Linkage to care for adolescents with newly acquired HIV

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Financial Disclosure Slide

I have no real or perceived financial disclosures to any commercial products or therapies.

I will not promote the use of any commercial products during this discussion.

I receive HRSA Ryan White Part D funding for working with Adolescents living with HIV.

Objectives

- Understand the statistics and data around linkage to care for adolescents in the USA.
- Understand the ideal linkage process for adolescents with newly diagnosed HIV.
- Review the barriers to successful linkage to care.
- Discuss ways to improve linkage to care.

What is the big deal?

Youth With HIV

Not all youth (aged 13 to 24) are getting the care they need. **For every 100 youth with HIV:**

56 received an HIV diagnosis

43 received some HIV care

31 were retained in care

30 were virally suppressed

For comparison, for every **100 people overall** with HIV, **86 received an HIV diagnosis**, **64 received some HIV care**, **49 were retained in care**, and **53 were virally suppressed**.

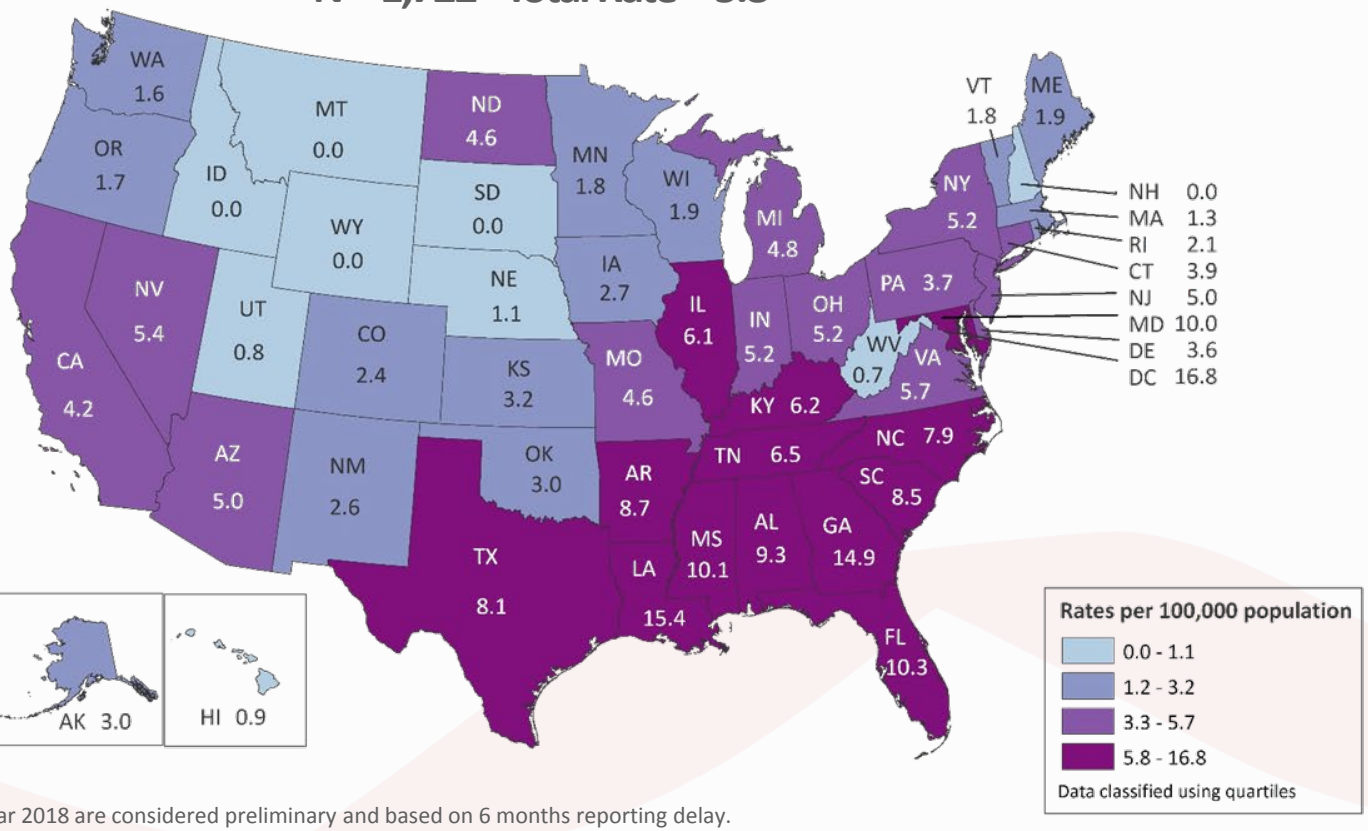
www.cdc.gov/hiv | 1-800-CDC-INFO

Get Tested. Get in Care. Stay in Care. Stay Healthy.

Source: CDC. Selected national HIV prevention and care outcomes (slides).
Based on the most recent data available in April 2020.

