



ILLINOIS HIV INTEGRATED PLANNING COUNCIL NEWSLETTER

Winter 2019

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FROM THE CO-CHAIRS

Hello, everyone.

On behalf of the Illinois Department of Public Health (IDPH) and the Illinois HIV Integrated Planning Council (IHIPC), we hope you enjoy this winter issue of the IHIPC Newsletter.

The IHIPC has had an eventful year! The series of eight community engagement meetings conducted by the HIV care and prevention lead agents in each region were completed in November. The IHIPC Needs Assessment Workgroup developed the needs assessment activity that was a major part of these meetings. The input received from community stakeholders will be compiled and used by the IHIPC and the IDPH HIV Section to update the statewide plan for HIV care and prevention and to develop strategies to meet our Getting to Zero (GTZ) Illinois outcomes – zero new HIV infections and zero people living with HIV not on antiretroviral medication. Thanks to everyone who participated. What a great opportunity to gather input directly from the community to guide our planning efforts!

I would also like to thank Mike Benner for his work as the 2019 IHIPC Community Co-chair; Mike's term ends December 31. Nicole Holmes will begin her term as the new Community Co-chair on January 1.

Submitted by Janet Nuss, HIV Community Planning Administrator, IHIPC Coordinator/Co-chair, IDPH

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CALENDAR OF UPCOMING EVENTS

February 7

National Black HIV/AIDS Awareness Day

March 10

National Women and Girls HIV/AIDS Awareness Day

March 16-18

2-day in-person IHIPC meeting (March 16-17), followed by an in-person IHIPC training day (March 18).

Springfield, IL

Registration information will be made available on the [IHIPC webpage](#) closer to the meeting date.

March 20

National Native HIV/AIDS Awareness Day

HIV SECTION TRAINING UNIT UPDATE

The HIV Training Unit is currently working to revamp their website with new features, including access to training registration links and a training newsletter. Stay tuned to this section for more updates.

If you have any questions about upcoming IDPH-sponsored trainings for funded agencies, please contact Michelle Ferguson at michelle.ferguson@illinois.gov.



SNIPPETS OF INFORMATION

Find all IHIPC documents, meeting schedules, and meeting registration links/recordings at <http://www.dph.illinois.gov/topics-services/diseases-and-conditions/hiv-aids/hpg>.

We have published video tutorials for navigating the IHIPC website and Webex™. View each video at the links below to learn more:

- [IHIPC Website Tutorial](#)
- [Webex™ / Registration Tutorial](#)

2020 STD New Counselor Trainings will be held March 24-27 and September 15-18. Please contact Lesli Choat at lesli.choat@illinois.gov if interested.

Interested in having your HIV planning news shared with the IHIPC membership and community stakeholders? Feel free to send your submissions for the newsletter to marleigh.andrews-conrad@illinois.gov.



IHIPC UPDATE

Thanks to everyone who participated in the October 21-22, 2019 in-person meetings of IHIPC. Our face-to-face meetings are a great opportunity to network and garner input from our community partners that is vital to successful HIV planning. Approximately 75 people, including some who participated remotely via webinar, attended each meeting.

Through everyone's participation in these meetings, the planning group was informed and there was discussion about the below topics. Detailed information about these topics, including presentation slides, can be accessed via the [IHIPC Meeting and Training Resource page](#):

- ❖ Regional Care and Prevention Lead Agent, IHIPC liaison, and the IDPH HIV Section updates
- ❖ Results of the needs assessment activities for at-risk youth/young adults conducted in 2018-19
- ❖ Barriers/Challenges to HIV prevention and care in rural and migrant communities
- ❖ Current/Future efforts to collaborate and align HIV Programs with the *GTZ-Illinois Plan*
- ❖ 2019 Updated State and Regional HIV Care Continua
- ❖ *Illinois' 2019 National HIV/AIDS Indicators Progress Report*
- ❖ Proposed changes to the *2020 HIV Prevention Interventions and Services Guidance*
- ❖ Proposed changes to the IHIPC Bylaws and Procedures
- ❖ Results of 2019 IHIPC New Member Recruitment and Selection Process

On Day One, the meeting concluded with Len Meyer, one of our voting IHIPC members who is also the Downstate Community Engagement Manager for Planned Parenthood of Illinois, providing a training entitled, "Gender Diversity and Why It's Important!" to the group. It was an excellent opportunity to increase our knowledge of appropriate gender terminology and understanding of gender diversity, that hopefully will assist us in being better advocates for people of all gender identities and expression.

