HIV & SMI: Fostering a Cooperative Approach to Addressing Unmet Needs
Needs Assessment Committee of the NY HIV Health & Human Services Planning Council
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1. Stigma

- Stigma affects every aspect of care for PWH, especially among populations whose quality of care and experience with stigma is impacted by intersecting identities and inequities
- In accordance with NYS's ETE blueprint, surveys were conducted by healthcare organizations providing HIV services in NY to measure levels of HIV-related and key population-related stigma among staff.[1] Findings from 12 participating sites show:
    - Out of six key populations, staff reported highest enacted stigma toward people living with a mental health diagnosis (PLMHD), 2-3 times that of trans individuals.
    - Almost 1 in 5 staff reported lack of comfort working with PLMHD (18%)
    - 36% of staff had not received training on stigma related to HIV or key populations and 17% were not aware of facility policies against discrimination
- Stigma-reduction strategies must address intersectionality[2] and be included in all levels of programming[3]
    - Need to improve visibility of mental health among providers and PWH to counteract misinformation and contradict negative attitudes and beliefs
    - Bolster contact and peer support networks for PWH to facilitate improved access to behavioral health services
    - PLMHD prefer approaches that address institutional and structural discrimination over public education
    - Addressing structural stigma, especially through legal and policy interventions to protect stigmatized groups, promotes physical and mental wellbeing

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[1] Ahmed, C. et al. Measuring and Addressing Stigma in Healthcare Settings: Key Findings from Staff Survey Results and Steps Taken
[2] Recommend Lisa Bowleg's May 21, 2020 webinar on intersectionality https://www.hivcenternyc.org/hiv-center-rounds
[3] For further reading on approaches to reducing stigma https://www.ncbi.nlm.nih.gov/books/NBK384914/

Relevant Discussion

- *Providing access to appropriate and comprehensive care reduces stigma*

2. Data

Coordinate data toward the development of a care continuum cascade for PWH with SMI to identify gaps in service and to target resources. The Council seeks collaboration to:

- Designate PWH with SMI as a priority population for inclusion on the NYS public facing data dashboard[4] in order to track the following measures:
    - Rates of HIV testing among people with SMI in OMH operated and/or licensed facilities
    - A HIV care continuum among PWH with SMI on rates of engagement in care, retention in care & viral suppression
- Identify where people with SMI are accessing HIV care to strengthen linkage, coordination and additional support
- Develop and track reportable HIV indicators for Health Homes
- Assess and build up the capacity of care centers, including psychiatric hospitals, for people with SMI in order to administer, support & measure:
    - HIV testing
    - HIV treatment access
    - PrEP/PEP access & support
- Implement systems-wide utilization of SHIN-NY, RHIOs and/or PSYCKES data to identify, engage and support clients lost to care
- Assess cost and client benefit for developing a state and city-wide integrated electronic medical record system to facilitate the coordination of care among people with HIV who receive funded services.
- Conduct recurring Medicaid matches utilizing the available Medicaid warehouse in the DOHMH Bureau of Mental Health to:
    - Identify clients who have indicative behavioral health encounters against the HIV registry to identify PWH with SMI and to coordinate care
- Conduct recurring matches of HARP recipients and applicants to both the NYC and NYS HIV Registry in order to identify clients that would benefit from:
    - Supportive navigation
    - ART access
    - Housing support

Relevant Discussion

- *What is the housing status for people with HIV and SMI? Broken down by borough?*
- *For hospital based diagnoses of HIV among people with SMI, did the HIC diagnosis occur during a client's first crisis or after multiple crises? Were clients younger or older upon initial HIV diagnosis? Psychotic breaks among people with schizophrenia frequently occur around ages 20-25. People with SMI are more likely to be diagnosed for HIV once they are in the medical system*
- *Is the HIV registry matched with Medicaid to better understand service utilization?*

[4] https://etedashboardny.org

- *Medicaid data is not in the registry*
- *Data sharing agreements with state for specific projects do exist, but none focusing on SMI*

- *People with SMI tend to migrate out of OMH system in order to get their HIV care – in very early days of HIV epidemic – many people left OMH system and were able to receive funded HIV hospice and end of life care.*

3. Testing/Prevention

Data from a small match conducted between the NYC HIV Registry with two Bureau of Mental Health datasets SPOA (Single Point of Access) and AOT (Assisted Outpatient Treatment) illustrate the need to diagnose HIV earlier, as later stages of HIV disease progression are associated with poorer health outcomes.