Rates of Diagnoses of HIV Infection among Adolescents Aged 13–19 Years
2018—United States and 6 Dependent Areas

N = 1,722 Total Rate = 5.8

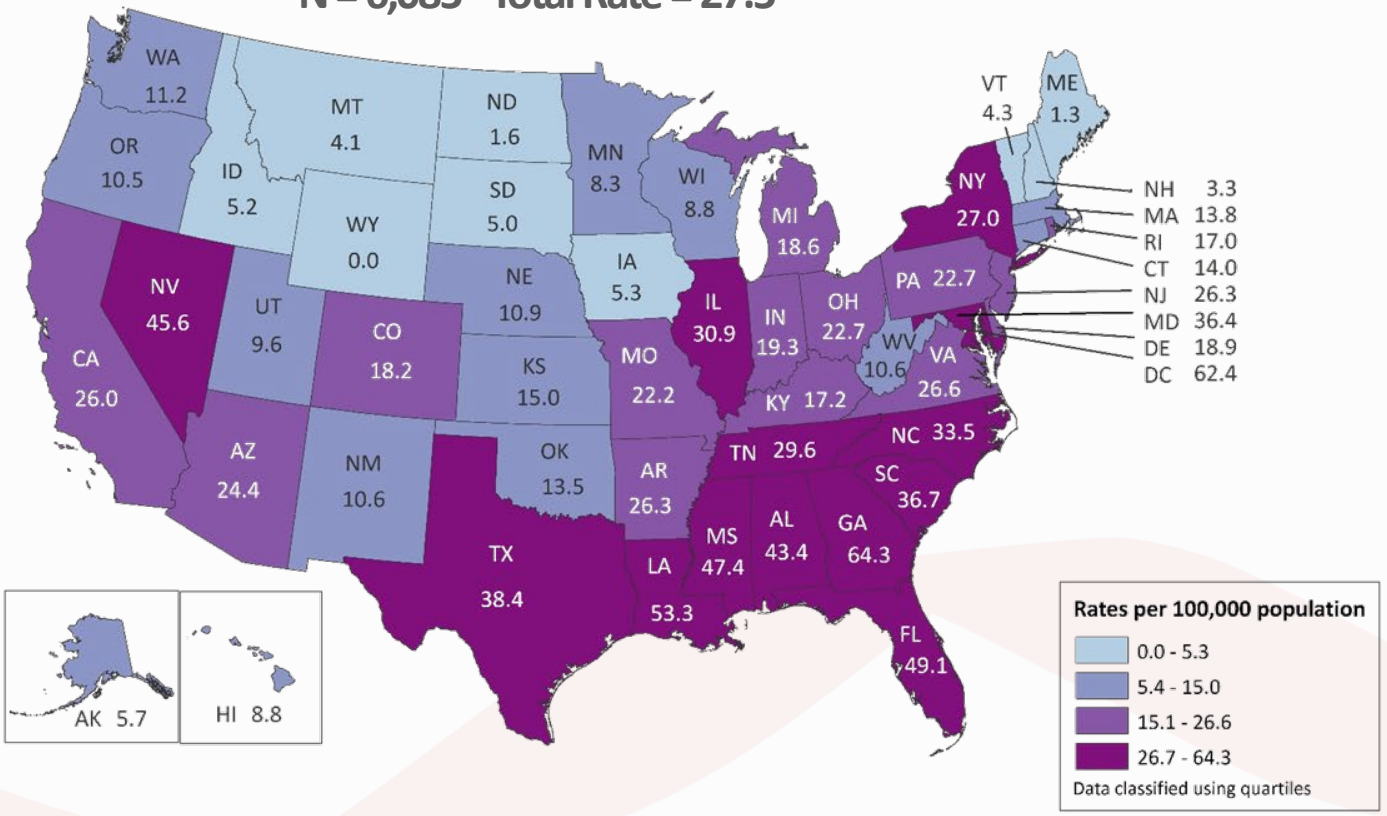


American Samoa	0.0
Guam	0.0
Northern Mariana Islands	0.0
Puerto Rico	5.3
Republic of Palau	0.0
U.S. Virgin Islands	0.0

Note. Data for the year 2018 are considered preliminary and based on 6 months reporting delay.

Rates of Diagnoses of HIV Infection among Young Adults Aged 20–24 Years
2018—United States and 6 Dependent Areas

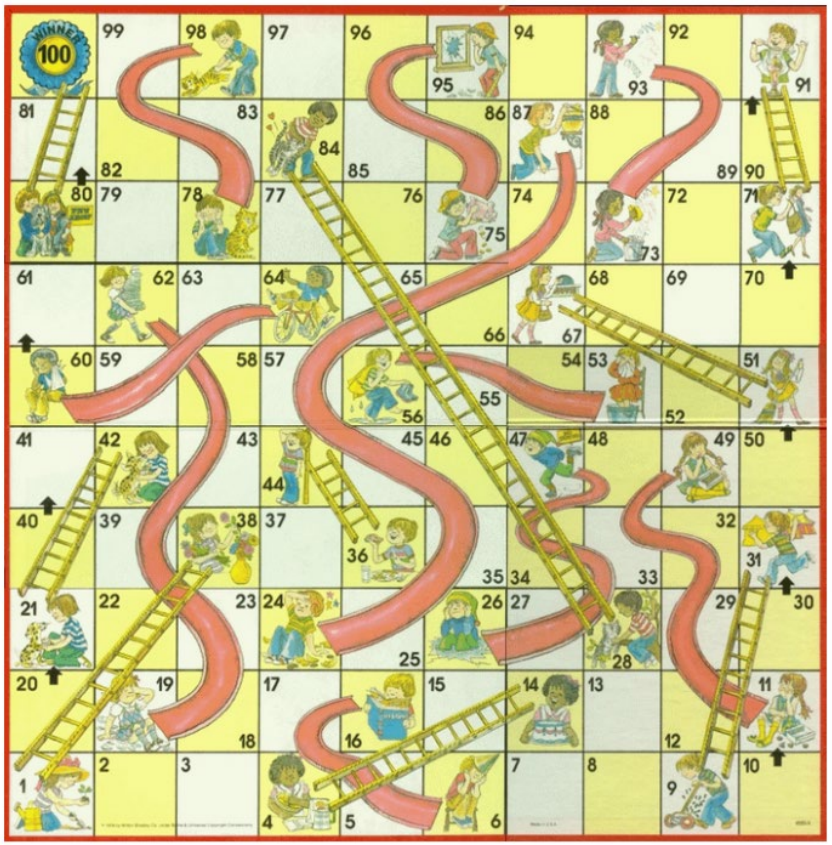
N = 6,085 Total Rate = 27.5



American Samoa	0.0
Guam	0.0
Northern Mariana Islands	0.0
Puerto Rico	26.6
Republic of Palau	0.0
U.S. Virgin Islands	0.0

Note. Data for the year 2018 are considered preliminary and based on 6 months reporting delay.

