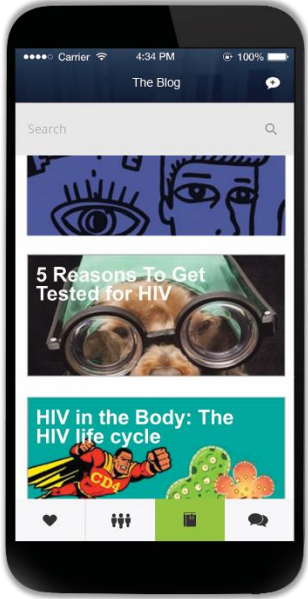
Positive Peers provides **h**ealth management tools that track activities and set medication and appointment reminders. They have a game-like feel and are housed under the My Health tab.

Interactive Med Notification!

Positive Peers has interactive medication notification.

All visitors that come to positivepeers.org will have access to information.

Positive Peers Provides

Accurate, easy-to-understand HIV health and wellness education information & curated community resources

Positive Peers has easy-to-understand HIV health and wellness education information & curated community resources.

Positive Peers Provides

Local social networking in a community conversation & private chats

(chats limited to 2 age groups – 13-17 year olds can only chat with each other, 18-34 year olds can only chat with each other)
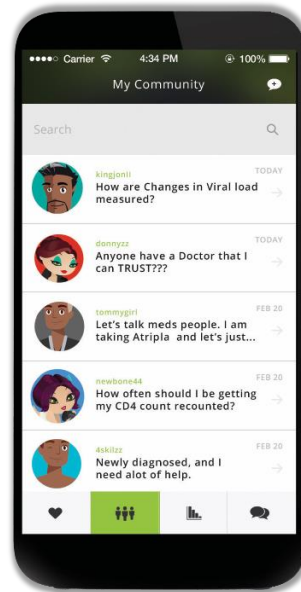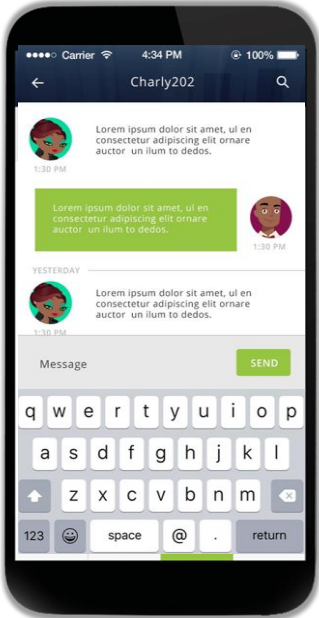

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Social networking is possible in a community conversation or private chats. The app creates a community where people can talk. People can only chat within their own group. This is similar to posting on a Facebook wall.

My Community
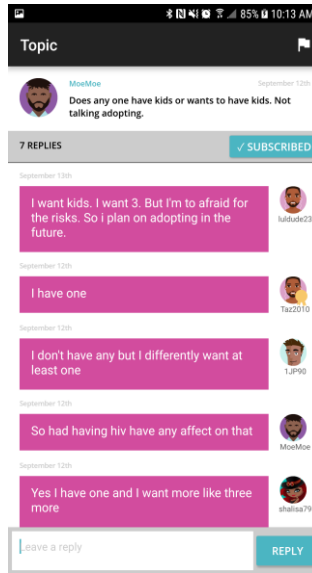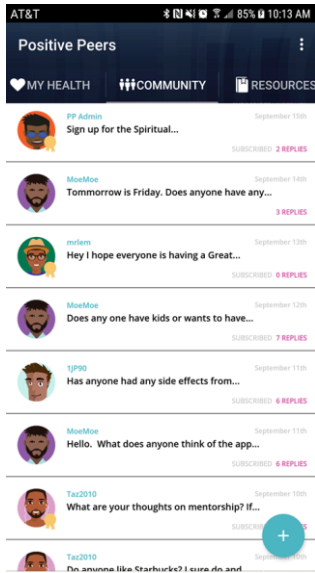
- Similar to posting on a Facebook wall
- Everyone shares one wall
- Everyone can see and reply to posts
- Can add in links to external or in-app content
- Can use emojis ☺
- Cannot upload and share pictures or videos

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Chat

Direct Messaging
- Users can message one another
- Completely private
- Divided by age (13-17 vs 18-34)
- Admin is available on app for DM too
- Similar to Facebook Messenger