On Day Two, the IHIPC voted on and selected six new IHIPC at-large members for 2020. Please join me in welcoming the following new members to our group:

- Tracy Box, Region 1
- Feliece Carabello, Region 7
- Derrius Carter, Region 6
- Tawana Howard, Region 4
- Ricardo Jimenez, Region 8
- Reverend Lamont Lewis, Region 9

James Kawolsky, the IHIPC's newly-appointed voting liaison from the Illinois Department of Human Services Division of Substance Use, Prevention, and Recovery was also introduced. It was also announced that three of our current at-large members, Kimberly Ramirez-Mercado, Christofer Rodriguez, and Larry Mayhew, would also be transitioning to voting members effective January 1, 2020. We welcome you all to our group!

Submitted by Janet Nuss, HIV Community Planning Administrator, IHIPC Coordinator/Co-chair, IDPH



OCTOBER IHIPC MEETING FOLLOW UP: COMPREHENSIVE SEXUAL HEALTH EDUCATION RESOURCES

At the October 21, 2019 IHIPC meeting, the “Results of the 2018-2019 Needs Assessments of Youth and Young Adults” presentation was followed by meaningful discussion on how to best address the following recommendations that resulted from those activities:

- **Advocate for comprehensive sexual health education** taught by trained health educators, for youth in schools and detention centers.
- **Gear sexual health campaigns towards youth and young adults** through simple, ‘real-life’ messaging and creative, engaging marketing. Campaigns should be focused on social media and in physical spaces that youth and young adults frequent.
- **Partner with schools, rehabilitation facilities, mental health facilities, and other youth-based community organizations/ events** to spread education and awareness about sexual health and sexual health services.
- **Partner with health care providers** to message sexual wellness and PrEP to youth and young adults during required physicals/office visits.
- **Work to educate parents about sexual health** and the importance of discussing healthy relationships and sexual practices with youth and young adults in non-judgmental ways.

In addition to the sharing of many great ideas and points of consideration, the following resources were identified during discussion and are available at the following websites:



[“Rights, Respect, Responsibility \(3Rs\)”](#) published by Advocates for Youth: *Rights, Respect, Responsibility is a free, K-12 sexuality education curriculum that is fully meets the [National Sexuality Education Standards](#). The curriculum seeks to address both the functional knowledge related to sexuality and the specific skills necessary to adopt healthy behaviors.*

F.L.A.S.H.

[The FLASH Curriculum](#): *FLASH is a widely used sexual health education curriculum developed by Public Health – Seattle & King County and designed to prevent teen pregnancy, STDs, and sexual violence. FLASH is available for elementary, middle, high school and special education classrooms.*



Let’s Talk Month Resources: *Let’s Talk Month is recognized each October to encourage young people and parents or trusted adults to communicate with each other about sexuality. Organizations like [Planned Parenthood](#) provide Let’s Talk Month resources.*



[Sex Positive Families](#): *Sex Positive Families provides parents and caring adults with the education, resources, and support to raise sexually healthy children using a shame-free, comprehensive, and pleasure-positive approach.*

Other ideas shared during this presentation and discussion can be found in the [October 21 meeting minutes](#).

Submitted by Marleigh Andrews-Conrad, HIV Community Planning Specialist, IDPH



DUAL STIGMA: HIV POSITIVE AND OVER 50

This article was adapted from “Dual Stigma: HIV Positive and Over 50” published by Diverse Elders Coalition on July 20, 2019. To view the full article, click [here](#).

