ACEs, social determinants of health + concurrent comorbidities in people who inject drugs living with HIV/HCV

Brit Culp, ADC-T, CPP | Chemical Health Counselor + Addiction Medicine Consult | Hennepin Healthcare – Positive Care Clinic | Brit.culp@hcmed.org

About me:

- I’ve been a chemical health counselor for close to 6 years between this clinic and other harm reduction based settings; I’ve worked in various capacities with marginalized populations through a harm reduction lens for over 10 years. I’ve been working at HHS with the Positive Care and Addiction Medicine teams for just over 4 years.
- I’ve been working in the social services field as a whole since 2004 with a variety of populations and marginalized communities. When I first started working in mental health specific settings in 2012, this is when I was also introduced to Harm Reduction and how we can apply it in our work; this is also when I was first introduced to Trauma Informed Care models as well, in the principle of “first do no further harm.”
- I’m NOT a licensed mental health professional, FYI. I do meet MN’s legal definition of “mental health practitioner” based on my cumulative hours/years of experience and trainings. The overwhelming majority of individuals I’ve worked with live with co-occurring disorders.

Comorbidities in People Living With HIV/HCV we’ll discuss:

- Acquired Brain Injuries
  - Both traumatic (via some external force) and non-traumatic (e.g. disease process, stroke, loss of pulse, anoxia, hypoxia, etc).
- Substance Use Disorder(s)
- Serious/Severe and Persistent Mental Illness(es).
- Other Traumatizing Life Experiences
  - There’s higher vulnerability and risks around incarceration and homelessness ¤ acquisition and/or exacerbation of any of these conditions, where we should be looking at ACEs as a SDOH.

What are ACEs?

- ACEs stands for “Adverse Childhood Experiences” (0-17 y/o) and describe potentially traumatic events such as experiencing violence/abuse/neglect, witnessing violence, a family member attempting or completing suicide; also included are aspects of the child’s environment like growing up in a household with others who are experiencing substance use problems, mental health problems, parental instability/separation/absenteeism, and incarcerated household members.
- ACEs have been directly linked to chronic health problems, developing a mental illness, and/or developing a substance use disorder in adolescence and adulthood; all of which have a negative impact on education, job opportunities, socioeconomic status.
- Children in marginalized communities and/or who are female are at greater risk for higher ACEs scores.

