HHS Public Access

Author manuscript

*AIDS Care*. Author manuscript; available in PMC 2025 January 06.

Published in final edited form as:

*AIDS Care*. 2023 May ; 35(5): 764–771. doi:10.1080/09540121.2022.2077296.

# "Take care of their hierarchy of needs first": Strategies used by Data-to-Care staff to address barriers to HIV care engagement

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## Abstract

Data-to-Care (D2C) is a public health strategy designed to engage out of care (OOC) persons with HIV (PWH) in HIV care. OOC PWH are identified through review of state and local HIV data and engaged in care through individualized efforts that address barriers to HIV care. Perspectives of D2C program staff, who work with OOC PWH to identify and address barriers to care, can contribute to D2C program development and sustainability. We conducted semi-structured interviews in 2017 with 20 D2C program staff from Louisiana (n=10) and Virginia (n=10), states with distinct D2C programs. We used content and thematic analysis to analyze interview transcripts. In both states, common barriers to care for OOC PWH include limited transportation, stigma, substance use, poverty, homelessness, and mental illness. To address these barriers and engage OOC clients in HIV care, D2C staff and programs provided transportation vouchers and housing assistance, integrated substance use and mental health services into care engagement processes, provided empathy, care and compassion, and assessed and addressed basic unmet needs. Identifying and addressing social and structural barriers to HIV care is a critical part of D2C staff's work and often a necessary first step in engaging OOC clients in HIV care. These findings can be used by D2C programs to aid in their design and implementation, facilitating engagement in HIV care for OOC PWH.

### Keywords

HIV; surveillance; program; data to care; qualitative analyses

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Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Declaration of interest

There are no conflicts of interest to report, or financial disclosures.

## Introduction

Linking and retaining persons with HIV (PWH) in HIV care is essential to meet national HIV prevention and treatment goals (National HIV/AIDS Strategy for the United States: Updated to 2020, 2015) and optimize health outcomes (Cohen et al., 2013; Eaton, Saag, & Mugavero, 2014; Kay, Batey, & Mugavero, 2016; Mugavero, 2016; Taiwo et al., 2013). However, not all PWH are engaged in care. Data collected from June 2018-May 2019 found that of all persons diagnosed with HIV in the United States (U.S.) in the 12 months prior to data collection, 81% were prescribed antiretroviral therapy, 78% were retained in care, and 62% were virally suppressed (<200 copies/mL) (Centers for Disease Control and Prevention, 2020). Out of care (OOC) PWH face individual, social, and structural barriers to HIV care that are complex and synergistic (Bauman et al., 2013; Berger et al., 2016; Christopoulos et al., 2013; Dombrowski, Simoni, Katz, & Golden, 2015; Durvasula & Miller, 2014; Holtzman et al., 2015; Maulsby et al., 2018; Sison et al., 2013).

"Data-to-Care" (D2C) is a public health strategy designed to identify and engage OOC PWH in HIV care. While there are numerous approaches to D2C program implementation (Mokotoff et al., 2019), most commonly OOC PWH are identified and linked to care either by health departments using HIV surveillance and laboratory data to identify those who are OOC and working to relink them to services, or by healthcare providers identifying their patients who are OOC and working with health departments to relink them to services. Both approaches rely on individualized outreach to OOC PWH that address their unique barriers to HIV care (Sweeney et al., 2019).

In 2018, the Centers for Disease Control and Prevention (CDC) began providing all U.S. state health department HIV control programs with funding to implement, expand, and support D2C efforts (https://www.cdc.gov/hiv/funding/announcements/ps18-1802/index.html). A critical component of the development and sustainability of D2C programs is engaging the perspectives of D2C clients, clinical providers, and program staff (Buchbinder et al., 2020; Dombrowski et al., 2016; Evans et al., 2015; Sweeney et al., 2019). D2C program staff understand firsthand the barriers to engaging and retaining OOC PWH in HIV care, and they develop and implement strategies to address identified barriers. To further the development and sustainability of D2C programs, we interviewed staff from two distinct D2C programs to assess client barriers to care, and the strategies employed to address reported barriers. These data were collected as part of a broader evaluation to identify effective approaches to implementing D2C programs and to understand how health departments use D2C strategies to link and (re)engage OOC PWH in care.

## Materials and Methods

### Study sites

This study was conducted in 2017 in two states in the Southern U.S., Louisiana and Virginia. In 2016, as a region the South accounted for 51% of annual new HIV infections and 45% of PWH infection while comprising 38% of the population (McCree et al., 2019). In 2017, Louisiana ranked 4th in the nation for HIV case rates and 10th in the estimated number of HIV cases (Louisiana Department of Health, 2017). In 2014, Virginia ranked 13th for total

number of annual reported new HIV disease diagnoses and had the 20th highest rate of HIV disease diagnosis in the U.S. (Virginia Department of Health, 2016).

