Notes on the GLAAD HIV Media Guide

Page 3

The reality of HIV and AIDS has evolved in the United States since it was first brought to public consciousness in the 1980s. While we have seen significant progress on prevention and treatment, public understanding lags and the unwarranted negative stigma associated with the disease continues to be an obstacle to eradication.

→ The "unwarranted negative" qualification suggests there is stigma that is warranted or appropriate.

→ The problem of stigma is framed here as an obstacle to "eradication" rather than recognizing its very real relationship to discrimination, criminalization, violence, treatment access and the other challenges people with HIV face directly because of stigma. Stigma isn't only a problem because it stands in the way of eradicating HIV; it is a problem present today in the lives of people with HIV.

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While the number of new HIV infections has decreased since the 1980s, new infections have remained at about 50,000 for more than a decade.

→ This should read "at about 50,000 per year"

Through treatment, people with HIV are living longer, reducing the chances for transmitting HIV to others, and lowering risk of developing non-HIV related illness.

→ Better to say "Through treatment, people with HIV are leading longer and healthier lives…"; it is about quality of life as well as longevity.

→ While treatment may lower the risk of developing some "non-HIV related illnesses" it also increases the risk of developing other illnesses that are treatment-related.

→ It it is misleading and reinforces inaccurate beliefs about HIV not to note here that research demonstrates that a person diagnosed today, who has access to treatment, has every reason to expect to live a normal lifespan.

The media plays a critical role in telling the story of HIV and AIDS, and it faces the challenge of reporting on prevention without stigmatizing those living with HIV.

→ Would GLAAD produce a guide about writing about race or gender and say *"the media faces the challenge of reporting on racism without stigmatizing people of color?"* This implies an inappropriate sympathy for the impulse to stigmatize and is, unfortunately, consistent with other references in the guide to "unwarranted negative stigma" and "unfounded stigma."

Indeed, as important as prevention is, according to many HIV and AIDS advocates, stigma is the greatest driver behind the epidemic.

→ This sentence is written in a manner that raises doubt about the assertion. By attributing the concern about stigma to "many HIV and AIDS advocates," rather than to the widespread opinion of public health experts, researchers, clinicians and other experts. The sentence construction also unhelpfully implies a tension between prevention and stigma.

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HIV infection/transmission: A person transmits or is infected with HIV, not AIDS. Do not use AIDS carrier, AIDS transmission, or AIDS infection.

→ From reading this media guide, no one ever "acquires" or "contracts" HIV, it is always a function of someone with HIV "transmitting" or "infecting" others. This section encourages journalists to frame it this way and encourages the use of the phrase "infected with HIV" when it would be better to suggest a "person has HIV."

→ The guide should explicitly note that use of the acronym "AIDS" is complicated and is, in generally, being used less in favor of classifying HIV disease in stages, as does the WHO and CDC (which then also includes a parenthetical reference to AIDS in the final stage, to bridge the gap between previous and current nomenclature). Many people suffer from or die of HIV related illnesses but do not or did not fit into the classical or legal definition of AIDS. Yet the Social Security Administration and some service providers may require an explicit "AIDS" diagnosis for someone to qualify for benefits.

HIV test: It is accurate to say "HIV test," which, to be exact, is a test to see if a person's body has produced HIV antibodies, which means the virus is present. So the technical term would be HIV antibody test, although in publications for a non-specialist audience, HIV test is acceptable.

→ Some of the most recently approved rapid tests do test for both antibody and antigen. Someone believed to have been recently exposed might also get a PCR test, which does directly measure the virus, rather than antibody. This section should explain the difference and encourage journalists to be precise.

> **HIV exposure/HIV transmission: These are not the same thing. During sexual contact with a person who is HIV-positive, the other partner maybe exposed to HIV, but the virus is not transmitted every time someone is exposed to it.**

→ This should note that "the other partner *may or may not* be exposed to HIV…" rather than equate any sexual contact with a person who has HIV with potential exposure to HIV. It also should make it clear that transmitting HIV via sex is far more difficult than transmitting almost any other STI; HIV is fragile outside the body and requires relatively high concentrations to infect another person

> **Bodily fluids that may be responsible for HIV transmission: These are blood, semen, vaginal fluids or secretions, breast milk, amniotic fluid, and pre-ejaculate. It is a good idea to list these for your audience from time to time, rather than just saying "bodily fluids," as there is widespread misunderstanding about which fluids can and can't transmit HIV (such as saliva).**

→ "Bodily fluids" should never be used unqualified; it should always be "some bodily fluids," and, preferably, "but not saliva or sweat."

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> **Antiretroviral therapy: This involves the use of one or more drugs to keep HIV from replicating (reproducing) in the body.**

→ Antiretroviral HIV therapy almost always requires multiple drugs; some are once-a-day combination pills, other regimens are comprised of several pills. As written, this implies single drug therapy is typical or effective.

> **Post-exposure prophylaxis (PEP):**
>
> **This involves the administration of antiretroviral drugs after a person has been exposed to HIV, in order to prevent infection. It might be used after someone has had condomless sex with a person living with HIV or has come into contact, in a healthcare setting, with a needle used on someone who is HIV-positive.**

→ This incorrectly suggests a person cannot safely have condomless sex with a person with HIV; it should say "may have been exposed to HIV through sex"

As other drugs may eventually be approved for PrEP, do not use "PrEP" and "Truvada" interchangeably.