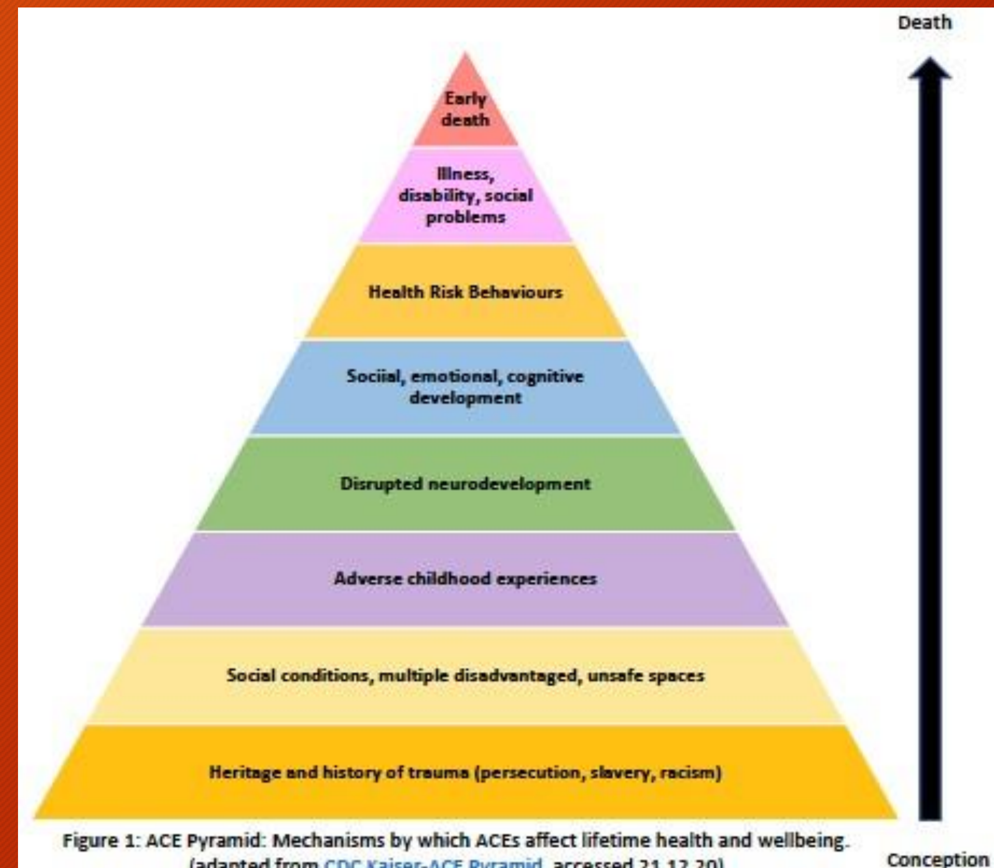


Figure 1: ACE Pyramid: Mechanisms by which ACEs affect lifetime health and wellbeing.
(adapted from CDC Kaiser-ACE Pyramid, accessed 21.12.20)

“As the ACE study has shown, child abuse and neglect is the single most preventable cause of mental illness, the single most common cause of drug and alcohol abuse, and a significant contributor to leading causes of death such as diabetes, heart disease, cancer, stroke, and suicide.”

Bessel van der Kolk – The Body Keeps the Score

What are SDOH?

- SDOH – Social Determinants of Health; conditions in environments where people are born/raised/live/work/commune/play/etc that impact a wide range of health, functioning, and quality-of-life outcomes/risks. SDOH can be grouped into five domaines:
  - Economic stability
  - Education access and quality
  - Healthcare access and quality
  - Neighborhood and built environment
  - Social and community context.
- When we measure a population's SDOH, we can see how they contribute to wide health disparities and inequities, which of course raises the risk of health conditions (cardiovascular illnesses, diabetes, obesity, cancers, etc).

“I wish I could separate trauma from politics, but as long as we continue to live in denial and treat only trauma while ignoring its origins, we are bound to fail. In today’s world your ZIP code, even more than your genetic code, determines whether you will lead a safe and healthy life. People’s income, family structure, housing, employment, and educational opportunities affect not only their risk of developing traumatic stress but also their access to effective help to address it. Poverty, unemployment, inferior schools, social isolation, widespread availability of guns, and substandard housing all are breeding grounds for trauma. Trauma breeds further trauma; hurt people hurt other people.”