- Expand the implementation of an HIV status neutral approach to prevention and treatment as part of a larger intervention to address stigma around SMI
  - PrEP and PEP protocols, including education, training and navigation should be built out at all OMH licensed/operated inpatient and outpatient mental health sites and programs, to ensure access to timely referrals[5]
- Build strategic partnerships to enhance capacity and establish routine HIV testing at sites where people with SMI regularly access care[6]
- Implement CDC guidance for HIV testing in OMH inpatient units & clinic settings
- Adapt the STIRR model[7] to routinize opt-out HIV testing, during annual medical assessments for all clients that access outpatient mental health programs
- Build capacity of mental health providers and institutions, including in-patient sites, to support HIV medication access and adherence among clients
  - Improve capacity among Behavioral Health providers to conduct referrals to HIV prevention and care services.
  - Facilitate seamless coordination of care between behavioral and physical health.

Relevant Discussion

4. Engagement & Navigation

Clients with serious disorders and/or psychosis are more vulnerable to becoming lost to care or experiencing gaps in treatment. Coordinating and integrating care can support better health outcomes.

[5] https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(20)30273-3/fulltext
[6] https://www.sciencedirect.com/science/article/abs/pii/S0033318217302189
[7] https://pubmed.ncbi.nlm.nih.gov/20810586/

- Fund support for increased communication and collaboration between HIV and Behavioral Health funders and programs in NYC to maximize EHE/ETE efforts
- Expand availability of low threshold services to facilitate client readiness for treatment: walk-in, late & weekend hours, etc.
    - Strengthen linkages & availability of readily available psychiatric care
    - Simplify referrals for inpatient and outpatient psychiatric services
    - Address barriers to engagement in HARP & HCBS programs for PWH with SMI
- Expand access to Modified Directly Observed Therapy (MDOT) for HIV, HCV, and psychiatric medications
- Improve capacity of CBOs (Community Based Organizations) to identify and manage people with HIV who may have SMI:
    - Develop best practices to inform agency specific crisis action plans
    - Streamline & accelerate access to additional support services, i.e., HARP, AOT, inpatient stays and other appropriate interventions, support and referrals
    - Build effective referral pathways, guidance and capacity to ensure people with HIV and SMI can access needed care from the full range of OMH operated and/or funded programs
    - Reduce staff turnover to strengthen client trust and engagement

Relevant Discussion

- People with SMI have a right to housing – but are unaware. Have met homeless people with SMI who have no idea they can qualify for housing- this info should be more accessible, as should points of service/access to social workers.
- NYNY1 provides housing for people with SMI. My experience with clients with SMI who are not on meds, and may be unstable – often become lost to care. May do well on ART but won't take psych meds.
- Clients are afraid of disclosing to case managers that they have had a substance use relapse – afraid they will lose their housing.
- Technology deserts and limited income – people do not have the technology to access some of the services that have come online, particularly since the pandemic began.
- Need to review rules and penalties imposed around housing considering the exacerbation of substance use during the pandemic
- Housing unit staff are not trained in harm reduction – not necessarily prepared to meet clients where they are, particularly if the client is actively using substances. When providers are not based in a harm reduction approach, clients may feel they will be penalized for disclosing their substance use.

5. Care/Service Integration

Research shows that integrated mental health care can increase HIV treatment access and improve overall health outcomes.