The Continuum of Care for Adolescents



Patient TR

- 17-year-old male who had sexual debut three months ago. He has had four male partners with both receptive and penetrative anal intercourse. He met three of these partners **on-line**.
  - He had a flu-like illness one month ago.
  - He decided to donate blood and was informed that his initial screen for HIV was positive.
  - His confirmatory testing was positive, and he was referred to our care. He was accompanied by his mother and she was informed of the diagnosis and plan.
  - He initiated rapid ART therapy within three weeks of his initial diagnosis.
  - **Within two months of diagnosis his HIV Viral load was undetectable.**

Patient CZ

- 16-year-old male who identifies as bisexual with newly acquired HIV through sexual contact with another male partner whom he met **on-line**.
  - Mother is unaware of his sexual orientation and practices.
  - He was discovered to be HIV positive by rapid HIV testing at a local LGBTQI Fair and referred to the health department.
  - He was lost to follow up from the health department

  - **Since his diagnosis and disclosure of HIV:**
    - **He initiated care at 10 months**
    - **He started medications at 12 months**
    - **He become virally suppressed at 15 months**

Latent HIV reservoir

https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/1593/latent-hiv-reservoir/

- Latent reservoirs are a group of immune cells which are infected with HIV but not actively producing the virus.
- Latent reservoirs are established during the earliest phase of HIV infection.
- **Rapid linkage to care and initiation of ART reduces the latent HIV reservoir in the individual and reduces the chance of spreading the infection to others.**

What is linkage to care?

https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf

- Linkage to care is a measure of time it takes from diagnosis disclosure to first office visit with an HIV care provider.

- Ideal linkage means that an individual has a viral load or CD4 count obtained during an appointment with an HIV provider and that this occurs within a month of diagnosis disclosure.

- Linkage to care is a process of steps.

Successful Linkage Process

1. Disclosure to the client
2. Informing Local Health Authority (LHA)
3. Surveillance monitoring
4. Disease intervention specialist
5. Early intervention services
6. Referral to an HIV care treatment center
7. Completion of first appointment with provider with lab work obtained
8. Medication initiation as rapidly as possible

Counseling adolescents with newly diagnosed HIV

https://www.cdc.gov/std/tg2015/hiv.htm

- The setting should be confidential and be done in person by a clinician.
- Providers should assess the necessity for acute medical care and psychological support after disclosure.
- Providers should educate clients on the importance of rapid initiation of treatment and care.
- Providers should discuss linkage services and follow up periodically until linkage has occurred.

Where are young people getting tested for HIV?

Setting	Advantages	Disadvantages
Clinic Based	Established client-provider relationship – more likely to accept recommendations around testing, diagnosis, follow -up, and referral Ability to engage parents with consent – ensures likely execution of linkage and treatment plan Cost of testing more likely to be covered by insurance	Established client -provider relationship – client maybe reluctant to discuss risk factors with a provider who has known him since childhood Client may fear parents will find out diagnosis, sexuality, or other risk factors Insurance Explanation of Benefit Form (EOB) can cause inadvertent disclosure to parent