Bessel van der Kolk – The Body Keeps the Score

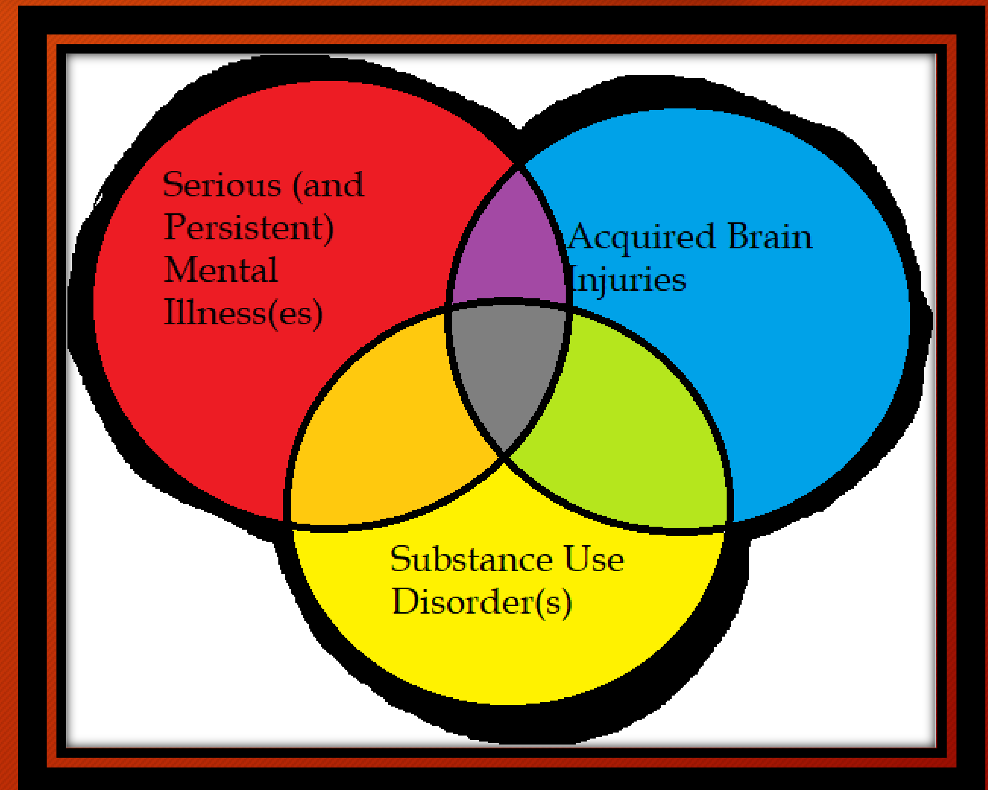
Higher ACEs and poorer SDOH are indicative of one another

And considering the intersectionality of ACEs and SDOH, it's worth looking at ACEs as SDOH. Ex: lower ACEs scores correlate with better SDOH just like higher ACEs scores correlate with poorer SDOH.

We also see that people who have a higher ACEs score and are experiencing poorer SDOH also experience the most barriers in accessing and staying engaged in care – a lot of which is driven by stigma.

Higher ACEs are also linked to higher vulnerabilities in brain injuries, mental illness, and substance use issues.

- Higher ACEs scores are directly linked to higher vulnerabilities and instances of Serious (possibly persistent) Mental Illness (SMI/SPMI), Acquired Brain Injuries (both Traumatic and non-Traumatic), and Substance Use Disorders (SUD).
- These comorbidities are increasingly common in the populations we serve, which adds to already existing barriers to care.