- Implement programs that improve viral load suppression for PWH with SMI and can be expanded with proof of concept.[8] Examples include:

[8] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3857330/

    - Psychiatrists that train medical providers on how to prescribe psychotropic medicine, currently used to help alleviate cost and create access in rural areas.
    - Establishment of a NYC and NYS ombudsman for serious mental illness, who can facilitate and address clients' crisis issues immediately
    - Focus on resources for psycho-social rehab and assistance to navigate interpersonal relationships - how to live your best life with serious mental illness
- Fund increased access to psychiatrists who are linguistically competent and have culturally humility
- Incentivize the inclusion of community health workers, ideally peers with lived experience
    - Coordinate and incentivize a dual/triple peer certification program: HIV, Behavioral Health, and substance use
    - Promote pathways to full time positions for peer community health workers
    - Create of a tax or payment structure for peer community health workers that ensures maintenance of benefits, financial stability and appropriate remuneration
- Coordinate and integrate physical and mental health treatment plans and ensure access by all providers, including support services
    - Pilot development of internal care coordination dashboards that highlight clients' care status through medication prescriptions, ART access/adherence, and viral load measures
- Further integrate and coordinate care for behavioral health, substance use and HIV care through the development of single site access for all services

Relevant Discussion

- Peers who are high level can act as a safety net in programming.
- Hard for people with SMI to engage through the current technological means
- Peers have been seen to provide the most effective impact
- Really necessary to have all of these entities here to ensure coordinated care for people with SMI
- OMH licenses facilities, especially ambulatory ones – providers have had to maintain in person capacity because we know that clients may not have the capacity to receive services over telehealth. OMH wants to know when that isn't happening – providers should make deliberate and deliberative assessment of who needs to be seen in person. Especially for folks who need services like injectables, or labs drawn – and OMH needs to hear when providers are not maintaining that capacity.

6. Intervention

Clients in need of psychiatric hospital stays rarely receive support for HIV care or ART access/adherence.

- Capacity building and funding to support maintenance/re-introduction of ART during psychiatric inpatient care and throughout systems of emergency care.
    - Primary care HIV providers should receive communication from psychiatric hospitals when clients are admitted
    - Continuity of HIV care should be part of EVERY discharge plan

- Prioritize and improve supportive housing access for PWH with SMI[9]
    - Streamline access to supportive housing for PWH with SMI with a client centered process

Relevant Discussion

- In 2016, won a terrific victory toward ending the HIV epidemic – every person who is income eligible (and eligible for public services) has a right to housing – nothing comparable in mental health – often leaves people trapped in the shelter system. A dual diagnosis can get someone housed through HASA, but people with mental health conditions are left in desperate straights.
- ACT teams showed up 12 hours after the incident – everyone says that another entity is responsible for stabilizing this person who lives in a congregate facility with me.
- People cannot travel with all of their medication
- When thinking about someone in a psych facility – they cannot reach people on the outside.

7. Re-engagement

- Designate people with HIV and SMI with unsuppressed viral loads as a priority population for outreach services that re-connect clients to care based on missed/high viral loads and missed prescription refills.
- Coordinate existing BH programs throughout NYS and NYC, i.e., NYC HRA, Comprehensive Psychiatric Emergency Programs (CPEP), Day Treatment, ACT Teams (many institutions conduct ACT teams - funded by DOHMH and OMH to facilitate client support)

Relevant Discussion

- People frequently use libraries to stay connected because they do not have minutes
- Prior to COVID, people with SMI would attend our support groups – but this isn't a way to connect people to care during the pandemic. Secured smart phones for clients – showed them how to use the phones – but frequently, clients lose their phones. Had to find innovative ways to keep clients safe and still deliver services

8. Follow Up

The Forum helped to identify areas where work is already underway to better support the needs of PWH with SMI as well as areas that have great potential for transformation. Follow up needs to be conducted on:

- Joseph Kerwin:
    - Further information about licensure and integration. Clarity around the barriers to this process can help refine and galvanize points of support.
    - Identifying streamlines mechanisms to develop a full picture of key metrics for PWH with SMI and facilitating recurring matches to ensure appropriate support for people in this population.