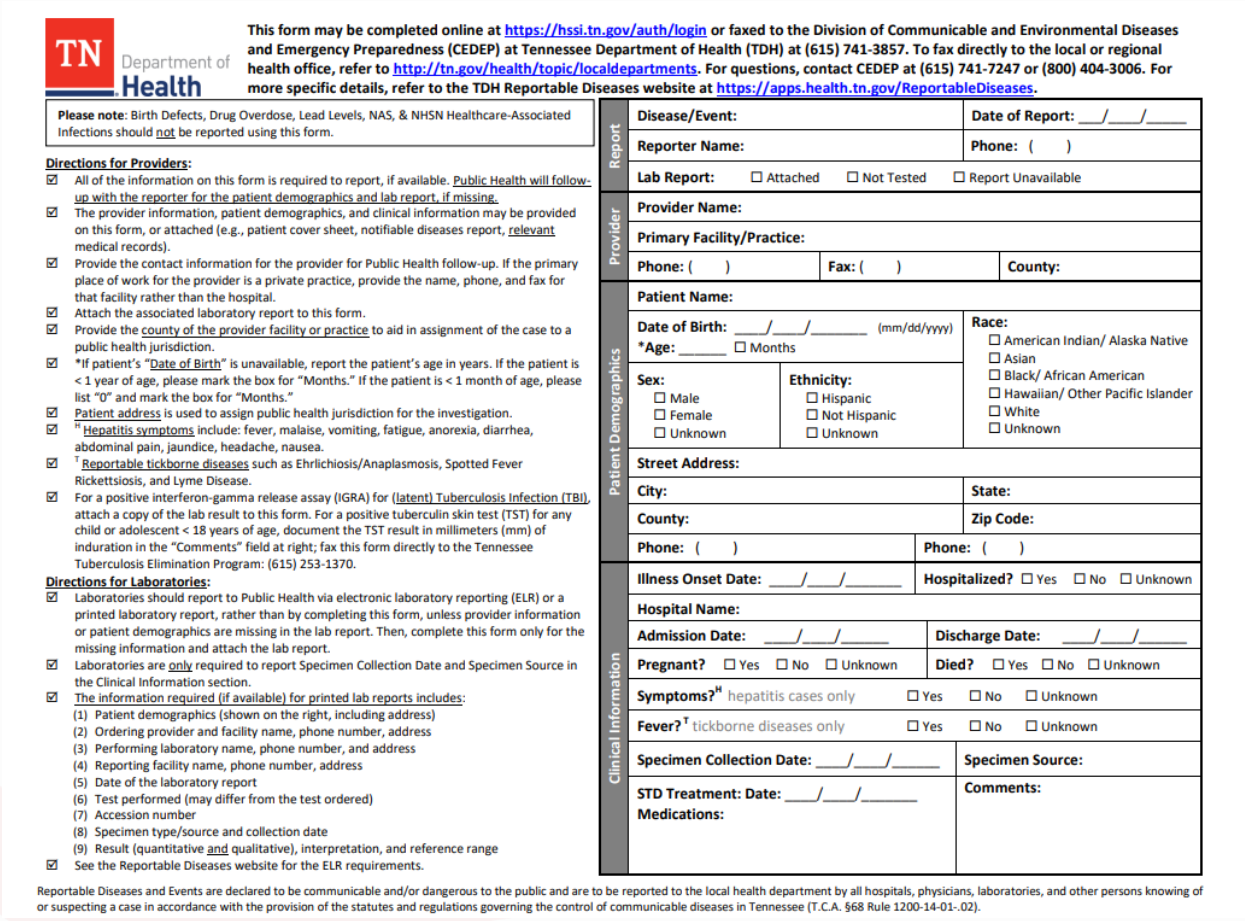
Where are young people getting tested for HIV?

Setting	Advantages	Disadvantages
Community Based	Youth can access more testing locations and venues Could be more anonymous to reduce stigma Trained staff usually present for positive tests to help client with linkage and other support services Cost usually covered by community organization	Referral to linkage services without client-provider relationship may have limited effectiveness and follow through Inadvertent disclosure to peers or community workers in the vicinity

Where are young people getting tested for HIV?

Setting	Advantages	Disadvantages
Self-Testing	Accessible Private with limited chance of inadvertent disclosure to others Test Kit provides hotlines for counseling and linkage	Cost not covered by insurance Lack of direct support services for individual with a positive diagnosis Rapid Tests may not pick up early infection

Reporting to the LHA



TN Department of Health

This form may be completed online at https://hssi.tn.gov/auth/login or faxed to the Division of Communicable and Environmental Diseases and Emergency Preparedness (CEDEP) at Tennessee Department of Health (TDH) at (615) 741-3857. To fax directly to the local or regional health office, refer to http://tn.gov/health/topic/localdepartments. For questions, contact CEDEP at (615) 741-7247 or (800) 404-3006. For more specific details, refer to the TDH Reportable Diseases website at https://apps.health.tn.gov/ReportableDiseases.

Please note: Birth Defects, Drug Overdose, Lead Levels, NAS, & NHSN Healthcare-Associated Infections should not be reported using this form.

Directions for Providers:

- ☑ All of the information on this form is required to report, if available. Public Health will follow-up with the reporter for the patient demographics and lab report, if missing.
- ☑ The provider information, patient demographics, and clinical information may be provided on this form, or attached (e.g., patient cover sheet, notifiable diseases report, relevant medical records).
- ☑ Provide the contact information for the provider for Public Health follow-up. If the primary place of work for the provider is a private practice, provide the name, phone, and fax for that facility rather than the hospital.
- ☑ Attach the associated laboratory report to this form.
- ☑ Provide the county of the provider facility or practice to aid in assignment of the case to a public health jurisdiction.
- ☑ *If patient's "Date of Birth" is unavailable, report the patient's age in years. If the patient is < 1 year of age, please mark the box for "Months." If the patient is < 1 month of age, please list "0" and mark the box for "Months."
- ☑ Patient address is used to assign public health jurisdiction for the investigation.
- ☑ [H] Hepatitis symptoms include: fever, malaise, vomiting, fatigue, anorexia, diarrhea, abdominal pain, jaundice, headache, nausea.
- ☑ [T] Reportable tickborne diseases such as Ehrlichiosis/Anaplasmosis, Spotted Fever Rickettsiosis, and Lyme Disease.
- ☑ For a positive interferon-gamma release assay (IGRA) for (latent) Tuberculosis Infection (TBI), attach a copy of the lab result to this form. For a positive tuberculin skin test (TST) for any child or adolescent < 18 years of age, document the TST result in millimeters (mm) of induration in the "Comments" field at right; fax this form directly to the Tennessee Tuberculosis Elimination Program: (615) 253-1370.

Directions for Laboratories:

- ☑ Laboratories should report to Public Health via electronic laboratory reporting (ELR) or a printed laboratory report, rather than by completing this form, unless provider information or patient demographics are missing in the lab report. Then, complete this form only for the missing information and attach the lab report.
- ☑ Laboratories are only required to report Specimen Collection Date and Specimen Source in the Clinical Information section.
- ☑ The information required (if available) for printed lab reports includes:
  - (1) Patient demographics (shown on the right, including address)
  - (2) Ordering provider and facility name, phone number, address
  - (3) Performing laboratory name, phone number, and address
  - (4) Reporting facility name, phone number, address
  - (5) Date of the laboratory report
  - (6) Test performed (may differ from the test ordered)
  - (7) Accession number
  - (8) Specimen type/source and collection date
  - (9) Result (quantitative and qualitative), interpretation, and reference range
- ☑ See the Reportable Diseases website for the ELR requirements.

