Using a Data-to-Care Strategy to Combat Social Inequities among Persons Living with HIV

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Louisiana Links Program Description

• Data-to-care strategy implemented across Louisiana from Oct 2013 – ongoing
• Utilizes surveillance data to identify PLWH who are:
  – Newly diagnosed and not linked to care
  – Previously diagnosed who need reengagement
  – In care, but experiencing virologic failure
• Linkage to care coordinators (LCCs) provide extensive services above and beyond the scope of traditional case management
Results from October 2013 through March 2017

- 967 enrollments (944 unique clients)
  - More than half of referrals that were contacted and eligible (57%)

- Demographics
  - 88% were black (62% enrollment rate)
    - Black referrals almost 2 times more likely to enroll than White referrals
  - 54% were males
  - 28% were 29 or younger
  - 43% identified MSM
  - 30% had no income, 91% had an annual income of $0-29,999
  - 26% had no HS degree, 55% had a HS degree or less
Results from October 2013 through March 2017 (cont’d)

- 90% of enrolled patients that were previously not engaged in HIV care were linked/re-engaged (n=685)
- 69% of enrolled patients that were previously in care and had constant viremia showed virologic control (n=141)
- 88% of patients ever enrolled in LA links are currently in care (n=850). Of these, 60% are currently virally suppressed (n=510)
Louisiana Links Approach

• Radically affirming, holistic approach;
  – Anti-racist, anti-heterosexist, anti-cissexist;
  – Understanding barriers and opportunities related to mental health, substance abuse, language access, poverty, immigration status, domestic violence, community violence, family dynamics
Client Outreach and Navigation Overview

• Finding Clients
  – Data from surveillance databases, Accurint, Correctional Facilities
  – LCCs attempt to locate clients until all methods are exhausted
  – Refusals and requests for no future contact are recorded

• Enrollment and Services
  – Intake needs assessment and survey
  – LCCs go to first few clinic and social service appointments with enrolled client
  – Facilitates linkage and engagement to additional supportive services in collaboration with Ryan White case managers
  – Follows up with enrolled clients for 3 months or longer
Linkage Procedures and Standards

• Choosing the right care provider
  – Need to know all available providers and service available
  – Based on client’s needs

• Making the appointment
  – Active referral to a known contact
  – Guaranteed red carpet treatment
  – Pre-planning and reminders
Collaboration and Partnerships

• Create Buy-in from Ryan White Partners
  – Differentiate Louisiana Links and Traditional Case Management
• Partner with referral agencies
• Work together with physicians and provider staff
• Build relationships with local DIS
• Continued nurturing of these partnerships
Successes: Case study #1

“This client appeared to have a very limited understanding of her HIV diagnosis when she first enrolled with LA Links, she was able to thrive after being connected to services. She has displayed success in managing her healthcare and has been proactive in scheduling her own transportation, applying for jobs, and scheduling needed appointments for herself and her son. She was able to take care of most of her needs on her own, but benefited from having someone to check in with and to encourage her.

This client had new labs done in late September, which showed her viral load was still undetectable and her CD4 was 335. The LCC worked on transitioning her to call her case manager with questions about her healthcare, but maintained that it is fine for her to still reach out to the LCC for added support.”
Successes: Case study #1

- HIV care and treatment literacy
- Navigation to care and services
- Tools to help reach client to independence and sustained health maintenance
- Employment and education
- Support system
- Link other family members, sexual partners, babies to testing, HIV care, other services
Successes: Case study #2

“This is a 26 year old African American transgender woman. The Linkage to Care Coordinator (LCC) sent a letter to the address in the referral list and received a call from her about one month later. She stated that she fell out of care after spending some time in jail and needed help getting back into care. She used to receive care at Covenant House, a residential facility for youth in New Orleans. She was no longer eligible for their services after she turned 24 and she didn’t know where else she could receive care. She stated she was disabled and had Medicaid but was receiving no care currently and was not taking any HIV medications. Her last lab records on file were from February of 2014 [a couple years ago]. The LCC and the client talked about the different options and she chose NO/AIDS Task Force because of all the services that were in the same building and because they specialize in HIV and has a history of serving transgender women. NO/AIDS Task Force offers HIV primary medical care and case management services.”
Successes: Case study #2

• Helping clients transition to a different provider after incarceration
• Knowing which clinics are welcoming to transgender women and gay/bisexual men
• Flexibility in communication (texting, weekend replies, etc.)
• Having access to case notes from other HIV care databases (Partner services, CareWare, etc.) to learn about patient’s gender and previous experiences
Other Successes

• Education and capacity of coordinators
• Health department badge gives coordinators authority
• Facilitation of communication between client and physician/ case manager
• Treatment adherence counseling
• Housing if available
• Navigation of public hospitals and social services
• Navigation of Medicaid/ Insurance/ Copays
Challenges: Case Study #3

“This is a 22 year old African American woman. She is a client who is experiencing failure of treatment. Her most recent viral load was 22,020 during that time and her most recent CD4 count was 437 during that summer.