[9] https://link.springer.com/article/10.1007%2Fs10461-020-02810-8

- Flavio Casoy:
    - Support for a targeted roll out of HIV testing, medication access and prevention support in OMH programs in relation to capacity.
    - More information on the performance opportunity program with Medicaid Managed Care – including HIV SNPs – how has the critical time intervention been adapted?
    - More information about how HARPS have impacted PWH with SMI? Who has and who can have access to PSYCKES?
    - More info on PSYCKES QI program
- Mark Manseau:
    - Explanation of integration of HIV into OASYS programs and proposal for how an integrated office would move forward.
- Jackie Treanor:
    - Further information about peer certification and best practices identified. Ensuring that developments are applied retroactively to facilitate work expansion among current peers. Question of how to support peer work and financial stability with benefits with state support.
- Joseph Kerwin:
    - More information about barriers to licensure integration – including challenges for smaller providers
    - Assistance with facilitating backdoor Medicaid matches to ensure that people are receiving both mental health and HIV care, as needed
    - Better understanding of merger process and which agency will take the lead on different issues
- Charles Gonzalez:
    - Development of peer certification focused on people with SMI
- Joanne Morne:
    - Facilitating support for social determinants of health
- The Council:
    - Advocate for a full list of ART medications to be included in Medicaid FFS.
    - Advocate for PSYCKES checks to be a standard of care in all ERs and psych facilities to ensure ART medication access.

9. Planning Next Steps

To move these findings forward, we need the assistance and support of all of the stakeholders in the room today. The NYS Office of Mental Health, Office of Addiction Support, AIDS Institute and Department of Health are critical partners to the development of strategies that will appropriately identify and support PWH with SMI.

What follows are notes from the discussion:

- How do we change the way we respond to individuals who need assistance when in crisis?
    - Models where mental health intervention instead of a public safety intervention

- Need more resources around housing, but do have resources in other areas
- Trauma informed care - this philosophy should saturate our services – helps individuals feel safe and supported
- Persistent mental health challenges without adequate support for lacking social determinants of health
- Engage and employ peers to facilitate programs – high functioning peers can act as a safety net.
- Preparing agencies and programs to deliver services/navigate/manage people with SMI
- Accessible site maps for navigating clients to SMI care
- Criminalization of mental health is a substantial issue
- COVID – multiplied needs and challenges around access- How do we increase access? Can we streamline access and transform how we help people move through crisis?
- Looking at models – expansion of trauma informed care grounded in trauma informed supervision.
- Include and enhance presence of persons with lived experience
- Peer certification advocacy for people with HIV, STI care and for PrEP – have not yet developed programs to try to train peers with SMI. In thinking of transformation of policing – this is an employment opportunity and way to develop societal holistic care. Peers have been shown to be highly effective – have not used that lived expertise for people with SMI -
- How do you engage people with SMI with high system utilization and challenges engaging in ambulatory care? For past 2 years – performance opportunity program with Medicaid Managed Care – including HIV SNPs. With persons who have been flagged – implementing a critical time intervention, care managers can intensively engage with individuals to access whatever services they need – can we provide some HIV navigation around this? Prevention/treatment? Hopeful we will see some of these high utilizers get connected to ambulatory care… (CAN WE GET MORE INFO)
- For PEP/PrEP Carve in of the pharmacy program into Medicaid FFS – should look through proposed formulary to ensure all ARVs are included in preferred drug program – to ensure physicians can avoid a complicated pre-authorization process
- Community based non- state operated, non-hospital clinic system the PSYCKES bureau is launching a continuous quality improvement program – specific focus on social determinants…PSYCKES must play a critical role in a preventive and supportive system. Voluntary clinic participation.
- Started many people on ARVs when they were admitted into psych service. Integrating the system – could only find that clients were on ART by checking the PSYCKES system – the DOHMH should make it the standard of care that anyone entering an ER who is on Medicaid has their PSYCKE profile pulled – we encourage this among our partners to ensure ART is continued
- Must look at Medicaid warehouse data – how often are HIV diagnosis included in claims – of those folks – are these being captured in BH settings? That's an easy question to answer with looking at the data -when are people on or off ARTs
- Critical information on clients must be accessible across systems