The D2C programs in Louisiana and Virginia are distinct from one another regarding time established, structure and design, and implementation approaches. Louisiana formally established their D2C program in 2013 (Anderson, Henley, Lass, Burgess, & Jenner, 2020; Sweeney et al., 2018). It is a centralized program, meaning it is implemented by the state department of health (DoH), and program staff are state employees. Lists of OOC PWH are created and prepared using surveillance data at the state office, and lists are shared with regional program staff who begin the process of locating and engaging identified OOC PWH. During the first three years of the program, from 2013–2016, 533 OOC PWH were offered or provided linkage or reengagement services through D2C efforts, and 480 were confirmed linked to care (90.1%) (Sweeney et al., 2018). Virginia's D2C program was formally initiated a couple of years later, in 2015 (Sweeney et al., 2018; Virginia Department of Health, 2016). Virginia's D2C program is decentralized, meaning the state DoH generates lists of OOC PWH from surveillance data and shares the lists with local/regional community-based organizations (CBOs), healthcare providers, and health departments, who locate and engage OOC PWH in care. During the first year of Virginia's D2C program, from 2015–2016, few OOC PWH were identified. During this start-up period, Virginia offered or provided linkage or reengagement services to nine OOC PWH, of which eight (88.9%) were confirmed to be linked to care through D2C efforts (Sweeney et al., 2018; Virginia Department of Health, 2016). Differences in implementation practices and policies, program capacity (staffing, resources, and data systems), data reporting requirements, and data reporting time period account for the variation regarding the number of OOC clients identified (Sweeney et al., 2018).

## Study population

Twenty D2C program staff participated in this study, ten from each state. A list of program staff who were involved in implementing one or more components of the local D2C program was compiled by each state DoH; staff were selected purposively and invited to participate in the study. Eligible participants were age ≥18 years and able to provide consent.

## Data collection

Semi-structured, in-depth interviews were conducted in Baton Rouge and New Orleans, Louisiana and several locations across Virginia, including Richmond, Fairfax, Accomac, Winchester, and Roanoke. Our interview guide included structured response items regarding participant employment characteristics. It also included a series of semi-structured, open-ended questions regarding client barriers to engagement in care, steps and strategies to engage OOC PWH, and programmatic strengths, recommendations, and lessons learned. Participants provided informed consent prior to being interviewed. The interview guide was reviewed by a subject matter expert and piloted with D2C staff who did not participate in the study. Both CDC and Virginia DoH Institutional Review Boards approved the study protocol and interview guides. Interviews, which lasted approximately 60 minutes, were audio-recorded and transcribed verbatim with personal identifying information redacted.

### Data analysis

A codebook was developed to reflect the structure and content of the interview guide. Coders were trained on how to use the codebook, and the codebook was subsequently piloted. We assessed inter-coder reliability using Cohen's kappa (Hruschka et al., 2004; Landis & Koch, 1977) to ensure a kappa score of 0.70 or higher, indicating substantial inter-coder agreement (Landis & Koch, 1977). Once coders achieved agreement, they completed coding of all the transcripts using NVivo software (version 11) (Leech & Onwuegbuzie, 2007). We reviewed data coded in the transcripts according to reasons why someone may be OOC, identified the most common barriers to care, and strategies described by D2C staff to address those barriers. We then selected exemplary illustrative quotes that described these barriers and strategies. Finally, we computed frequencies for the staff's employment characteristics.

## Results

### D2C staff employment characteristics

In Louisiana, D2C program staff worked at the state DoH (n=10) and more than half (n=7) reported working in HIV prevention programs for ≥11 years. In Virginia, most participants worked for a CBO (n=7), and more than half worked in HIV prevention programs for <10 years (n=6). Length of time working in D2C programs was reflective of the age of their respective program; in Louisiana, more than half of the staff worked in D2C programs 3–10 years (n=6), while in Virginia, more than half worked in D2C programs ≤2 years (n=6) (see Table 1).

### Client barriers to HIV care and D2C staff strategies to reduce those barriers

Despite differences in time established, program structure and implementation practices, we found uniformity regarding reported client barriers to care (see Table 2), and strategies used by D2C staff to address those barriers. Below, we present the most commonly described barriers for OOC PWH accessing and remaining in HIV care from staff in Louisiana and Virginia, along with strategies used to address those barriers. Table 3 provides illustrative quotes and how D2C staff assisted their clients with overcoming these barriers.