HIV/AIDS used to be considered a disease of the young. In the early 1980s, when doctors first reported cases of HIV, nearly 70% of diagnoses were among people under 40. Fast forward four decades later and more than 50% of Americans with HIV are now over 50. By 2020, that number is expected to reach 65% to 70%. This is largely due to major medical improvements in the effectiveness of anti-retroviral therapy (ART) in suppressing the virus and transforming HIV from an often-fatal disease into a chronic condition, like diabetes or hypertension.

But health care, services, and supports for Americans with HIV/AIDS hasn't adapted its approaches to match this demographic shift. Prevention, testing and care efforts are focused on younger people. Ageism promotes the invisibility of older adults with HIV. On top of that, HIV stigma causes some to keep their status private, rendering this population even more invisible. Ageism is destructive to HIV prevention efforts as well. Risk does not diminish with age, yet doctors are less likely to test older people for the virus, resulting in more late diagnoses and dual diagnoses of HIV/AIDS — a more complicated and challenging condition to manage.

For people with HIV, status is only one part of their overall health. Older people with HIV are, of course, at risk for the common health problems that any older person might face, and research shows that this population is particularly susceptible to conditions we associate with aging like arthritis and cardiovascular disease.

Looking at mental health, older people with HIV/AIDS are frequently depressed, lonely, and isolated. A 2018 study of people with HIV age 50 or older in San Francisco showed 62% of respondents reported experiencing depression. When measuring loneliness with a 10-question survey, 21% respondents scored as “lonely,” and another 22% as “very lonely.”

Advocates and experts say health care must develop a better standard for those who are aging with HIV. Some experts have combined forces to strategize a model of care for those aging with HIV after geriatric medicine. The model would have doctors approach older people with multiple chronic health conditions not by treating every symptom and condition, but by strategizing care that allows the person to have the best functioning possible — and functioning that aligns with their life and health goals. When health systems are more integrated and have better communication and use electronic health records, a patient's multiple doctors and specialists can more easily treat and manage conditions and systems — seeing the person holistically and not siloing the care.

Beyond in-clinic care, older adults in their 50s and 60s with HIV often need services that other older adults get from senior centers, but many don't qualify because services like meals, benefit assistance, recreational activities and more are only offered to people 65 and older. Even if hubs of programs and resources for older adults do expand their offerings to people in their 50s and early 60s, is a 50-something with HIV going to feel comfortable among a place with mostly people in their 80s? It is necessary to acknowledge that HIV services and aging services are quite separated. Those serving people living with HIV should be familiar with aging services so that patients can be connected to appropriately.



POSITIVE LIVED EXPERIENCE

My name is James Charles. I am 48 years old and have been living with HIV and AIDS for over twenty-two years. I was 26 and building a life with my first husband when I received my diagnosis. I had a modest career and we were very comfortable with the life that we had built. I had just taken a risk on a position at work with a substantial pay increase but an equal increase in responsibility.

My first symptoms were typical of average flu but lasted well beyond the typical length of time. I was offered an HIV test after several visits to my doctor but became hospitalized before the results had returned. I was started on AZT (Azidothymidine – an antiviral HIV medicine) while in the hospital and eventually went home. I attempted to continue working because the only health insurance I had was through my job. My friends at work made allowances for me since both the disease and the treatment made me very sick, but eventually I could not continue. The staff at the SIU clinic and the SIU Care Connect program helped me with what they could, however, the medical bills from my initial hospitalization crushed me financially. When I asked what my prognosis was, I was told that average life expectancy at the time was five years.

I struggled with depression and medication side effects, and I went off treatment twice because of both. I have had three major illnesses related to complications from HIV and AIDS from which I wasn't expected to recover. I am now on much better medications which I take in only one pill (that fact never stops amazing me, by the way). I am virally suppressed, and my CD4 count has finally increased to above 500.