- How often are MH settings including an HIV diagnosis in their settings – do we know?
- Need to take a deeper dive to understand the full picture.
- Housing is primary to ensure adherence and stability for clients. Housing must be a priority – safety first then address conditions – from personal experience, know that housing first facilitates all other stability needed to live your best life
- None of the critical medical information is connected across facilities – people with SMI are often transient – need more coordination to access supportive care and not get lost
- Medicaid is undergoing changes that are in line with the forum. Office of Health Insurance Programs (OHIP) have done a few webinars
    - Current waiver pending with the federal govt – next waiver priorities are value based payment and social determinants of health. Waiting on current budget to see integrated licensure and recognition of having more programs go forward in an integrated fashion. Integration of OMH and OASYS – merits of having programs go forward in an integrated fashion
- Grant funded peer certification – HIV, HCV and Harm Reduction tracks - tried to model OASYS. barriers: everything proposed to the feds has to have a budget neutrality component.
- In Medicaid – advised to work with DSRIP (which ended last year, state re-applying, previously declined by Trump admin). Previously, peers did a lot of navigation. – NY Presbyterian had peers in the ER. Had a lot of demo experience – at end OHIP wanted to know what best practices can be made permanent – see a lot of possibility – re-engage concept of peer delivery – either through best practices in last DSRIP, or now that more integrated avenues are taking place- could we have essential peer certification coded into the agencies – existing structure is not interdisciplinary but initial steps are being taken to move in that direction..
- Licensure – seen challenges with integration on the article 28 side, and the loading in of low threshold primary care services – challenge Dept is wrestling with- trying to make such licensure more accessible for smaller providers – attempt to lower threshold of requirements is still challenging for the smaller providers, especially when looking at article 32s.
- Peers are instrumental – creating a new track 4 mental health – and opening up tracks for peer certification. Some trainings that are required across different peer services – trying to figure out how to certify peers across multiple fronts – ie take cultural core for SERPA, for peer certification – can streamline this to facilitate certification. Having preliminary convos on how to help peers get certified in multiple areas, like agencies and hospitals. If you have to take a core course for multiple certifications – idea is to take the course and allow it to count against multiple certificates.
- Multiple entities would need to be part of a data matching program to get a better picture of how PWH with SMI are faring – will follow up with Joseph Kerwin – include surveillance and state access to the Medicaid data warehouse. Bring some more people to the table - including people at AI. [Key to include Tri-County area}
- Unknown if systematic testing for HIV is happening in OMH licensed and operated programs