Report

Disease/Event:	**Date of Report:** ___/___/____
Reporter Name:	**Phone:** ( )
Lab Report: ☐ Attached ☐ Not Tested ☐ Report Unavailable	

Provider

Provider Name:		
Primary Facility/Practice:		
Phone: ( )	**Fax:** ( )	**County:**

Patient Demographics

Patient Name:		
Date of Birth: ___/___/_____ (mm/dd/yyyy) ***Age:** _____ ☐ Months		**Race:** ☐ American Indian/ Alaska Native ☐ Asian ☐ Black/ African American ☐ Hawaiian/ Other Pacific Islander ☐ White ☐ Unknown
Sex: ☐ Male ☐ Female ☐ Unknown	**Ethnicity:** ☐ Hispanic ☐ Not Hispanic ☐ Unknown	
Street Address:		
City:		**State:**
County:		**Zip Code:**
Phone: ( )		**Phone:** ( )

Clinical Information

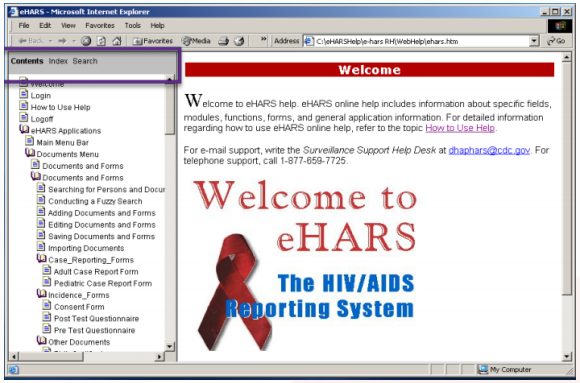
Illness Onset Date: ___/___/_____	**Hospitalized?** ☐ Yes ☐ No ☐ Unknown
Hospital Name:	
Admission Date: ___/___/_____	**Discharge Date:** ___/___/_____
Pregnant? ☐ Yes ☐ No ☐ Unknown	**Died?** ☐ Yes ☐ No ☐ Unknown
Symptoms?[H] hepatitis cases only ☐ Yes ☐ No ☐ Unknown	
Fever?[T] tickborne diseases only ☐ Yes ☐ No ☐ Unknown	
Specimen Collection Date: ___/___/_____	**Specimen Source:**
STD Treatment: Date: ___/___/_____ **Medications:**	**Comments:**

Reportable Diseases and Events are declared to be communicable and/or dangerous to the public and are to be reported to the local health department by all hospitals, physicians, laboratories, and other persons knowing of or suspecting a case in accordance with the provision of the statutes and regulations governing the control of communicable diseases in Tennessee (T.C.A. §68 Rule 1200-14-01-.02).

Surveillance Monitoring

https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html

- Local Health Authority (LHA) will assign a Surveillance Officer (SO) to investigate the case:
  - SO will check the Enhanced HIV/AIDS Reporting program (eHARS)



  - The SO can use this database to see if the client was lost to care in another locality or is a true new diagnosis.

Disease Intervention Specialist (DIS)

- DIS officer will meet the client in person in location of client's choice.
- DIS have been trained on maintaining confidentiality over the phone in case parents or partners have access to client's messages.
- DIS has four goals during the meeting: (Guidelines on HIV Self-Testing and Partner Notification: Supplement to Consolidated Guidelines on HIV Testing Services
    1. Make sure client is aware of the HIV diagnosis and understand what that means
    2. Offer immediate referral for treatment services and options of where to go
    3. Do a risk factor analysis (IV drug use, transactional sex, substance abuse, homelessness)
    4. Perform a confidential case contact identification

Early Intervention Services (EIS)

Can be through LHA or other community-based AIDS related organizations

Goals

1. Interview the client and do a medical and psychosocial assessment.
2. Tailor specific support services based on this interview (e.g. mental health services, Intravenous drug use support services, legal services).
3. Assess and establish insurance and medication coverage.
4. Assess whether the client can self-navigate services, or whether they will try and involve a parent, guardian, or partner.
5. Refer the client to HIV treatment team based on client's needs and preferences.
6. Establish an ongoing form of communication and follow up for 6-9 months in order to ensure successful linkage and engagement in care.
7. EIS can help with housing, meals, transportation, and other barriers to care during this first 6-9 months.

Where are Adolescents being linked to care?

- A majority of 16-22 y/o diagnosed with HIV are being referred to adult HIV care centers.

- In urban and academic centers (Atlanta, Memphis, Birmingham, Nashville, Raleigh, Miami) Adolescent oriented clinics are helping with the large burden of newly diagnosed teens. These settings provide services and support which are specifically tailored to youth.

- The youngest patients are being referred to Pediatric HIV centers.

Immediate ART initiation

- "ART should be initiated as soon as possible after diagnosis, including immediately after diagnosis, unless [the] patient is not ready to commit to starting therapy (evidence rating A1a)." International AIDS Society -USA https://aidsetc.org/blog/immediate-art

- Rapid Initiation for adolescents must be discussed in the context of feasibility with the family barriers, confidentiality, and insurance coverage.