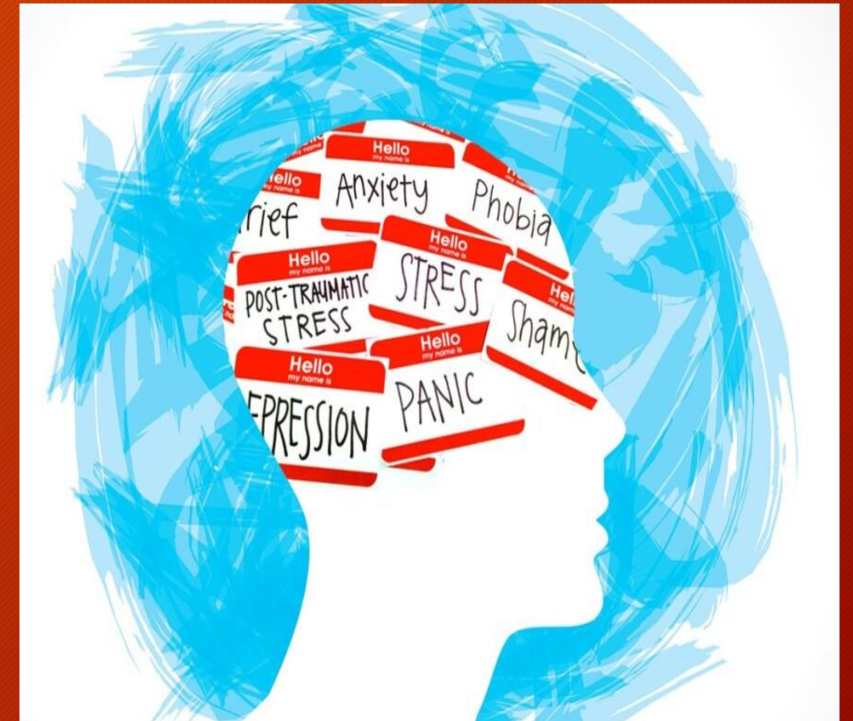


ACEs, SDOH and Acquired Brain Injuries

- Prolonged exposure to toxic stressors as well as an upbringing where any form(s) of abuse were experienced led to significantly greater odds in reporting an acquired brain injury than in those with zero ACEs *(Guinn et al 2020)*.
- The issues with higher impulsivity noted in individuals with brain injuries *(Goldman et al 2022)* can also be reflected in coping mechanisms that are unhealthy (e.g. earlier onset of substance use issues) and higher risk (ex: in sexual encounters, how a substance is used, etc)
  - This of course increases the vulnerabilities and risk factors for infectious diseases, lack of access in prevention, and inconsistencies in receiving care.
- The lack of control over various emotions and lessened distress tolerance in brain injuries can last a significant amount of time. This has a significant impact on one's self-esteem, depression, anxiety – and can also be linked to Post Traumatic Stress Disorder *(Goldman et al 2022)*.

ACEs, SDOH and Serious (and at times persistent) Mental Illness(es)

- Per the American Psychological Association, multiple studies have shown that around 1/3 of all mental disorders internationally are attributable to exposures to adverse childhood experiences.
- Cumulative childhood trauma exposures is more likely to lead to psychiatric illness in adulthood, as well as poorer social functioning.
- Symptoms in certain disorders are higher risk sexual encounters as well as higher risk forms of substance use (e.g. more likely to inject drugs).



ACEs, SDOH and Substance Use Disorder(s)

- “My gateway drug was trauma.” – Louise Beale Vincent (Urban Survivors Union) plenary at White Earth Harm Reduction Summit 2018
- Looking at SUD through the biopsychosocial framework, there’s continuously clear links of higher ACE scores and/or poorer SDOH and the increased vulnerabilities around negative impacts on mental health and risks around developing a SUD (or in absence of a diagnosable disorder, higher risk substance use).
    - Included in “higher risk substance use” is of course injection drug use. There can also be the intersection of some aspect of sex trade/encounters (voluntary, coerced, survival-based, forced) with the higher risk substance use.
- PWUD are at higher risks for morbidity/mortality from overdose, HCV/HIV, soft tissue infections, and other drug related infectious diseases such as endocarditis (Muncan et al, 2020).
    - Many of these complications are associated with acquired brain injuries.

Co-infections and comorbidities

Adding in the intersection of HCV and HIV

All of these impacted populations with any number of these disabling conditions are also over-represented amongst the populations with HCV, HIV, and other drug related infectious diseases.

- How they intersect creates added challenges around engagement and retention in care, including treatment adherence.
- All of these impacted populations are also over-represented in settings that add to the difficulties in care engagement/continuity such as incarceration and being unhoused/unsheltered.
- Each of the identities of having: substance use disorder, brain injury, mental illness, being unhoused, history of justice involvement, living with HCV/HIV/infectious disease(s) are each on their own a stigmatized and marginalized identity – and in every intersection of these identities, the individual becomes more marginalized and stigmatized.

S(P)MI, SUD, TBI/nTBI over-representation in HCV and HIV infections

- People with serious/severe and persistent mental illness haven't been seen as high of a risk for HCV infection as they should be – despite having heightened viral presence; further, they're largely underserved by the more traditional outpatient models of care, as physical health screenings and maintenance can easily be deprioritized when the individual is dealing with acute mental health and social issues (Braude et al, 2022).
- Populations over-represented in homelessness and/or incarceration are also higher risk populations for infection(s) like HCV/HIV
- *"The people disproportionately affected by hepatitis are often those who are marginalized by societies and underserved by health systems…without equitable access to appropriate prevention, testing and treatment programs, hepatitis is allowed to devastate those communities."* – Cary James, World Hepatitis Alliance CEO, 2021.