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Users can directly message and chat with people individually and privately. Chat also has an age group limitation.
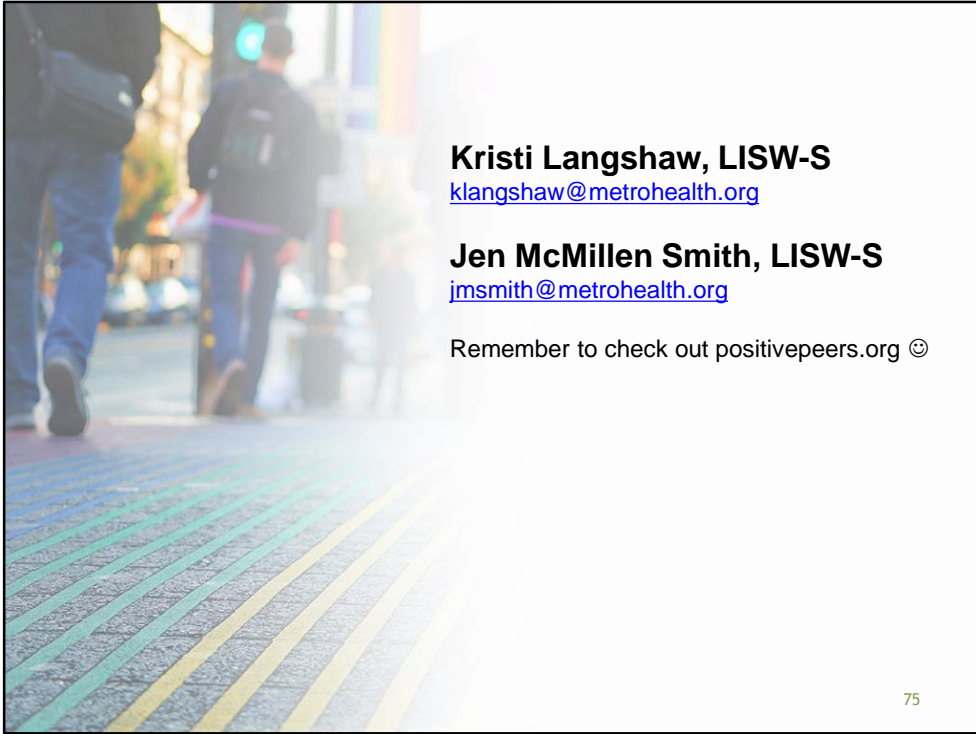
Positive in CLE – Instagram, Twitter, YouTube & Facebook

Positive in CLE is on Instagram, Twitter, YouTube, and Facebook. Users of these social media platforms engage with Positive in CLE. Users like and comment on posts.

This picture shows evidence that we're hitting one of our goals – STIGMA SMASHING!

Kristi Langshaw, LISW-S
klangshaw@metrohealth.org

Jen McMillen Smith, LISW-S
jmsmith@metrohealth.org

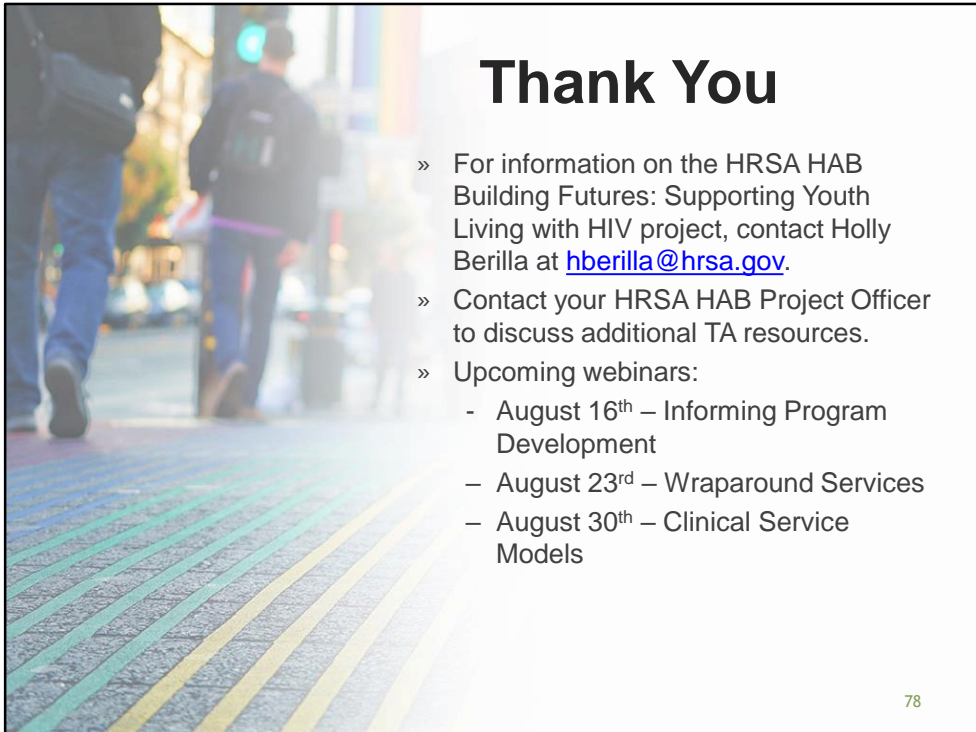Remember to check out positivepeers.org ☺

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Q & A

We will now be taking questions from participants. Remember you can raise your hand and we will unmute your line so that you can ask your question verbally. In order to do so however, you need to have put in your audio pin. You can also type your question into the chat box in your webinar control panel.

Translating the Toolkit into Practice

Dialogue with the Providers

Thank you for those questions. We would just like to end presentation with a few final questions to our providers.
- Are there specific resources that you found helpful?
- What suggestions do you have for other providers who will be using the toolkit?

Thank You

» For information on the HRSA HAB Building Futures: Supporting Youth Living with HIV project, contact Holly Berilla at hberilla@hrsa.gov.

» Contact your HRSA HAB Project Officer to discuss additional TA resources.

» Upcoming webinars:
- August 16th – Informing Program Development
- August 23rd – Wraparound Services
- August 30th – Clinical Service Models

If you have any questions about the toolkit or the Building Futures project, please contact Holly Berilla. If you would like additional TA resources, please contact your HRSA HAB project officer. There will be 3 webinars remaining in the series. If you haven't done so, please register for any or all of the open remaining webinars you are interested in attending. If the webinar you are interested in is closed, please contact AJ Jones whose information can be found on the webinar registration page to be placed on the waiting list.

Remember at the completion of this webinar there will be a survey which opens automatically, it is important that you complete the survey. Thank you.

This webinar will be archived and posted on the TARGET Center website. Remember that the technical assistance toolkit will be available soon and will be found at the same location on the TARGET Center website.