**Transportation—**Lack of transportation was the most commonly reported client barrier to HIV care among D2C program staff. Staff noted that lack of public transit and personal transportation was problematic, especially among those PWH living in less urban areas. If clients needed to travel for more than two hours to access treatment, they may forgo their HIV care appointments.

D2C program staff described how they helped clients overcome transportation barriers by arranging ride-sharing services to transport clients to appointments, or by providing bus tokens for public transportation. Staff also coordinated with clients' family members to secure rides to appointments or provided gas cards for clients with personal transportation.

**Stigma—**D2C program staff reported that stigma was a significant barrier to care engagement. Clients may have internalized stigma or have feelings of self-hatred or denial

about their HIV status. Staff also report that clients may feel uncomfortable in public health clinics because of health facility stigma (the clinic being affiliated with public health or HIV), long or uncomfortable waits, or fear of being seen by someone they know thereby exposing their HIV status.

To counteract stigma, D2C program staff stated that it was essential to have conversations explaining the importance of staying in care, and to give newly diagnosed clients time to process their HIV diagnosis. Some staff mentioned treating people with empathy and communicating common understanding and shared experiences as a way to deal with stigma. Staff also discussed providing social and emotional support and the importance of expressing care and compassion to the client to counteract biased or stigmatizing experiences and interactions.

**Substance use—**D2C program staff reported that substance use was a considerable barrier to their clients receiving consistent HIV care, and may be a precipitating factor to other barriers (e.g., housing instability, unemployment). Substance use complicated medication adherence, and some staff found it challenging to support and encourage HIV care if their client's substance use concerns were not first addressed.

Addressing issues of substance use was challenging for some D2C program staff. Staff recommended consistent, non-judgmental communication, and referrals to treatment programs. Some programs employed substance use counselors on-site or had funds available for treatment programs for clients.

**Homelessness—**D2C program staff described homelessness and housing instability as a barrier to HIV care, and that the client's need for stable housing would likely take priority over HIV treatment. Staff discussed addressing homelessness and housing instability by collaborating with other agencies to help pay the client's first month of rent. Staff also negotiated with Section 8 housing programs to pay rent on behalf of their clients. In Virginia, staff also referred to an in-house emergency assistance program that can pay rent for those who are on the verge of being evicted. In addition to monetary support, staff also counsel clients to make plans to ensure stable housing.

**Poverty—**Another barrier to HIV care mentioned by D2C program staff was poverty, low-income, and low socioeconomic status. Clients living below the federal poverty guidelines are often marginalized or underserved and more likely may be out of care, compared to those not living in poverty.

To address issues associated with low-income and poverty, D2C program staff conduct needs assessments during the first appointment with clients. Staff recognize the importance of addressing their clients' most fundamental unmet needs first, such as food and housing, to enable engagement in HIV care. Staff discussed how they help clients with enrollment in social service programs such as social security, food stamps, and disability. In Virginia, staff mentioned that some programs provide emergency food cards to clients.

D2C program staff stated that for clients experiencing multiple unmet needs, navigating medical and social service systems can be overwhelming. They stressed that providing this type of assistance cannot be time-limited, and that they needed to show compassion toward their clients. Staff who navigated clients through health and social service systems report the unique structural barriers faced by their clients to their administrative service coordinators.

**Mental illness—**D2C program staff reported mental illness was a notable obstacle to clients engaging in HIV care. Mental illness may also present among those with substance use or without access to medical care. Some clients with untreated mental illness are marginalized and do not trust the medical system. Encouraging those with mental illness to remain in care was a challenge for D2C program staff. To address these barriers, programs provide clients with mental health clinicians and support groups. Staff also make referrals to specialists and provide psychosocial assessment on intake.

## Discussion

Our study identifies common barriers to HIV care among OOC PWH in Louisiana and Virginia, and the strategies used by D2C program staff in those states to address identified barriers and help their clients access and remain in HIV care. Despite the distinctions between program time established, design and implementation practices, we found notable similarities regarding client barriers and methods to address those barriers. D2C program staff describe limited transportation, stigma, substance use and mental illness, homelessness and housing instability, and poverty as persistent social and structural barriers that impede their client's ability to seek and receive HIV care. To address these barriers and facilitate reengagement in HIV care, staff draw upon programmatic capacity to provide transportation incentives, rental assistance and housing support, and substance use and mental health resources, and their insight and interpersonal skills to provide open, supportive and non-judgmental communication, empathy, and social support. These components of program implementation, program and staff capacity, are key to D2C program success (Sweeney et al., 2019).