My first husband and I separated after nine years; we had grown apart but parted as friends. My second husband and I have been together for 16 years (17 in February). He is HIV negative and his name is Chris; I love him very much. I volunteer with SIU Central Illinois Care Connect and the IHIPC, both of which have allowed me the opportunity to give a little back in exchange for all that I have been given over the years. I was able to return to school and finish my associate's degree, and I have learned how to bake and enjoy the therapy of making bread by hand. I try to focus on living in the moment more than anything else.

Living with HIV is very different today from when I was diagnosed. I am hopeful for the future now and grateful that we have a future for that matter. I want to give thanks to those long-term survivors that went ahead of me. Many have been lost, but some are still here and still fighting hard to make a future for everyone living with HIV. They are my heroes.



Submitted by James Charles, IHIPC Member, Epidemiology/ Needs Assessment Committee Co-Chair

The Positive Lived Experience Feature in the IHIPC newsletter is a space for people living with HIV to share about their experience with HIV. If you are a person living with HIV and would like to submit a Positive Lived Experience article, please contact marleigh.andrews-conrad@illinois.gov for more information.



FDA APPROVES DESCOVY FOR PrEP

This article contains excerpts from “FDA approves Descovy (F/TAF) for PrEP” published by San Francisco AIDS Foundation on October 11, 2019. To view the full article, click [here](#).

Seven years after Truvada (F/TDF) was approved for HIV prevention as PrEP, we now have another PrEP medication option. On October 3, 2019, the U.S. Food and Drug Administration (FDA) approved the medication Descovy (F/TAF) as PrEP for people who are HIV-negative and at-risk for sexually acquired HIV through anal sex.

The phase 3 DISCOVER study provided evidence of F/TAF’s HIV prevention efficacy. Statistically, it demonstrated that F/TAF (Descovy) was “non-inferior” to F/TDF (Truvada) in terms of HIV prevention, with researchers indicating the study wasn’t large enough to statistically determine that F/TAF works better than F/TDF.

How is Descovy (F/TAF) different than Truvada (F/TDF)?:

- **A smaller pill:** Descovy is a smaller pill than Truvada. This may not be important to some people, but if pill size is an issue, it is important to have this option for PrEP.
- **Renal/bone health and safety:** Descovy (F/TAF) contains TAF, a prodrug of tenofovir that concentrates at higher intracellular levels (where most experts believe the drug is needed and has the bulk of its effect) with lower drug levels present in the bloodstream. This likely contributes to Descovy’s marginally improved safety profile in terms of kidney and bone health.
 - Although these improved outcomes may be marginal, Descovy may offer a PrEP alternative for people who have compromised kidney function or who otherwise may be worried about side effects. For people whose age is associated with an increased risk of pre-existing kidney or bone health issues, Descovy for PrEP may be meaningfully safer.
 - While any patient may wish to elect Descovy for PrEP because of its marginal safety improvements, there is significant experience administering Truvada for PrEP in young, healthy individuals with negligible risk of irreversible renal and bone side effects.
- **Weight gain:** There is some evidence that F/TAF causes progressive weight gain in people taking it for PrEP or in combination with other drugs for HIV treatment.
- **Changes in LDL cholesterol:** People taking F/TAF as HIV treatment have been shown to experience greater increases in LDL cholesterol compared to those taking F/TDF. High levels of LDL (the “bad” cholesterol) can promote plaque buildup in arteries, which can lead to coronary artery disease, stroke, and other health problems. While the magnitude of these changes is not alarming, overall these relatively small changes in LDL among those taking F/TAF need to be evaluated for possible clinical significance in the context of an individual’s age, lifestyle issues, and other cardiac risk factors.
- **Descovy for those who may be exposed to HIV by vaginal exposure:** There are no clinical data to support the use of F/TAF for PrEP in cisgender women, transmasculine individuals, and other individuals who have receptive vaginal sex as these populations were not included in the DISCOVER study. Thus, the FDA committee voted down a recommendation of F/TAF for cisgender women and the FDA approval excluded people who may be exposed to HIV vaginally.



