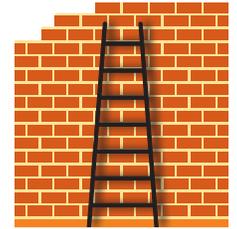


# Structural and Social Determinants of Health (SSDHs)



## What are structural and social determinants of health?

### Basic definitions (and why SSDHs matter)

From the Centers of Disease Control and Prevention (CDC): “The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities. These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors. Social determinants of health are shaped by the distribution of money, power, and resources throughout local communities, nations, and the world.” (<https://www.cdc.gov/nchhstp/socialdeterminants/definitions.html>)

From the World Health Organization: “Many factors combine together to affect the health of individuals and communities. Whether people are healthy or not, is determined by their circumstances and environment. To a large extent, factors such as where we live, the state of our environment, genetics, our income and education level, and our relationships with friends and family all have considerable impacts on health...The context of people’s lives determine their health, and so blaming individuals for having poor health or crediting them for good health is inappropriate. Individuals are unlikely to be able to directly control

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many of the determinants of health.” (<http://www.who.int/hia/evidence/doh/en/>)

Where most US public health interventions focus on individual knowledge and behaviors, SSDHs look at the broader context.

### An example: getting to the gym more

#### Our intervention options under an individual/behavioral focus:

- ▶ Do nothing
- ▶ Positive messaging (Michelle Obama’s Let’s Move Campaign)
- ▶ Negative messaging (scare someone about diseases, shame their current body shape)
- ▶ Increasing knowledge (information on accessing the gym, how to exercise, the effects on health)
- ▶ Offer benefits/incentives (free training services, financial incentives via insurance, discounts/rebates)
- ▶ Create consequences (insurance penalties)

#### What if there are structural barriers?

- ▶ The gym is very far and there’s no public transit
- ▶ The gym is really expensive
- ▶ The gym equipment is old and dangerous
- ▶ Signs/services are all in a language someone doesn’t know
- ▶ Gym hours are too early/late

#### What if there are social barriers?

- ▶ The gym staff is really bitter and mean

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- ▶ People make fun of someone or insult them
- ▶ Someone doesn't feel like they fit in with other people at the gym

#### What if there are other personal barriers?

- ▶ Joint pain and no insurance/doctor to help
- ▶ Need assistance with mental health issues (depression, anxiety disorder, history of trauma)
- ▶ Need help addressing alcohol or drug use
- ▶ Too busy trying to meet basic needs (housing, food, safety)

**Conclusion:** No matter how empowered or knowledgeable someone is, no matter how much they may want to change their behavior, they won't be able to get to the gym unless we address these other issues. The same goes for HIV prevention. We do a disservice to our communities by only focusing on behavioral change and education and ignoring structural, social, and other personal barriers.

*HIV prevention interventions must be about more than education and behavior change!* We will not end the epidemic with new social media campaigns and behavioral counseling alone; we must address local, state, and national policies.

**HIV prevention interventions must be about more than education and behavior change!**

## Nine common structural and social barriers (and areas for policy advocacy)

To maximize HIV prevention efforts in the United States, there are a number of key policies and laws that we would need to change. Here are some priority areas, in no particular order, that are of immediate importance for HIV prevention policy advocates.

### 1. Criminalization of HIV

**The problem.** The majority of U.S. states have some form of HIV-specific law that criminalizes HIV transmission or the possibility of HIV transmission. Many of these laws do not take into account new advancements in HIV prevention such as treatment as prevention (TasP) and pre-exposure prophylaxis (PrEP) and criminalize behaviors that cannot transmit

HIV, such as biting and spitting. In many other states, other laws, such as assault or attempted murder, have been used to prosecute people living with HIV. Many times these laws are applied in cases where transmission wasn't even possible. Criminal disclosure laws place an undue burden on people living with HIV in communities and situations where it is dangerous to talk about one's HIV status.

The modernization or possible repeal of such laws is a priority for prevention advocates. There is no proof that such laws stop any forward HIV transmission, but many experts believe that such laws could have a significant chilling effect on testing efforts. More research needs to be done, but at least one study out of Canada found that 17% of a high-risk cohort of men who have sex with men (MSM) said that criminalization laws affected their willingness to get tested for HIV.<sup>1</sup>

#### Examples of policies to target:

- ▶ State laws criminalizing HIV transmission in some way—here is a compilation of criminal laws by state provided by the Center for HIV Law and Policy (through May 2015): <http://hivlawandpolicy.org/sites/www.hivlawandpolicy.org/files/HIV%20Crim%20Manual%20%28updated%205.4.15%29.pdf>
- ▶ The CDC also has a complete list: <https://www.cdc.gov/hiv/policies/law/states/index.html>

#### National organizations to connect with:

Fortunately, there are a number of amazing criminalization activists working on these laws at the state and national levels:

- ▶ The SeroProject listserv ([seroproject@googlegroups.com](mailto:seroproject@googlegroups.com)) is a great way to keep up on ongoing discussions.
- ▶ The Center for HIV Law and Policy ([www.hivlawandpolicy.org](http://www.hivlawandpolicy.org)) is another great organization leading the fight on these issues.