Addressing social and structural determinants of health is essential to reduce HIV incidence (Dean & Fenton, 2010; Walcott, 2016), and a critical component of D2C programming (Mulatu et al., 2022; Sweeney et al., 2019; Sweeney et al., 2018). In both D2C programs, we found that attending to social and structural barriers to HIV care is a critical part of the work done by D2C staff, and in many cases, a necessary first step to engaging OOC clients in HIV care. The significance of D2C programs addressing client social determinants of health as part of their overall approach to HIV care reengagement cannot be overstated. As noted by one D2C program staff in Louisiana, staff need to acknowledge and address their client's hierarchy of needs first (Maslow, 1943), because the client will always prioritize stable access to food, housing, and employment before engaging in HIV care. Our findings confirm that D2C programs should continue to assess and address basic unmet needs and structural barriers to care when working to reengage OOC PWH, and we recommend that D2C program staff ensure provision of caring, empathetic, non-judgmental support needed to engage clients in care.

### Limitations

There are several limitations that should be noted. First, this study was cross-sectional and had a small sample size, so findings may not be generalizable or reflect the current status of the two programs. Second, data collected were opinions of those interviewed, so there is a possibility of response bias. Third, some of the staff interviewed from Virginia also worked simultaneously in other efforts to engage OOC PWH. Thus, their responses may not have been exclusively about their work in D2C, rather more generally of their experiences with the OOC population. Fourth, we did not collect data on training requirements for working in the D2C program or the specific resources available to the staff to conduct D2C activities. Finally, these data were collected from two states with very different D2C programs regarding time established, structure, and implementation, and the number of OOC PWH that were identified in the initial stages of program implementation. Despite these differences, the two programs reported very similar barriers and unmet needs experienced by their clients and strategies used to overcome these barriers to engage their clients in care, which is the focus of our analysis. We believe that documenting shared experiences by heterogenous programs may strengthen our findings. We acknowledge this study was conducted prior to the COVID-19 pandemic, which likely has interrupted or changed the process or ability of D2C programs to link and engage clients into HIV care in both states.

### Conclusions

D2C program staff have insight into the complex and synergistic barriers to HIV care that OOC PWH experience, and work to overcome those barriers and engage clients in HIV care. As health departments, CBOs, and healthcare providers continue to develop and implement D2C programs, it is important to assess the perspectives and experiences of both D2C program staff and clients from diverse programs to learn how to effectively reengage OOC PWH. We believe these findings will provide developed and nascent D2C programs with ideas and approaches to address client barriers to care, ultimately leading to more consistent engagement in HIV care for OOC PWH.

## Acknowledgements

Some authors are federal government employees, and this report is not subject to copyright in the United States. Special thanks to Nanette Benbow, PhD (Northwestern University Feinberg School of Medicine), the Louisiana Department of Health - Office of Public Health Region 1 and Region 2 offices, the Virginia Department of Health, the D2C program staff in Louisiana and Virginia, and the study team who collected and analyzed the data.

#### Funding

This work was conducted under CDC Contract #200-2013-57341/0004.

## References

Anderson S, Henley C, Lass K, Burgess S, & Jenner E (2020). Improving Engagement in HIV Care Using a Data-to-Care and Patient Navigation System in Louisiana, United States. J Assoc Nurses AIDS Care, 31(5), 553–565. doi:10.1097/jnc.0000000000000150 [PubMed: 31899701]

Bauman LJ, Braunstein S, Calderon Y, Chhabra R, Cutler B, Leider J, Rivera A, Sclafane J, Tsoi B,Watnick D (2013). Barriers and facilitators of linkage to HIV primary care in New York City. J Acquir Immune Defic Syndr, 64 Suppl 1, S20–26. doi:10.1097/QAI.0b013e3182a99c19 [PubMed: 24126445]

Berger MB, Sullivan KA, Parnell HE, Keller J, Pollard A, Cox ME, Clymore JM, Quinlivan EB (2016). Barriers and Facilitators to Retaining and Reengaging HIV Clients in Care: A Case Study of North Carolina. J Int Assoc Provid AIDS Care, 15(6), 486–493. doi:10.1177/2325957415616491 [PubMed: 26567224]

Buchbinder M, Blue C, Juengst E, Brinkley-Rubinstein L, Rennie S, & Rosen DL (2020). Expert stakeholders' perspectives on a Data-to-Care strategy for improving care among HIV-positive individuals incarcerated in jails. AIDS Care, 1–7. doi:10.1080/09540121.2020.1737641

Centers for Disease Control and Prevention. Behavioral and Clinical Characteristics of Persons with Diagnosed HIV Infection—Medical Monitoring Project, United States, 2018 Cycle (June 2018–May 2019). HIV Surveillance Special Report 25. https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-special-report-number-25.pdf. Published May 2020. Accessed [8/6/2021].