The Linkage to Care Coordinator (LCC) sent a mailer to the address in eHARS. About a week later, the LCC received a call from the client. She said she had been having trouble paying for her medications because she could not afford the Medicaid copay. She said she does not have a case manager and would like help accessing programs to help her pay for her medications.

The client was at the clinic for an appointment with an ear doctor. She was about 15 minutes late after driving from a suburb through heavy traffic. She signed in at a kiosk, which is standard procedure, and then waited to be helped although no staff persons were visible. While waiting, the LCC and the client completed the necessary paperwork and talked about her needs. She was recently diagnosed with HIV about a year ago. She was referred to an HIV doctor and has been to see him a couple of times. She was prescribed medication a number of months ago but has not picked it up yet because there was a copay at the pharmacy that she was unable to afford. She recently went to the emergency room because she was having trouble hearing. That is where she learned she was pregnant. She said she had not yet had an O.B. appointment because she did not have enough gas to get there and had to reschedule. She was approximately 10 weeks along at this time. She had another child who was two years old at this time. They lived with her mother in a house with many other children and adults. After over half an hour had passed and they had not yet been helped, the LCC flagged down a worker behind the clinic’s partition. They were told that registration staff had already left for the day, which is why no one helped her. They were also told that while the doctor was still there, there was no referral in her file, so she could not be seen. She was scheduled to come back in for an ear exam in two months. The client was frustrated by this and stated that the emergency room doctor had told her there was nothing they could do for her and told her to come to this clinic. She was frustrated that she would have to wait for two months while she could not hear very well out of one ear. The client stated that she had an appointment with her Infectious Disease (ID) doctor at a different clinic in a few days and stated she would like the LCC to meet her there.”
Challenges: Case Study #3

- Navigating fragmented healthcare system can be confusing and frustrating, even with the help of linkage coordinator
- Patient may be dealing with other co-morbidities
- Timely assistance is needed for pregnant clients
- Providers are too busy to help patients with basic issues and can create barriers to accessing care treatment
- Patients often have an unstable or dependent living situation
Challenges: Case Study #4

This was a 38 year old African American man. He was placed on the out of care list in 2015. At the time, this client’s most recent lab work showed (2014) his viral load was 313 and his CD4 was 638 from Orleans Parish Prison System (OPP). The Linkage to Care Coordinator (LCC) searched the OPP detention center roster and docket and did not find the client in that system. The LCC sent a mailer to the residential address on file in 2015. The mailer was not returned to sender, which indicated it may have reached the destination. Although the LCC didn’t hear from him, a year later she noticed the client received lab work several times in secession, and demonstrated an increase in viral load to 86,000 in early 2016. The LCC talked to the client about LA Links. He said he needed help with issues including homelessness and Social Security. An intake was scheduled for the following day at his mother’s house. The LCC and the client also talked about transitional housing as an option but he said he was not interested as he did not want to live in a facility where certain areas were shared. He said he was interested in rental assistance.

He said that he had no source of income at that time. He used to receive SNAP (formerly known as food stamps) benefits but he said this was cancelled after one month due to a work requirement. He said he needed to get a paper from his doctor stating that he couldn’t work. He said he lost his last job in the food service industry because he didn’t want to disclose his HIV status but he knew he shouldn’t be working with food. The LCC informed him that his HIV status did not disqualify him from working with food or in any other industry.

He said it was also hard for him to work because he was blind in one eye. He said he applied for disability once and received a denial months earlier. He wasn’t sure what the next step was in that process. After LA Links intake paperwork was finished, the LCC agreed to follow up with his case manager and find out when his next medical appointment was scheduled, what the next step in his Social Security application process was, and how he could apply for housing assistance. The LCC agreed to contact the client again with the updated information.

Since that time (a month later), the LCC did not hear back from the client. The LCC left messages on the mother’s phone but did not receive a call back. No new labs were seen in the STD/HIV surveillance system. The LCC checked the Orleans Parish Detention Center roster and did not see the client there.
Challenges: Case Study #4

• Clients are dealing with many different socioeconomic issues including homelessness
• Difficulty qualifying for social assistance programs
• Clients may eventually be overwhelmed by social circumstances and lost to follow-up
Challenges: Refusals

• Claimed to have already been in care
• Declined to give specific information about their healthcare
• Those who needed some information or remote assistance with getting back into care, but declined further assistance or LA Links enrollment
• Neutral or agitated responses
• Did not believe in medical intervention
Other Challenges

• Transportation
• Housing
• Scheduling appointments in regions with a lack of providers
• Hospital/Clinic environment
• Lack of support system
• Substance abuse
• Incarceration
• Inaccurate surveillance data
• Viral suppression
Next Steps

• Address observed institutional barriers
  – Help providers meet clients’ needs and provide client-centered care regardless of social circumstances
  – Feedback to Medicaid regarding transportation issues

• Disseminate data from program

• More collaboration
Thanks!

Questions? Contact:
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