### 2. Criminalization of marginalized populations

**The problem.** The United States locks up around 2% of its adult population; around one in nine American men and one in 56 American women is likely to spend time in prison in their lifetimes. One in three Black men and one in six Latino men are likely to spend time in prison in their lifetimes, as compared to one in 17 white men. This racial disparity also exists for women—while one in 111 white women will spend time in prison, for Latina women this likelihood is increased

to one in 45 and for Black women one in 18. LGBTQ populations are also disproportionately impacted by mass incarceration, particularly for transgender populations. Laws that lead to the criminalization of LGBTQ people (e.g., the recent wave of transgender bathroom bills), sex workers, undocumented populations, and drug use—and unusually harsh enforcement of these laws in marginalized communities—leads to an enormous burden of mass incarceration. In 2010, the rate of diagnosed HIV infection among inmates in state and federal prisons was more than five times greater than the rate among people who were not incarcerated, yet according to the CDC, HIV testing and prevention options are often limited or hard to access due to HIV-related stigma within jails and prisons.

#### Examples of policies to target:

- ▶ State and federal laws criminalizing drug possession, sex work, LGBTQ rights, undocumented communities
- ▶ State and federal policies on HIV testing and prevention in jails, prisons, immigrant detention centers

#### National organizations to connect with:

Several organizations are doing amazing work addressing criminalization of marginalized communities. A few organizations to look up:

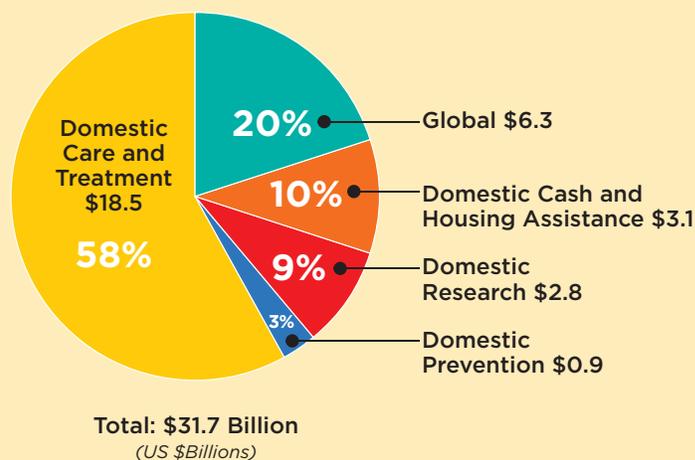
- ▶ Black Lives Matter
- ▶ United We Dream
- ▶ Lambda Legal
- ▶ The Sex Workers Project
- ▶ American Civil Liberties Union

More advocacy is desperately needed to address HIV prevention in prisons. Lambda Legal and the ACLU Prison Project may be resources for this and The Center for Prisoner Health and Human Rights may have more information.

### 3. Funding

**The problem.** Prevention has been very poorly funded in comparison to other areas of HIV for many years. In FY 2014, U.S. federal funding to combat HIV totaled \$29.5 billion. Of this, 55% was for care, 10% for cash and housing assistance, 9% for research, **3% for prevention (mostly U.S. Centers for Disease Control and Prevention activities)**, and 22% for the global epidemic.<sup>2</sup> On the state level, funding may be mismanaged or misallocated. In Georgia, the state

### U.S. Federal Funding for HIV/AIDS, by Category, FY 2016 Request



Note: Categories may include funding across multiple agencies/programs; global category includes international HIV research at NIH.

Source: Kaiser Family Foundation, U.S. Federal Funding for HIV/AIDS: The President's FY 2016 Budget Request; February 2015

department of health failed to spend \$8 million in 2014 and it was returned to the federal government. Budgets can also be very urban-focused, even though several Southern states continue to have a large portion of their epidemics in more rural areas and smaller cities.