- Many types of OMH programs – no standard HIV policy that cuts across all programs – clinic program, expectation that on admission, a thorough health assessment will be conducted – within that we provide different guidance. Every program has a different standard of care. In clinic programs, there is an expectation that there will be a comprehensive standard of care.
    - Are people in OMH operated and licensed facilities being tested for HIV/is access to HIV meds facilitated?
    - Where can we insert an HIV protocol into OMH services?
    - Still see significant gaps
    - Dr. Manseau was instrumental in facilitating the survey
    - Directors of state licensed OMH program understand a portion of their clientele do have HIV or may need PrEP –
    - In OASYS - can apply to OMH over time. OASYS require testing for HIV and HCV – can be incorporated into OMH – should be flagged for inclusion -as we plan for the merger – creates some complications around CONSENT. Many people are being treated involuntarily – question ability to have capacity to give consent. Both systems have limited treatment capacity – OASYS is working on that – includes resource limitations and workforce issues – even if a program cannot directly treat - Linkage or referral could be included in guidance from a state agency
- Many people are being treated involuntarily – question of capacity to give consent – but these can be managed with guidance. Linking to treatment is the tricky part – both systems have limited treatment capacity. OASAS is working on this. Resource limitations and workforce issues – but can provide linkages
- There was an HIV policy in OMH, required HIV assessment/testing but a lack of capacity to implement. HIV assessment should be done in outpatient programs – but law did not apply to outpatient only inpatient programs
- People with SMI – have no more or less capacity to consent to medical treatment than anyone else – shocking how little capacity average people have – very low threshold to consent to something that is not invasive.
- In different regs for different programs – generally more vague than realized – given guidance and recommendations and OMH is happy to engage in a convo about how to enhance capacity of system to address HIV and co-occurring disorders i.e. substance use – can set guidance and standards of care – testing and point of access is important – but there are barriers - many clinics lack clinicians on a full time basis, many don't have nurses – necessary to think about these things.
- Given that people with SMI die 15-25 years earlier than gen pop the lack of integrating medical care into the treatment for people with SMI is a call to action. Death is an important issue in HIV and SMI. Lack of adequate medical care contributes to the premature death rate.

10. Acronyms (in alphabetical order)

2016 FINAL RULE 42 CFR 438 *Service Authorization and Appeals. More info here*

ACT Teams: *Assertive Community Treatment. More here and here*

AI: *New York State AIDS Institute*
AOT: *Assisted Outpatient Treatment. More here and here*
CBOs: *Community Based Organizations*
DOH: *New York State Department of Health*
EHE: *Ending the HIV Epidemic – federal initiative. More info here*
EMA: *Eligible Metropolitan Area – refers to Ryan White funding jurisdictions*
HARP*: Health and Recovery Plans. More here*
HCBS: *Home and Community Based Services. More info here*
HCV: *Hepatitis C Virus*
HCW: *Health Care Worker, can be, but is not necessarily, a peer worker*
HIV Care Continuum*: A visual method for illustrating key metrics related to care. More here*
HIV Status Neutral Approach: *People at risk of HIV exposure taking daily PrEP and people with HIV with sustained viral load suppression do not acquire or transmit HIV. More information here*
Intersectionality: *Describes the way people's social identities can overlap. More info here and here*
mDOT: *Modified Directly Observed Therapy. More here*
NYS Blueprint to End the Epidemic: *Often referred to as* ***ETE.*** *More info here*
NYS Public facing ETE Dashboard: *Tracks metrics related to the NYS HIV epidemic. Found here.*
OASAS: *New York State Office of Addiction Services and Supports*
OMH: *New York State Office of Mental Health*
Peer Certification: *NYS currently operates three non-overlapping peer certification programs through OMH, OASAS and the AI.*
PEP & PrEP: *Using HIV drugs to prevent HIV transmission. More here*
PHS's Enhanced Data to Care Concept Paper *found here*
PLMHD*: People living with a Mental Health Diagnosis*
Psycho-social rehab: *helps people develop the social, emotional and intellectual skills they need in order to live happily with the smallest amount of professional assistance they can manage. More here*
PSYCKES (*Psychiatric Services and Clinical Knowledge Enhancement System): Developed by the New York State Office of Mental Health (OMH), PSYCKES uses administrative data from the NYS Medicaid claims database to generate quality indicators and summarize treatment histories. More info here*
PWH: *People with HIV*
RHIO: *Regional Health Information Organization. More info here*
RWPA*: Ryan White Part A (Other parts are B, C, E and F) More info here*
SHIN-NY: *Statewide Health Information Network for New York. More info here*

SMI: *Serious Mental Illness*

SPOA: *Single Point of Access to help providers connect people with serious mental illness to mental health services that can accommodate them. More here*

STIRR Model: *Screen, Test, Immunize, Reduce risk, and Refer. More info here and here*

TG/NC: *Transgender/Non-Conforming (**NB**: Non-Binary)*