Barriers to linkage unique to adolescents

- Lack of parental disclosure and confidentiality issues
- Stigma
- Systemic barriers

Explanation of Benefits form

- Patient CZ has employee-based insurance through his mother, and he was informed by the EIS team that an itemized EOB form would be sent to his mother describing any diagnosis and tests he received which were billed to insurance. If his mother receives an itemized EOB this would force a difficult conversation for CZ because he has not disclosed to his mother that he is bisexual and that he has HIV. At the same time, he is dependent on his mother financially and for transportation to clinic visits. In his belief it is easier to deal with no care for his newly acquired HIV than to face the trauma associated with disclosure to his mother.

- Laws vary state by state, but private insurances are the primary culprit.
  https://www.guttmacher.org/state-policy/explore/protecting-confidentiality-individuals-insured-dependents

Patient Portals and After Visit Summaries

Thompson, L.A., et al., *Meaningful Use of a Confidential Adolescent Patient Portal.* J Adolesc Health, 2016. **58**(2): p. 134-40.

- Few of the patient health information portals are designed with the needs of adolescents in mind.
- Parents might have access to labs, diagnoses, and medications or even be notified of appointments.
- Printed after visit summaries can reveal medications, diagnosis, and other sensitive information.

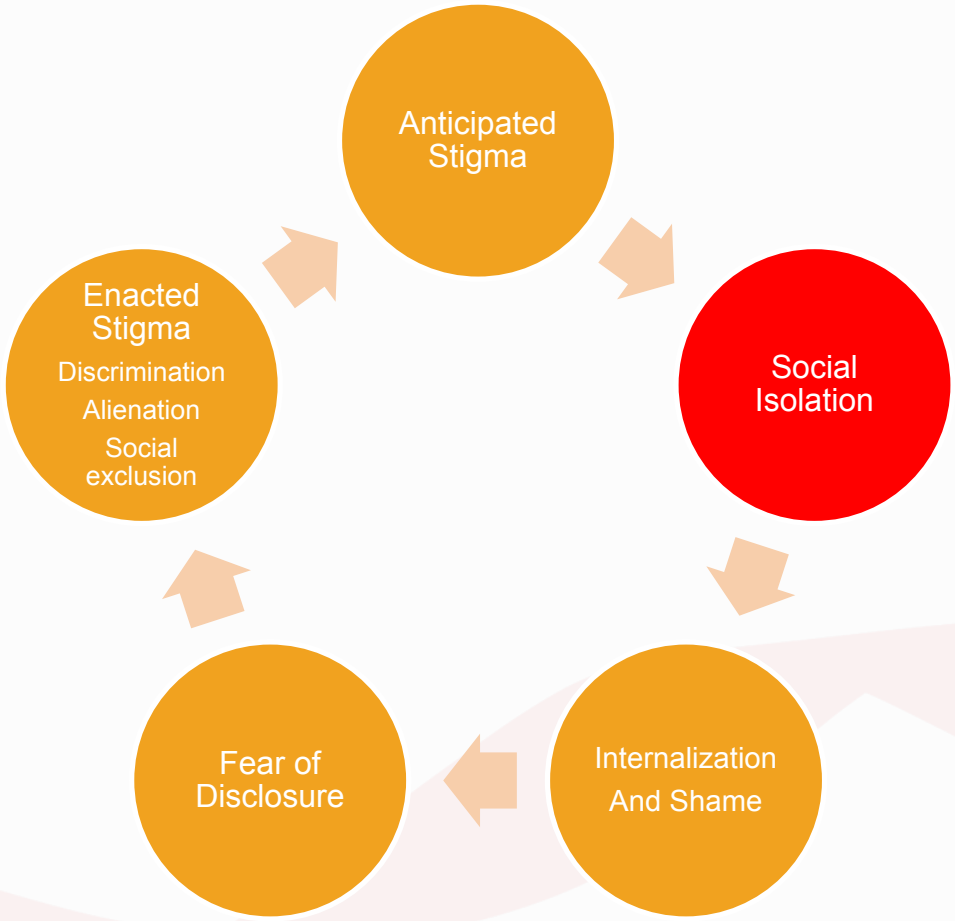
Stigma

Fortenberry, J.D., et al., *Linkage to care for HIV-positive adolescents: a multisite study of the adolescent medicine trials units of the adolescent trials network.* J Adolesc Health, 2012. **51**(6): p. 551-6.

- CZ was diagnosed and disclosed to at a local health fair by a nonprofit HIV related organization. The organization has a full team for linkage services, but CZ has refused to go to this facility because of fear that someone may recognize him in the waiting room and have inadvertent disclosure of HIV status.
- The process of successful linkage requires teens to disclose their status to more people and health systems.
- Successive disclosure to others can cause angst, guilt, and shame which may promote further social isolation.

The Cycle of Stigma for People living with HIV

Quinn K, Dickson-Gomez J, Broadus M, and Kelly J. "It's almost like a crab in a barrel situation: Stigma, social support, and engagement in care among black men living with HIV. AIDS Education and Prevention, 2018 30(2), 120-136.



The rural Southeastern United States

https://aidsetc.org/sites/default/files/resources_files/SEAETC_Strengthening_HIV_Workforce_11022016_Final.pdf

Linkage factors

Philbin, M.M., et al., *Factors affecting linkage to care and engagement in care for newly diagnosed HIV-positive adolescents within fifteen adolescent medicine clinics in the United States.* AIDS Behav, 2014. **18**(8): p. 1501-10.