As we make strides toward a future where there are a variety of PrEP options available—and people are free to choose the medication and delivery method that works best in their lives—we must remain committed to equity in terms of access and affordability. Emphasizing patient education and patient-centered choice in selection of suitable and comfortable PrEP options is an important start.



NCS D FORMALLY ENDORSES U=U

This article contains excerpts from “Supporting U=U and Sexual Health: A Statement by National Coalitions of STD Directors Formally Endorsing U=U ” published by the National Coalition of STD Directors on September 5, 2019 . To view the full article, click [here](#).



Science has proven that a person with sustained, undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners (undetectable = untransmittable or U=U). The National Coalition of STD Directors (NCS D) celebrates this fact and we stand committed to raise awareness of U=U.

It is on us, the public health community, to empower people to make choices that promote sexual health across a lifetime. To do so, STD prevention and U=U must go hand in hand within a broader sexual health framework, one that emphasizes sex-positive approaches to informed decision making. This will require a paradigm shift in how we operate in the STD and HIV fields. We must think outside of our silos and embrace allies in primary care, mental and behavioral health, women’s health, reproductive health, LGBTQ health, and beyond.

To meet the full promise of U=U, the intertwined HIV and STD epidemics must be addressed. STDs are one of the underlying causes of new HIV infections. Research shows that 10 percent of new HIV infections are caused by gonorrhea and chlamydia alone and it is estimated that the risk of transmission from syphilis is even greater. Progress has been made in reducing new HIV infections due to sustained advocacy and investment, and groundbreaking advancements such as Treatment as Prevention (TasP). Unfortunately, these advancements have not been mirrored in the STD field, and cases have ballooned to all-time highs for several years in a row.

The same forces that drive HIV also drive other STDs, fueled by health disparities and stigma. U=U provides an unprecedented opportunity to fight stigma and to engage and sustain people in HIV and STD care. This engagement must include continued promotion of condoms as a proven STD prevention tool, but also the frank acknowledgment that condoms are not for everyone. We must also recognize that biomedical advancements such as PrEP and TasP will remain inaccessible to some due to structural and financial barriers and personal choices. The full suite of prevention strategies—including condom use, promotion of risk reduction and safer sex practices, STD testing and treatment, comprehensive sex education, and access to biomedical prevention tools—remain essential in the fight against both STDs and HIV.

The public health infrastructure that supports U=U must also rise to the STD challenge. NCS D calls on the community, the administration, and public health leaders at the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and other Department of Health and Human Services offices and agencies, to take urgent action. This action should include advancing programs, awareness campaigns, and science around STD tracking, diagnostics, and therapy. We also implore Congress to support funding for the Ending the HIV Epidemic initiative, STD prevention at CDC, and STD research at NIH.

We cannot be shortsighted. The HIV epidemic taught us that we must be proactive and prepare for what new sexually transmitted infection may be around the corner. Embracing U=U, HIV prevention, and STD prevention as interdependent and fundamental parts of broader sexual health will provide the best opportunity to realize the goal of an HIV-free world.



CHAMPAIGN-URBANA SUPPORTS THE GETTING TO ZERO PLAN

This article contains excerpts from “C-U Mayors Endorse ‘Getting to Zero’ Plan to Eliminate HIV in Illinois”, published by Illinois Public Media on September 24, 2019. To view the letter, click [here](#).

City officials from both Champaign and Urbana have signed onto a plan to eliminate HIV in the region, as part of a statewide initiative in Illinois called “Getting to Zero.”

The initiative led by the AIDS Foundation of Chicago aims to reduce the number of new HIV cases in Illinois to less than 100 by the year 2030.

The program focuses on increasing access to a preventive medication known as Pre-Exposure Prophylaxis, or PrEP, and ensuring those who already have HIV get access to antiretroviral treatment to help prevent its spread.