Christopoulos KA, Massey AD, Lopez AM, Geng EH, Johnson MO, Pilcher CD, Fielding H, Dawson-Rose C (2013). "Taking a half day at a time:" patient perspectives and the HIV engagement in care continuum. AIDS Patient Care STDS, 27(4), 223–230. doi:10.1089/apc.2012.0418 [PubMed: 23565926]

Cohen MS, Smith MK, Muessig KE, Hallett TB, Powers KA, & Kashuba AD (2013). Antiretroviral treatment of HIV-1 prevents transmission of HIV-1: where do we go from here? Lancet, 382(9903), 1515–1524. doi:10.1016/S0140-6736(13)61998-4 [PubMed: 24152938]

Dean HD, and Fenton KA. 2010. "Addressing Social Determinants of Health in the Prevention and Control of HIV/AIDS, Viral Hepatitis, Sexually Transmitted Infections, and Tuberculosis." Public Health Reports 125 (Suppl 4): 1–5.

Dombrowski JC, Carey JW, Pitts N, Craw J, Freeman A, Golden MR, & Bertolli J (2016). HIV provider and patient perspectives on the Development of a Health Department "Data to Care" Program: a qualitative study. BMC Public Health, 16, 491. doi:10.1186/s12889-016-3152-4 [PubMed: 27286654]

Dombrowski JC, Simoni JM, Katz DA, & Golden MR (2015). Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program. AIDS Patient Care STDS, 29(5), 279–287. doi:10.1089/apc.2014.0346 [PubMed: 25826007]

Durvasula R, & Miller TR (2014). Substance abuse treatment in persons with HIV/AIDS: challenges in managing triple diagnosis. Behav Med, 40(2), 43–52. doi:10.1080/08964289.2013.866540 [PubMed: 24274175]

Eaton EF, Saag MS, & Mugavero M (2014). Engagement in human immunodeficiency virus care: linkage, retention, and antiretroviral therapy adherence. Infect Dis Clin North Am, 28(3), 355–369. doi:10.1016/j.idc.2014.06.004 [PubMed: 25151561]

Evans D, Van Gorder D, Morin SF, Steward WT, Gaffney S, & Charlebois ED (2015). Acceptance of the use of HIV surveillance data for care engagement: national and local community perspectives. J Acquir Immune Defic Syndr, 69 Suppl 1, S31–36. doi:10.1097/QAI.0000000000000573 [PubMed: 25867776]

Holtzman CW, Shea JA, Glanz K, Jacobs LM, Gross R, Hines J, Mounzer K, Samuel R, Metlay J, Yehia BR (2015). Mapping patient-identified barriers and facilitators to retention in HIV care and antiretroviral therapy adherence to Andersen's Behavioral Model. AIDS Care, 27(7), 817–828. doi:10.1080/09540121.2015.1009362 [PubMed: 25671515]

Hruschka DJ, Schwartz D, St. John DC, Picone-Decaro E, Jenkins RA, & Carey JW (2004). Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. Field Methods, 16(3), 307–331. doi:10.1177/1525822X04266540

Kay ES, Batey DS, & Mugavero MJ (2016). The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future. AIDS Res Ther, 13, 35. doi:10.1186/s12981-016-0120-0 [PubMed: 27826353]

Landis JR, & Koch GG (1977). The measurement of observer agreement for categorical data. Biometrics, 33(1), 159–174. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/843571 [PubMed: 843571]

Leech NL, & Onwuegbuzie AJ (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. School Psychology Quarterly, 22(4), 557–584. doi:10.1037/1045-3830.22.4.557

Louisiana Department of Health (2017) Louisiana Department of Health. 2017 STD/HIV Surveillance Report. http://ldh.la.gov/assets/oph/HIVSTD/std/STDAnnualReports/2017_STDHIV_SURVEILLANCE_REPORT.pdf. Accessed August 31, 2021.

Maslow AH (1943). A theory of human motivation [American Psychological Association doi:10.1037/h0054346]. Retrieved

Maulsby C, Enobun B, Batey DS, Jain KM, Access to Care Intervention Team, Riordan M, Werner M, Holtgrave DR (2018). A Mixed-Methods Exploration of the Needs of People Living with HIV (PLWH) Enrolled in Access to Care, a National HIV Linkage, Retention and Re-Engagement in Medical Care Program. AIDS Behav, 22(3), 819–828. doi:10.1007/s10461-017-1809-3 [PubMed: 28550379]

McCree DH, Williams AM, Chesson HW, Beer L, Jeffries WL 4th, Lemons A, Prather C, Sutton MY, McCray E (2019). Changes in Disparities in Estimated HIV Incidence Rates Among Black, Hispanic/Latino, and White Men Who Have Sex With Men (MSM) in the United States, 2010–2015. J Acquir Immune Defic Syndr, 81(1), 57–62. doi:10.1097/QAI.0000000000001977 [PubMed: 30964805]