S(P)MI, SUD, TBI/nTBI over-representation in HCV and HIV infections

- In the United States, approximately 21% of HIV or HCV cases include both co-infections (NIH 2021).
  - If we look only at PWID, this percentage of coinfected individuals jumps to anywhere between 62-80%.
- Higher rates of co-infection are associated with individuals living with serious mental illness and/or substance use disorders (Lippincott et al, 2009).
- Both HIV and HCV can also cause neuropsychological + neurocognitive impairments related to their disease progressions (Lippincott et al, 2009).

“I have met countless patients who told me that they ‘are’ bipolar or borderline or that they ‘have’ PTSD, as if they had been sentenced to remain in an underground dungeon for the rest of their lives… None of these diagnoses take into account the unusual talents that many of our patients develop or the creative energies they have mustered to survive.”

Bessel van der Kolk – The Body Keeps the Score

Further compounding these in how accessible/inaccessible care is, is stigma

Accessibility of course includes ability to afford care/get health insurance, as well as ability to physically get to a medical and/or behavioral services provider.

Accessibility also means how accessible the care feels to people. Marginalized identities such as people with serious mental illnesses, BIPOC folks and/or immigrants, lacking stable housing, LGBTQIA2S+ community members, people with certain diagnoses such as HIV/HCV, people who use drugs, people with justice involvement, people with cognitive concerns such as brain injuries, etc – have all experienced health encounters they've felt were harmful with how they were treated due to the stigma of the provider/stigma rooted attitudes of the healthcare setting.

The Seven Types of Stigma

TYPE 1	TYPE 2	TYPE 3	TYPE 4	TYPE 5	TYPE 6	TYPE 7
Public Stigma This happens when the public endorses negative stereotypes and prejudices, resulting in discrimination against people with mental health conditions.	**Self Stigma** Self-stigma happens when a person with mental illness or substance-use disorder internalizes public stigma.	**Perceived Stigma** Perceived stigma is the belief that others have negative beliefs about people with mental illness.	**Label Avoidance** This is when a person chooses not to seek mental health treatment to avoid being assigned a stigmatizing label. Label avoidance is one of the most harmful forms of stigma.	**Stigma by Association** Stigma by association occurs when the effects of stigma are extended to someone linked to a person with mental health difficulties. This type of stigma is also known as "courtesy stigma" and "associative stigma."	**Structural Stigma** Institutional policies or other societal structures that result in decreased opportunities for people with mental illness are considered structural stigma.	**Health Practitioner Stigma** This takes place any time a health professional allows stereotypes and prejudices about mental illness to negatively affect a patient's care.

PUBLIC STIGMA

This happens when the public endorses negative stereotypes and prejudices, resulting in discrimination against people with mental health conditions.

SELF-STIGMA

Self-stigma happens when a person with mental illness or substance use disorder internalizes public stigma.

PERCEIVED STIGMA

Perceived stigma is the belief that others have negative cognitions about people with mental illness.

LABEL AVOIDANCE

A person chooses not to seek mental health treatment to avoid being assigned a stigmatizing label. Label avoidance is one of the most harmful forms of stigma.

STIGMA BY ASSOCIATION

Stigma by association occurs when the effects of stigma are extended to someone linked to a person with mental health difficulties. This type of stigma is also known as courtesy stigma and associative stigma.

STRUCTURAL STIGMA

Institutional policies or other societal structures that result in decreased opportunities for people with mental illness are structural stigma.

HEALTH PRACTITIONER STIGMA

This takes place any time a health professional allows stereotypes and prejudices about mental illness to negatively affect a patient's care.