#### Examples of policies to target:

- ▶ Annual budgetary processes (typically starts in January with the President's proposed budget and ends with Congress passing a budget by April and the President signing it soon after). It is important for advocates to pay attention to how much money is being proposed for HIV prevention, and how much of that is going toward abstinence-only education (which is not supported by available scientific evidence).
- ▶ CDC HIV prevention funding proposals—typically issued through their Department of HIV/AIDS Prevention (DHAP)
- ▶ State and local HIV prevention budgets

**It is important for advocates to pay attention to how much money is being proposed for HIV prevention, and how much of that is going toward abstinence-only education.**

**National organizations to connect with:**

► Budgetary processes are complex and often very hard to follow, however, they are an important area for prevention advocates. Getting involved with the Federal AIDS Policy Partnership (FAPP) and joining their listserv can be a great way to connect with national HIV budget advocacy. AIDS United is another national organization with headquarters in Washington, D.C. that keeps an eye on funding for HIV. Finding ways to monitor state and local prevention dollars is also essential to make sure that enough money is being invested in the right places—large AIDS service organizations or LGBTQ advocacy organizations may be involved in such efforts in your state.

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**4. Education**

**The problem.** According to the CDC, many youth are not receiving the education they need in schools around sexual health. Although we don't have good data on the availability of comprehensive sexual education, it is almost certain that most LGBTQ individuals are not receiving enough information on sexual health and HIV-related risks. Given that education policies are primarily state and local matters, there is tremendous need for advocacy for comprehensive HIV and sexual health education in schools all across America.

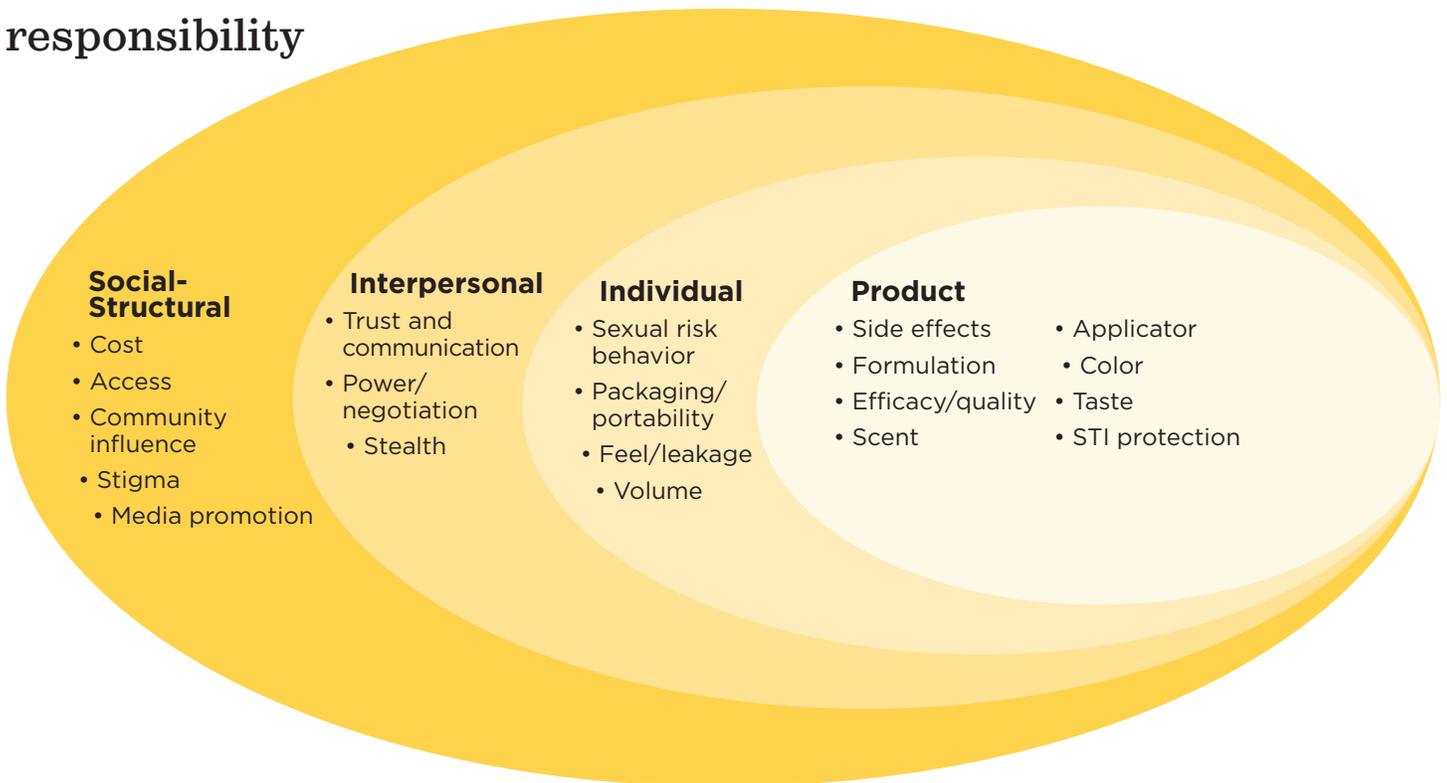
**Examples of policies to target:**

► State, local, and school board policies on evidence-based sexual education for youth, including LGBTQ-inclusive curricula