Mokotoff ED, Green Ruth K, Benbow N, Sweeney P, Nelson Sapiano T, McNaghten AD Data to Care: Lessons Learned From Delivering Technical Assistance to 20 Health Departments. J Acquir Immune Defic Syndr. 2019 Sep 1;82 Suppl 1:S74–S79. doi: 10.1097/QAI.0000000000002022. [PubMed: 31425400]

Mugavero MJ (2016). Elements of the HIV Care Continuum: Improving Engagement and Retention in Care. Top Antivir Med, 24(3), 115–119. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/27841983 [PubMed: 27841983]

Mulatu MS, Carter JW Jr, Flores SA, Benton S, Galindo CA, Johnson WD, Wilkes AL, Mbaka CK, Prather C (2022). Expanding Data to Care Programs to Improve HIV Care Continuum Among Men Who Have Sex With Men and Transgender Persons: Key Processes and Outcomes From Project PrIDE, 2015–2019. Public Health Rep. 2022 Jan 21:333549211058175. doi: 10.1177/00333549211058175.

National HIV/AIDS Strategy for the United States: Updated to 2020. (2015). Retrieved from https://files.hiv.gov/s3fs-public/nhas-update.pdf

Sison N, Yolken A, Poceta J, Mena L, Chan PA, Barnes A, Smith E, Nunn A (2013). Healthcare provider attitudes, practices, and recommendations for enhancing routine HIV testing and linkage to care in the Mississippi Delta region. AIDS Patient Care STDS, 27(9), 511–517. doi:10.1089/apc.2013.0169 [PubMed: 23991689]

Sweeney P, DiNenno EA, Flores SA, Dooley S, Shouse RL, Muckleroy S, & Margolis AD (2019). HIV Data to Care-Using Public Health Data to Improve HIV Care and Prevention. J Acquir Immune Defic Syndr, 82 Suppl 1, S1–S5. doi:10.1097/QAI.0000000000002059 [PubMed: 31425388]

Sweeney P, Hoyte T, Mulatu MS, Bickham J, Brantley AD, Hicks C, McGoy SL, Morrison M, Rhodes A, Yerkes L, Burgess S, Fridge J, Wendell D (2018). Implementing a Data to Care Strategy to Improve Health Outcomes for People With HIV: A Report From the Care and Prevention in the United States Demonstration Project. Public Health Rep, 133(2_suppl), 60S–74S. doi:10.1177/0033354918805987 [PubMed: 30457958]

Taiwo B, Matining RM, Zheng L, Lederman MM, Rinaldo CR, Kim PS, Berzins BI, Kuritzkes DR, Jennings A, Eron JJ Jr., Wilson CC (2013). Associations of T cell activation and inflammatory biomarkers with virological response to darunavir/ritonavir plus raltegravir therapy. J Antimicrob Chemother, 68(8), 1857–1861. doi:10.1093/jac/dkt120 [PubMed: 23599363]

Virginia Department of Health. Virginia HIV Epidemiologic Profile (2016). Virginia Department of Health, Office of Epidemiology. https://www.vdh.virginia.gov/content/uploads/sites/10/2017/02/HIV_Epi_Profile_2016.pdf

Walcott M, Kempf M, Merlin JS, Turan JM (2016) Structural community factors and sub-optimal engagement in HIV care among low-income women in the Deep South of the USA, Culture, Health & Sexuality, 18:6, 682–94, doi: 10.1080/13691058.2015.1110255

**Table 1.**

Participant employment characteristics by jurisdiction (n=20)

| **Current employer type** | **Louisiana** | **Virginia** | **Total** |
|---|---|---|---|
| City or county health department | 0 | 2 | 2 |
| State health department | 9 | 1 | 10 |
| Community-based organization and/or HIV clinic or care provider | 0 | 7 | 7 |
| Other[1] | 1 | 0 | 1 |
| **Length of time working with current employer** [2] | | | |
| 0–2 years | 3 | 3 | 6 |
| 3–5 years | 3 | 3 | 6 |
| 6–10 years | 1 | 4 | 5 |
| 11–20 years | 1 | 0 | 1 |
| 21+ years | 2 | 0 | 2 |
| **Length of time working in HIV care or treatment programs** [3] | | | |
| 0–2 years | 1 | 1 | 2 |
| 3–5 years | 1 | 2 | 3 |
| 6–10 years | 1 | 3 | 4 |
| 11–20 years | 4 | 2 | 6 |
| 21+ years | 3 | 2 | 5 |
| **Length of time participating in D2C efforts in jurisdiction** | | | |
| 0–2 years | 4 | 6 | 10 |
| 3–5 years | 5 | 3 | 8 |
| 6–10 years | 1 | 1 | 2 |

[1] Participant worked in the state DoH, but was not an employee.