Source: Overcoming Stigma | NAMI: National Alliance on Mental Illness www.nami.org › Blogs › NAMI-Blog › October-2018

Impacts of stigma(s) on accessibility to engage in and remain in care

- Medical providers have just as easily as anyone else been influenced by the same societal stigma with PWUD, as learning more in-depth on substance use, addiction, and harm reduction isn’t generally a part of the medical training, per Dr. Sarah Wakeman, Medical Director for SUD at Mass General Brigham in Boston: “I think there sometimes is cognitive dissonance for health care providers in that they’ve been taught that drug use is bad… there’s this notion that drug use is harmful to your health, so if someone is engaging in that behavior, they must not value their health.”

Impacts of stigma(s) on accessibility to engage in and remain in care

- The initial concept of stigma places people outside of what is considered the societal “norms” which creates a sense of alienation and others view said person as less desirable, and there’s an invisible but noted marker of having a “spoiled identity.”
- When the stigma around a “spoiled identity” becomes internalized, this is associated with poorer health outcomes/healthcare system engagement; further the enacted stigmas produce a reactive avoidance of seeking care (related to anticipated + internalized stigmas) and can contribute to rising morbidity/mortality in one’s comorbidities. The denial of dignity in vulnerable populations predisposes them to increased stress and risky behaviors, increasing odds of poorer health outcomes (Muncan et al, 2020).

Impacts of stigma(s) on accessibility to engage in and remain in care

"They look at us like junkies, but you know what? This junkie right here bleeds the way you bleed, have feelings the way you have feelings, love the way you love, hate the hate you hate, hold grudges the way you hold grudges. I walk the same way you walk. What's the difference between your love and my love? … They're so judgmental that they would literally come out and speak about you behind your back."

"After waiting two months, and then I just did a walk-in and when I met the doctor, everything was fine. As soon as I took off my coat for her to see, that was it. She went from being super nice, to okay, maybe you should go to the emergency room… the whole entire face changed, the smile, the whole mood (because she could see track marks)."

"It's different out there… I don't know how to explain it. The whole aura, the way that people look at us addicts as different. You get treated bad. I've never been to a hospital out here for an overdose. In the hospital… I refuse to go… You definitely going to get treated differently like if you're a drug user."

"People disrespected me, dehumanized me, mocked me, and put me into a deeper hold of my drug use… The community needs to understand how much of a part they play. Instead of putting people down, give them some kind of resource. That goes a long way. This person is a human being. People act like drug users come from another world, like aliens, outcasts… people where something went wrong."

Engaging people in care

… and also retaining them in care and services

Integrated models

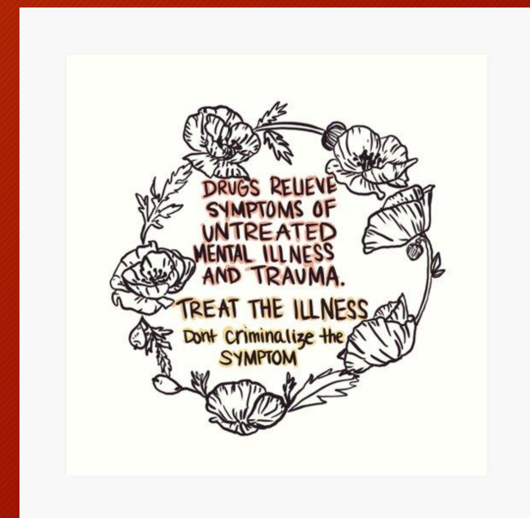
- Psychiatrist and Addiction Medicine provider, Dr. Mark Willenbring, MD, has long suggested integrated healthcare models are highly important in the various treatments for these populations – including integration of social services.
  - Many patients with any combination of these comorbidities struggle with housing security, food security, justice involvement complications, income barriers – all barriers to treatment and management of care.
- Fragmenting where patients get their care and treatment often means breakdown in communication between providers, patients getting lost to care, patients dropping out of care and overall poorer outcomes.