**National organizations to connect with:**

► Sexuality Information and Education Council of the United States (SIECUS) is a national organization that is working to improve sexual education for youth. GLSEN works more broadly on LGBTQ safety in schools and may be an ally in this work.

**More than individual responsibility**



Source: Newman PA, Rongprakhon S, Tepjan S. A social ecology of rectal microbicide acceptability among young men who have sex with men and transgender women in Thailand. *J Int AIDS Soc.* 2013 Aug 1;16:18476. Figure 1, A social ecological model of rectal microbicide acceptability among gay/bisexual men and transgender women in Chiang Mai and Pattaya, Thailand.

## 5. Healthcare access

**The problem.** Healthcare coverage is a basic requirement for comprehensive prevention services—it is extremely challenging to gain access to PrEP and other biomedical technologies without public or private insurance. Under the Affordable Care Act (ACA) the situation improved dramatically for millions of Americans, particularly thanks to the expansion of Medicaid program for poorer citizens.

It is extremely important that Medicaid be expanded in all states to help several highly vulnerable communities access prevention services that require access to healthcare. Unfortunately, politicians in power in the United States in 2017 tend to support repealing the ACA and slashing Medicaid spending by turning it into a sort of “block grant” that restricts the level of funding provided to each state by the federal government—thus leading to extreme rationing of services for our poorest and most marginalized citizens. This would likely be devastating for HIV prevention efforts in some of the populations who need biomedical interventions the most.

Even once an individual has healthcare coverage, insurers can make it unnecessarily difficult to get necessary prevention services covered. Insurers may try and deter members from accessing those benefits, especially with pharmaceutical options that are extremely expensive, such as PrEP. Requiring extra paperwork for prior authorization, inadequately covering prevention and testing services, or requiring that clients use mail order pharmacies for PrEP can all keep vulnerable individuals from quickly accessing the services they need.

### Examples of policies to target:

- ▶ State and federal plans for Medicaid expansion, strong ACA replacement
- ▶ Insurance policies that restrict or hinder access to testing and prevention services (such as prior authorization requirements, mandatory mail ordering, specialty tiers for PrEP/post-exposure prophylaxis (PEP) medications)

**It is extremely important that Medicaid be expanded in all states to help several highly vulnerable communities access prevention services that require access to healthcare.**

### National organizations to connect with:

- ▶ The Kaiser Family Foundation ([www.kff.org](http://www.kff.org)) has great resources regarding Medicaid and other payer programs important to HIV prevention and care. Knowing how these programs work, how they are funded, and the populations and services they cover is very important for federal, state, and local advocacy efforts.

## 6. Housing

**The problem.** Studies show strong correlations between improved housing status and reduced HIV risk, improved access to medical care, and better health outcomes. Homelessness or unstable housing is directly related to increased HIV risk among vulnerable persons. Furthermore, homelessness is a barrier to starting care, staying in care, and accessing antiretroviral therapy (ART), which has been shown to reduce viral load and reduce the risk of transmitting the virus.

Data gathered by the CDC from 8,075 persons with HIV show that, compared to stably housed persons with HIV and controlling for other factors, persons with HIV who lack stable housing are: 2.9 times more likely to engage in sex work; 2 times more likely to have unprotected sex with an unknown status partner; 2.3 times more likely to use drugs; and 2.75 times more likely to inject drugs.<sup>3</sup> Having stable housing—renting or owning a home—has been shown to increase the odds that a participant would achieve protective levels of PrEP in their system during one study by more than double.<sup>4</sup>

### Examples of policies to target:

- ▶ Federal funding for housing initiatives
- ▶ State and local funding for housing, policies to prevent and sustain housing, increased availability of shelters.

### National organizations to connect with:

- ▶ Housing Works is a New York-based organization that works nationally and internationally on housing advocacy, particularly for communities impacted by HIV. The Ali Forney center is also involved in anti-homelessness efforts for LGBTQ youth.