[2] Totals reflect months/years with current employer. Can include multiple positions within an agency.

[3] Totals reflect months/years across all agencies or organizations, even if that time is not contiguous.

**Table 2.**

Frequency of reported client barriers to HIV care, by jurisdiction (n=20)

| Barrier | Louisiana | Virginia | Total n (%) |
|---|---|---|---|
| Transportation/limited public transit | 4 | 8 | 12 (60%) |
| Stigma | 5 | 5 | 10 (50%) |
| Substance use | 6 | 4 | 10 (50%) |
| Homelessness/unstable housing | 7 | 3 | 10 (50%) |
| Poverty/low income/low SES | 4 | 5 | 9 (45%) |
| Mental illness | 5 | 2 | 7 (35%) |

**Table 3.**

Illustrative quotes

| Barrier | Quotes regarding the barrier | Quotes regarding approaches to address the barrier |
|---|---|---|
| Transportation | *"Transportation is a big factor. Especially in the rural areas." (LA staff)*<br><br>*"In other parts of the state, transportation becomes the biggest difficulty. A patient who thinks that they're going to have to take a two-and-a-half hour bus ride to get to a doctor's appointment may easily say, "No."" (VA staff)* | *"…[W]e had one agency…they also had transportation funds so they would use Uber or Lyft. So they can go into rural parishes and pick [clients] up and help [them] get back into care…[T]ransportation is a big issue, but you know, our transportation really helped." (LA staff)*<br><br>*"We don't have very good public transportation. We do have bus tokens for people who can get to their appointment…" (VA staff)*<br><br>*"So some of these barriers to care, we address them by looking for means of transportation, working with them to secure bus tokens, asking if there are extended family or friends who can transport them from point A to B on a certain day and time—not necessarily every day, but perhaps we've got this appointment." (LA staff)*<br><br>*"[W]e have gas cards. We do have bus tickets for town here. We do have two drivers that…have vehicles that we can pick up people for their medical appointments…"(VA staff)* |
| Stigma | *"There have been issues with stigma surrounding why they're not in care." (VA staff)*<br><br>*"…[S]tigma plays a big part in people who are not following up with their care." (LA staff)*<br><br>*"For someone who is really having a difficult time with that stigma, denial, self-hatred, self-hurt, self-harm… there's a lot of extra work that has to go into them." (LA staff)*<br><br>*But a lot of people are going through the public health clinic, which is stigmatized. You go in there, you see people you know. You're not comfortable. You wait forever. (LA staff)*<br><br>*"So, it's mainly stigma…A lot of people are not educated on what HIV actually is. So, when a person is diagnosed, they choose not to come because they're afraid of what, if someone that they know sees them in the Health Department, they're going to automatically associate them with being sick or having HIV. And some people are just not comfortable with that being known." (VA staff)* | *"[Because of stigma] …I…have to really talk to that person to explain how important it is to stay in the care…[W]hen people are newly diagnosed, they need time to process stuff…And some people need more time than others…" (LA staff)*<br><br>*"[Dealing with stigma]… [I]t's treat people how you want to be treated type thing…[P]eople don't want you to feel sorry for them…there's an empathy versus sympathy… [T]he other part of that is, I can easily be where [they] are… I could be sitting in that chair that you're sitting in. And it's believable because it's real and it's true what I'm saying…" (LA staff)*<br><br>*People really at some point just need another real person to really care about them and care about their HIV health and not view them in some kind of biased or stigmatized fashion." (LA staff)*<br><br>*"I'd call it the scarlet letter… I'm just one of a great team that shows the care and compassion for their patients…For some patients, we're the only family they have, or the only family that they feel comfortable enough to talk about this illness. So compassion and care is a great thing, you know?" (VA staff)*<br><br>*"…[T]hen I think that it just works, also, as like a support system for these persons because things are so stigmatized. A lot of these individuals, maybe they don't have, some of them, where they can easily talk about living with HIV. So I think it helps just for emotional support. (LA staff)* |
| Substance use | *"Substance abuse is a big factor, huge factor…. Then they become homeless. They don't have a job and it's a cycle of sorts where maybe they stopped and they get clean, they get a job and it's great, but then they relapse for whatever reason." (VA staff)*<br><br>*"[When] a person has…substance abuse issues, it's kind of hard…. to stress going into care…. when I know they need to tackle their substance abuse" (LA staff)* | *"So active drug users. The only thing that I've found that works…is constant connection, communication, no judgement – and it cannot be time-limited…I don't usually take a traditional approach." (VA staff)*<br><br>*"Drug use – that's tricky sometimes. A lot of times we try to get them referred to a drug program to help them understand and get some understanding of their drug use and what they need to do to stay drug free. But getting them to agree to that is always hard." (VA staff)*<br><br>*"We have a substance abuse counselor that's on some sites, so they can pretty much meet with her. If they need further follow-up, if they want to go into rehab, stuff like that, I think we have some funds for that, actually." (VA staff)* |
| Homelessness | *"…[W]hen we see a lot of homeless individuals, they're usually out of care." (LA staff)* | *"Housing is just a big issue. We do have different agencies we work with, we collaborate with to help maybe pay the first month rent…" (VA staff)* |