Partnering with community based services and harm reduction programs

- PWUD/PWID see syringe service + harm reduction programs as central to their daily lives, especially where there's a "drop-in" model that includes access to hygiene, laundry, meals, computers, etc. Many also develop social networks here, received sterile equipment + education around safer use, had some level of engagement in medical care (including testing for STIs and other infectious diseases they're vulnerable to), on-site PrEP or treatments for HCV, and mental/chemical health counseling if they desired (Muncan et al 2020).
- These programs and the harm reduction modality as a whole is a strategy against stigma (Sekaran 2022) and these programs work to foster senses of self-worth with their participants, and they see the workers there as non-judgmental, understanding, and accommodating, making them feel more comfortable in accessing and continuing their care (Muncan et al 2020).

Affirming the dignity, intelligence, and agency of our patients

- Harm reduction gives people the space and freedom to manage and participate in their own health without judgment.
- Engage around patients' experiences around trauma, social barriers, substance use, mental health, etc with a sense of curiosity – how are they currently managing, what help do they want, and what resources are we able to share with them?
- In all stigmatized and marginalized identities, we need to draw attention to the human cost of stigma – lives cut short, opportunities missed – and challenge dehumanizing language (addict, junkie, clean/dirty, crazy, idiotic, retarded, etc) and be accountable to lead by example in person first language that isn't pejorative (Sekaran 2022).



Questions? Feedback?

- How have you integrated care for patients living with multiple comorbidities and barriers?
- Are you in any sort of partnership with any of your local harm reduction organizations/syringe service programs?
- If you were to ask your patients about how comfortable they are in clinic, if they've felt judged, or what could be more welcoming, what do you think they'd say?

Fin

Works cited:

- Bonn, M. (2021, July 28). *World Hepatitis Day 2021 platforms a crisis that "Can't wait"*. Filter. Retrieved April 4, 2023, from https://filtermag.org/world-hepatitis-day-2021-covid/
- Braude, M., Phan, T., Con, D., Woolley, I., Sundram, S., Clarke, D., Dev, A., & Sievert, W. (2022). Hepatitis C virus in people with serious mental illness: An analysis of the care cascade at a tertiary health service with a pilot 'identify and treat' strategy. *Internal Medicine Journal*. https://doi.org/10.1111/imj.15604
- *Centers for Disease Control and Prevention*. CDC. (n.d.). Retrieved March 28, 2023, from https://www.cdc.gov/traumaticbraininjury/pdf/prisoner_tbi_prof-a.pdf
- Guinn, A. S., Ports, K. A., Ford, D. C., Breiding, M., & Merrick, M. T. (2018). Associations between adverse childhood experiences and acquired brain injury, including traumatic brain injuries, among adults: 2014 BRFSS North Carolina. *Injury Prevention*, *25*(6), 514–520. https://doi.org/10.1136/injuryprev-2018-042927
- Kidman, R., & Kohler, H.-P. (2019). Adverse childhood experiences, sexual debut and HIV testing among adolescents in a low-income high HIV-prevalence context. *AIDS*, *33*(14), 2245–2250.
- Muncan, B., Walters, S. M., Ezell, J., & Ompad, D. C. (2020). "they look at us like junkies": Influences of drug use stigma on the healthcare engagement of people who inject drugs in New York City. *Harm Reduction Journal*, *17*(1). https://doi.org/10.1186/s12954-020-00399-8
- Philip, T. J., Crosby, K. M., Frank-Pearce, S. G., Wendelboe, A. M., Solberg, M., Weakly, J., & Williams, M. B. (2022). Factors impacting medication adherence in a birth cohort at higher risk for Hepatitis C infection. *Medicine*, *101*(50).
- Sekaran, S. (2022, September 12). *Stigmatizing drug use is killing us, but why is it so hard to stop?* Filter. Retrieved April 4, 2023, from https://filtermag.org/drug-use-stigma/