- One local factor improving linkage is the quality of the collaboration between local health departments and HIV treatment sites.
  - Formal memoranda of understanding
  - Outreach workers could access newly diagnosed youth
  - High quality data sharing
  - Youth Friendly services

How can clinicians provide Youth Friendly Services?

- Training in adolescent specific needs
  - Importance of Confidentiality
  - HEADDSSS psychosocial review
  - Incorporation of family in collaborative decision making
- Training and comfort with sexual and reproductive health services
  - Contraceptive services
  - Fertility/Pregnancy counseling
- Training in comprehensive care of youth
  - Mental health, social determinants of health
  - Providers must be comfortable and adept at addressing non HIV related medical care “Do you have any other unmet health needs?”

How can we make Youth friendly Clinic Structure?

- Training all staff in Youth friendly services and competency (Front desk, nurses, clinical assistants, social workers, pharmacists, and managers)
- Overt symbols and signs of acceptance, safety, and equality
  - Transgender Youth are welcome (Electronic Records that can allow gender preference)
  - Lesbian Gay, Bisexual youth are welcome
  - Homeless youth are welcome
  - Persons from all races and nationalities are welcome (Map of the World)
- Waiting room with other adolescents and young adults
- Adolescent friendly clinic hours and cancellation/late policy and friendly patient health information portals

How can we meet the needs and preferences of the client?

- Motivational interviewing to meet the client where they are in the stages of change in behavior or acceptance of health issues
- Remain nonjudgmental and non-biased with open ended questions and dialogue
- Strengths based approach – make sure the client is aware of their own resiliency factors (family, education or work, peers)
- Flexibility and reassurance that we are in this provider-client relationship for the longer term

Approaches to address confidentiality breaches on EOB forms

https://www.guttmacher.org/state-policy/explore/protecting-confidentiality-individuals-insured-dependents#

PROTECTING CONFIDENTIALITY FOR INSURED DEPENDENTS

STATE	STATE EXPLICITLY REQUIRES INSURER TO PROVIDE CONFIDENTIAL COMMUNICATIONS UPON WRITTEN REQUEST OF INSURED DEPENDENT	PROTECTIONS SPECIFIC TO EOBs	PROTECTIONS FOR MINOR DEPENDENTS	
			Confidentiality for STI Treatment	Broader Confidentiality Provisions
California	X			
Colorado	X†			
Connecticut			X	
Delaware			X	
Florida			X	
Hawaii				Health care provider must inform insurer when "minors without support" request confidentiality
Illinois	‡			
Maine				Minor may refuse parents' request for EOB or claim denial
Maryland	X			
Massachusetts	X	X		
New York		X		
Oregon	X			
Washington	XΩ	X	X	Insurer may not disclose private health information, including through an EOB, without minor's authorization
Wisconsin		X		
TOTAL	**6**	**4**	**4**	**3**

* An insurer may grant requests for sensitive services or for services whose disclosure may endanger the dependent.

† Applies only to adult dependents.

Ω For adult dependents, applies to sensitive services or to all services if the patient has specified a particular person who may not receive information. For minors, applies to all services unless minor has authorized that information may be disclosed.

‡ Illinois protections only apply to sensitive services provided to Medicaid participants.

Barriers to Linkage and Potential Solutions

Barrier	Solution
Insurance EOB forms , patient portals, or pharmacy access causing inadvertent parental disclosure	Youth obtain temporary or permanent insurance and Medication Assistance through Ryan White (maybe challenging because financial records are needed) Suppressing items on Patient Portals or After Visit Summaries Adolescent friendly portals and communication Coaching Adolescents about benefits of disclosing to parents or personal support individual (PSI)

Barriers to Linkage and Potential Solutions

Barrier	Solution
Stigma with fear of inadvertent disclosure to others (Waiting room, Laboratory, Pharmacy)	Removing any identifying names to Clinic (eg HIV Clinic) Embedding Adolescent HIV care into a general clinic to increase diversity of clients in waiting room Training all clinic staff Youth Friendly Services Red carpet Programs Back-Door Entry to Treatment Clinics Escort from EIS officer, parent, or peer Peer led social engagement Engagement of a Personal Support Individual (PSI)

Barriers to Linkage and Potential Solutions

Barrier	Solution
Lack of specific client communication between LHA and Treatment Facility	Memorandums of Understanding for communication and referral Linkage Care conferences and coordinated data sharing[8] Case Manager and EIS communication

Barriers to Linkage and Potential Solutions

Barrier	Solution
Socio-economic barriers (Housing, transportation, financial)	Transportation Vouchers Insurance covered ride services Wrap around case management services Meal Vouchers for Clinic visits Outreach services to meet clients in non-clinical settings

Stay Tuned . . .

- Mobile Health interventions to increase uptake of testing and success of linkage
- More Red-Carpet Programs
- Use of Personal Support Individuals and other peer engagement (games, phone applications etc.) to improve linkage
- Youth driven linkage – Peer accountability