| Barrier | Quotes regarding the barrier | Quotes regarding approaches to address the barrier |
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| | *"We don't have housing here [in rural area] for patients living with HIV. So, while they're focusing on trying to find suitable housing, they're not really focused on the illness. They're just trying to make sure they have somewhere to lay their head, like, their basic needs are met…So, when they have to choose somewhere to live or coming to my appointment, they're going to choose finding somewhere to live." (VA staff)* | *"We're working with Section 8 housing. I work one-on-one with landlords to ask if we can work with the rent being paid… These are just some of the different creative measures that we're using to help clients to overcome some of the barriers that they face on a daily basis." (LA staff)*<br><br>*"We, personally, at [Organization] have an Emergency Assistance Program, EAP. Pretty much it helps out people who are behind who have a notice, who are about to get evicted or kicked out of their current living situation. And we help them with up to like two months with rent and figure out what we can do with going on, going forward so that doesn't happen again – planning, budgeting and figuring out what can be done next month because it doesn't go on forever, you know." (VA staff)* |
| Poverty | *"[F]rom what I've seen, the population who's most out of care is the ones that's living in poverty. And it's not a commitment to their health that they lack. It's an access to resources. You know, that's kind of precipitating a lot of… [other barriers to care]". (LA staff)*<br><br>*"Just like any Ryan White clinic, you're dealing with underserved persons, so they're at least between 400–200% below the federal poverty guideline. You're dealing with marginalized communities" (VA staff)*<br><br>*"…[T]hose in lower incomes. They're sometimes out of care when compared to higher income populations." (LA staff)*<br><br>*"We would also ask [the client], "What stops you from coming? What stops you from coming to your appointment?" And a lot of them will say, "I just didn't have the extra money to come to the appointment. My money's running short at this point of time of the month."" (VA staff)* | *"…[W]ith case management, you have to always work from the top [of the list of priorities]. If it's an issue with food, they're not going to care about getting in care…[T]hey're not going to care about getting into care if they're living from house to house. So you have to…take care of those needs first, and then you can get them engaged in care…[Y]ou really, really have to learn to take care of their hierarchy of needs first." (LA staff)*<br><br>*"During [our first appointment I ask] about what are the barriers… 'Is food access an issue? Is transportation?…Is housing an issue? Let's get you on these lists.' Mental health, that kind of stuff." (VA staff)*<br><br>*"[W]e've done…social security appointments. They didn't know that they could apply for social security or they could apply for disability…Also…we look at if they're qualified to apply for food stamps, any type of measure that will help them to sustain themselves and to be self-sufficient as much as possible." (LA staff)*<br><br>*"There's money to help toward giving them bus tickets if they get here. There's emergency food cards if the patient needs them. So I'd say this is a good year for Ryan White funding because we can help some of the supportive issues that really steer whether or not they walk in the door." (VA staff)*<br><br>*"The [health and social service] system is complicated. I think that individuals get overwhelmed trying to navigate that system, especially if they're marginalized populations that don't have the resources for transportation, for childcare, for housing, food." (VA staff)*<br><br>*"I think that the [linkage to care coordinators] do an excellent job of helping folks navigate… [T]hey're patient. They're not time-limited. They're compassionate…They also…do a good job of reminding [program administrators] about structural barriers and interpersonal barriers." (LA staff)* |
| Mental illness | *"You're dealing with people that have ongoing, untreated mental illness or struggle to stay in treatment with that – people that are suffering substance abuse, people who don't have access to medical care, and along with marginalized communities, people that don't have trust of the medical community." (VA staff)*<br><br>*"During the day, the city seems all at peace, but there are a lot of pockets of mental illness…folks just, you know, trying to get them to comply with remaining in care is a challenge." (LA staff)* | *"Well, we have a mental health therapist. We have the patient as part of their intake meet with them and do a psychosocial…assessment of needs…Also, we do have support groups here. We have also a psychiatrist… if the patient needs that, we can have that arranged as well." (VA staff)*<br><br>*"We do have mental health clinicians here as well as licensed clinical social workers who can speak with them…" (VA staff)* |