## 7. HIV Prevention-related stigma

**The problem.** Several focus groups and implementation projects looking into PrEP knowledge, access, and uptake within different key populations have shown that, just like with HIV treatment, stigma poses a major barrier for individuals trying to access biomedical prevention. Some of this may be related to actual stigma of the virus, i.e., fear of being associated with HIV in some way, but a lot of it has to do with stigma related to marginalized populations and risky behaviors. Racism, transphobia, homophobia, misogyny, and any other form of hostility toward marginalized communities, particularly within healthcare systems, can greatly hinder access to comprehensive prevention options. Additionally, stigmatization of behaviors associated with HIV transmission, such as condomless sex and intravenous drug use, can create challenges to access, particularly when providers will not offer PrEP for fear of encouraging “bad behavior.”

### Examples of policies to target:

- ▶ Healthcare provider education: Working with medical schools, medical boards, medical associations, state and local departments of health, etc., to encourage and require understanding of comprehensive prevention, stigma, and cultural competency.
- ▶ Academic and government research: Pushing at an institutional or government policy level for greater understanding of HIV prevention-specific stigmas (including the stigmatization of condomless sex) and its impact on access to comprehensive prevention tools would better inform our ability to deliver services. Additionally, ensuring that transgender men and women, Black and Latino gay and bisexual men, youth, and other priority populations are included in HIV prevention research is essential to addressing population-specific stigmas.

### National organizations to connect with:

- ▶ PrEP Facts, on Facebook, has become a group that works quite a bit on stigma related to PrEP and HIV prevention. The Stigma Project is another national organization with resources.
- ▶ Any number of organizations dealing with HIV and/or healthcare concerns for specific marginalized populations may be helpful. The Transgender Law Center has done a great deal of work on

transphobia within healthcare; the Black AIDS Institute and NMAC work on many issues involving the intersection of HIV and race/ethnicity.

## 8. Data and surveillance

**The problem.** Advocates need solid, timely data in order to know where the problems are in the epidemic and how to direct their advocacy. But on the national level, the CDC has been repeatedly criticized for taking too long to get important HIV prevention information out. Also, transgender women and other populations continue to be largely invisible. On the state and local levels, we need the best information we can get for new infections, diagnoses, prevalence, and high-risk behaviors for all priority populations, but too often this information is not collected or made available. Not having the right statistics can make it impossible to get funding for a particular issue or to simply raise awareness.

**Advocates need solid, timely data in order to know where the problems are in the epidemic and how to direct their advocacy.**

### Examples of policies to target:

- ▶ Engaging with the CDC for official commitments to reform HIV surveillance systems, including the National HIV Surveillance System, the National HIV Behavioral Surveillance, and the Youth Behavioral Risk Surveillance System. If advocates feel that the wrong information is being collected, additional information is needed, or we need information in a timely manner, we can seek a commitment from the CDC’s Division of HIV/AIDS Prevention.
- ▶ Surveillance and data policies within state and local departments of health: Tired of not having transgender data for your location? Meet with your local or state department of health and advocate!

### National organizations to connect with:

- ▶ If you find in your advocacy that you don’t have the data you need, it can be important to work with other advocates to press the CDC, state, and local health departments to collect and distribute that data. Treatment Action Group has a long history of this kind of advocacy and can help talk you through your concerns about data and surveillance.

## 9. Access to syringes

**The problem.** A number of national, state, and local laws make it very difficult to get unused needles and syringes, despite the fact that this is our most effective intervention for stopping HIV and other blood-borne diseases among those who inject drugs, hormones, steroids, or other substances. Until recently, one of the most significant national obstacles was a ban put in place by Congress on the use of federal public health dollars to fund syringe programs. Fortunately, the federal ban was lifted at the end of 2015; however, we still need new funding to be established to help scale up syringe access programs. States that do not have laws allowing syringe access programs or over-the-counter sales of syringes are ill-prepared to prevent new HIV infections and large outbreaks similar to what we witnessed in southern Indiana. A 2015 report looking at state laws in 30 states, Puerto Rico, and Washington, D.C. found that only 17 of those states had laws specifically allowing syringe programs and over-the-counter sales, leaving much room for advocacy in other states.

**States that do not have laws allowing syringe access programs or over-the-counter sales of syringes are ill-prepared to prevent new HIV infections and large outbreaks.**

### Examples of policies to target:

- ▶ CDC HIV prevention funding: Moving funding from less-evidence based interventions into syringe access programs.
- ▶ State and local restrictions on establishing syringe access programs

### National organizations to connect with:

- ▶ The Foundation for AIDS Research (amfAR) has several online resources related to syringe access advocacy (<http://www.amfar.org/endtheban/>) and the Harm Reduction Coalition ([www.harmreduction.org](http://www.harmreduction.org)) is a continual leader on this important prevention issue.

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