Champaign-Urbana Public Health District (C-UPHD) Administrator Julie Pryde said the District has been working on fighting the AIDS epidemic since the ‘80s.



From left to right: Urbana Mayor Diane Marlin, Julie Pryde, and Champaign Mayor Deborah Frank Feinen

Pryde said with the support of both Champaign Mayor Deb Feinen and Urbana Mayor Diane Marlin, public health workers will be able to step up efforts to address barriers to HIV treatment “to make sure that everybody has access to the medications, everybody has access to the information.”

The number of new HIV cases in Illinois dropped 28% from 2006 to 2015, according to a fact sheet compiled by the AIDS Foundation of Chicago. Additionally, mother-to-child transmission has been nearly eliminated in the state.

However, HIV continues to disproportionately affect black and Latino communities. Among those seeing an increase in HIV cases are black gay men and Latinos of all genders. More than three-quarters of the women living with HIV are black.

Pryde said there’s a lot of work to do to address racial disparities in HIV treatment. “We’re going to be working on eliminating stigma, dismantling racism, prioritizing trauma prevention and trauma-informed care,” she said. “We have to make sure that young people of color, and especially people who are in lower socioeconomic situations, are aware of this and are accessing these services.”

Pryde said she hopes people will reach out to the C-UPHD to get connected to resources in the community that can help anyone in need of treatment get it, regardless of ability to pay.



RECOGNIZING RETIRING MEMBER STEVEN ST. JULIAN...

After 26 years of tireless advocacy for people living with HIV

Steven St. Julian returned home to Southern Illinois (from San Francisco) in the summer of 1992 to die. Soon after, he found a home of friends and a mission at Jackson County Health Department (JCHD). Steven began volunteering at JCHD in 1993, with the Regional Implementation Group for Region 5. Soon he was involved in the statewide advisory groups, in which he has served for 23 years. In the year 2000, Steven was hired and named HIV Care Project Director for Region 5. Steven served in this role for five years. In 2005, Steven returned to his true love of community prevention education. Steven's passion, educational outreach skills, and commitment to reducing the transmission of HIV is evident. Steven's interaction with clients, being a role model, and teaching/preaching treatment adherence has been so valuable for hundreds of clients over the years. Who better to provide prevention education and treatment adherence than Steven, a person who has fought the fight for over three decades?



Steven is known statewide for his efforts in HIV prevention and care programming. Steven has also received numerous statewide awards including *the 2007 Mary Dickson Illinois HIV/AIDS Advocacy Award* and the *2010 Arlene Valentine Sustained HIV/AIDS Leadership Award*. He has helped put JCHD on the map as a leader in HIV programming in the southern part of Illinois. There is always positive feedback about Steven's presentations, energy, enthusiasm, and commitment to the fight against HIV/AIDS.

Steven has kept extremely current on his knowledge of HIV treatment and has always looked for new ways to integrate HIV education in various venues whenever possible. Many times, he serves as staff educator, keeping the rest of his division current on new findings and treatments. Most recently, Steven has helped establish rapid Hepatitis C testing. This service is provided to those most at-risk during an HIV testing session. This new initiative is assisting many people in finding out their Hepatitis C status and referring them into care. Steven also has initiated outreach services via various social media sites, offering testing and risk reduction education service referrals through online sites. And now-- due to great medical advances, at the end of his career, Steven gets to refer people to the most current advancement in years, a once-a-day pill to prevent HIV - PrEP! He's very grateful he has lived to see this monumental prevention strategy and has been able to be a part of it!

Bottom line, whatever it takes, Steven is committed to reaching various targets and assisting them in living a healthier life!

Steven continues to share his enthusiasm and compassion with all that encounter him. We are so grateful to have had Steven as part of our team. Steven is looking forward to spending time with his long-time partner Bruce, exercising, traveling, and constantly mowing his 7 acres of beautiful Southern Illinois hillsides! Congratulations on a well-deserved retirement!

Submitted by Paula Clark, Director of HIV Services, Jackson County Health Department