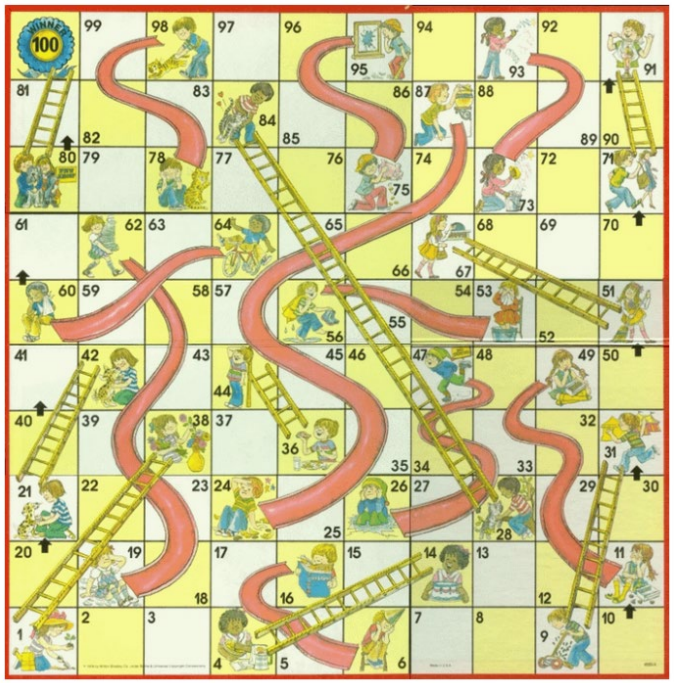
South Eastern Pediatric and Adolescent HIV Collaborative

- Improve quality of health for children and adolescents living with HIV in the South Eastern US
  - Research
  - Education
  - Exchange of best practices
  - Vanderbilt, Emory, St Jude's Children's Research Hospital, and University of Alabama - Birmingham

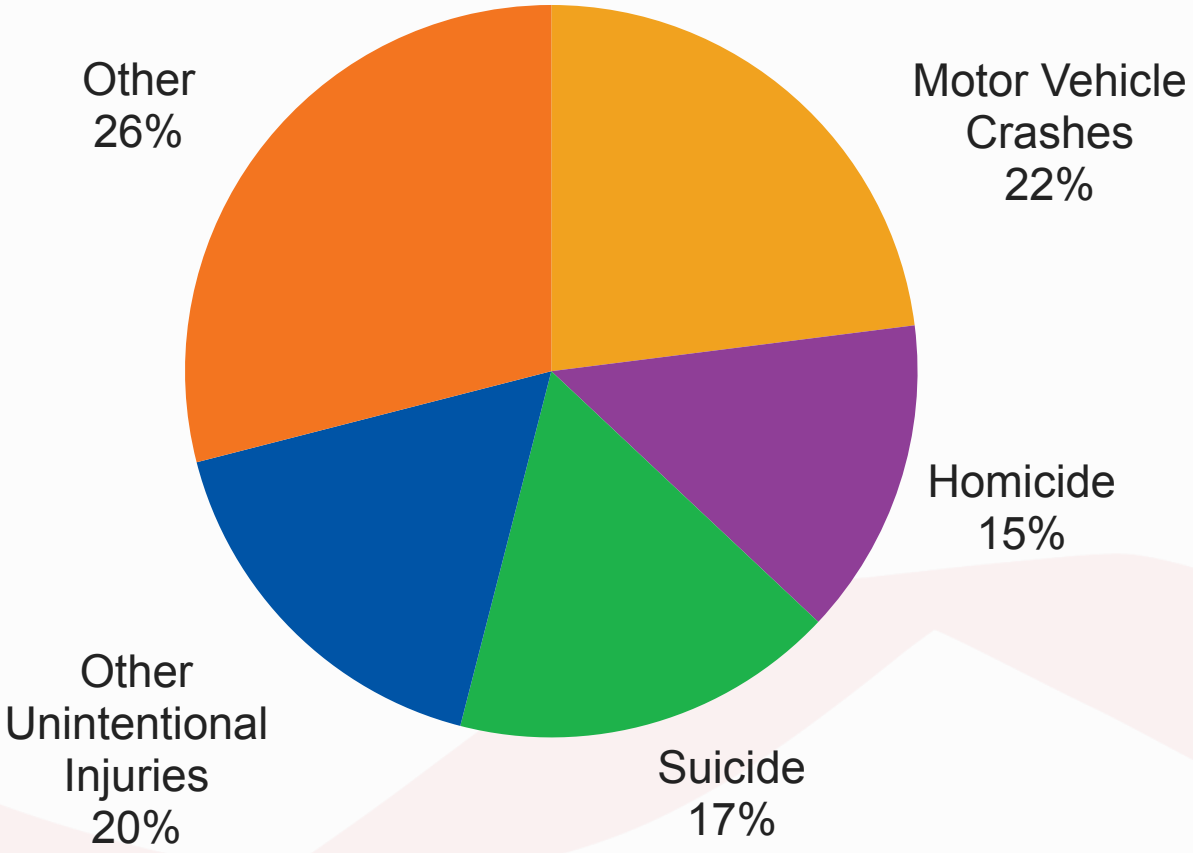
Updates . . .

- Patient TR linked to care and became adherent in appropriate time. He is struggling with severe depression and had one recent suicide attempt because his parents are pursuing “conversion therapy” through the church counselor.

- Patient CZ who struggled with acc ence is now virally suppressed. He has n graduated high school, is attendin n the LGTBQI community on campus.



Leading Causes of Death Among Persons Aged 10 – 24 Years in the United States, 2016 – Youth Risk Behavior Survey



The balance beam of resilience in adolescents and young adults

Substance misuse
Mental health illness
Stigma
ACEs/Trauma

Family Support
Social Engagement
Education
Peer Support
Vocation

Key Summary Points

- Learners should recognize the gaps in outcomes of adolescents on the continuum of care including linkage.
- Learners should understand the process of linkage to care for adolescents newly diagnosed with HIV.
- Learners should recognize the major barriers to success for linkage to care for young people.
- Learners should strategize ways to facilitate linkage.

Special Thanks

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