→ This may serve the branding interest of the manufacturer, Gilead, but it isn't clear what the relevance is in this document.

Page 7

Undetectable viral load: This is the level of HIV in a person's blood.

→ "Undetectable viral load" is NOT "the level of HIV in a person's blood" it is the phrase used to describe the level of HIV in a person's blood when that level is so low it cannot be measured by available technology.

A viral load will be declared "undetectable" if it is under 40-75 copies in a sample of blood (the exact number depends on the lab performing the test).

→ We are not sure where the "40-75 copies" reference comes from, as should just say "if there is no virus or so little virus it is not measurable by available technology."

When a person's viral load is so low it is undetectable, he or she is extremely unlikely to transmit HIV.

→ "Extremely unlikely" is very different from *"virtually no chance of transmitting HIV"* or *"there's never been a documented case of sexual transmission of HIV from someone known to be undetectable at the time of the sexual contact"* or *"so unlikely to transmit HIV, it isn't measurable and not even proven that it is possible"* or *"renders a person non-infectious"* or *"virtually non-infectious."*

Infection vs. contamination: A person is infected with HIV, not contaminated.

→ Perhaps in a scientific journal, "a person is infected with" is sometimes appropriate usage, but in general media it should be "a person has HIV"; we don't say someone is "infected with cancer." This section implies that the preferred language is to say a person "in infected with HIV."

Safer sex: Preferable to "safe sex," as "safe sex" implies there is zero risk of infection. "Safer sex" means choices can be made to reduce or minimize the possibility of HIV transmission.

→ There is a place for both terms, but this guidance implies there is no use for the phrase, or perhaps even any such thing as, "safe sex," which isn't true. There is a distinction between "safe sex" and "safer sex", to be sure, but there also are many ways to have sex with a person with HIV that is entirely safe. The guide should have explained the distinction between how the phrases are appropriately used, as well as suggesting the use of "risk reduction options."

People living with HIV: Use this term instead of "people with AIDS" as not everyone with HIV develops AIDS.

→ The reason the preferred descriptor is "People with HIV" or "person with HIV" is not necessarily to distinguish the individual from a "person with AIDS"; it is because we are people first. That should be made clear, as well as where this comes from (The Denver Principles) and how this linguistic construction is now a preferred model in all sorts of different communities and disease states. It should also explicitly promote the phrase "person with HIV" as well; we are also individuals, not just a monolithic group.

Injecting drug user: This is preferable to the derogatory and stigmatizing terms "drug addict" or "drug abuser."

→ Even less derogatory and stigmatizing is the preferred descriptor, "a person who injects drugs."

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Terminal illness, fatal illness: Do not use these terms when referring to AIDS, as it is not accurate, due to advances in treatment. AIDS can be more accurately described as a life-threatening disease. Also, avoid using sensationalistic terms such as "scourge" or "plague" when referring to AIDS. (Also, for context, remember there are hundreds of life-threatening illnesses including ulcers, diabetes, flu, and asthma.

→ Is this just about referencing AIDS or also HIV? Immediately above this section it notes that one doesn't die of AIDS, but here it is suggested that AIDS be described as a life-threatening disease. The distinction between having HIV and having AIDS is inconsistent throughout the guide.

→ This should make clear it is not appropriate to refer to HIV as terminal or fatal illness, but instead as a "chronic manageable condition" or "treatable" illness or viral infection, and may be "life-threatening" when treatment and care are not available. While the other diseases cited can be life-threatening, they aren't generally referred to that way except when left untreated or in extreme

circumstances.

> **Barebacking: Do not use. This is a sensationalistic term often used to describe sex without a condom, and implying a high risk of HIV transmission. But it also includes condomless sex between persons of the same HIV status, or condomless sex that may not otherwise pose a measurable or significant risk of HIV transmission.**

→ "Barebacking" is a term that has meaning with specific communities (including some heterosexuals) that may or may not imply any significant risk of HIV transmission. It is fraught with baggage, to be sure, but to dictate that it *never* can be used is to shame it, which is not helpful.

> **Down Low: A controversial term describing MSMs who publicly identify as heterosexuals and maintain sexual relationships with women, the "Down Low" has become synonymous with sensationalized claims that MSM are spreading HIV into "the general population." Avoid inaccurate claims that the "Down Low" is a phenomenon exclusive to communities of color.**

→ Rather than simply advise avoiding the use of "down low" in a context exclusive to communities of color, it would be better to simply discourage its use except in a quote or for individuals who so self-identify. This is stated explicitly in another section of the media guide, but not here.

→ "MSMs" turns an acronym, MSM, used to describe a behavior into a descriptor of individuals. Better to drop the "s" and change it to "gay men and MSM." Having a self-identity as a gay man and also "being on the down low" are not mutually exclusive.

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> **Include voices of people living with HIV.**
>
> **Often, news coverage silences those who are most impacted by developments in HIV and AIDS issues. Hearing from people living with HIV and AIDS - not just caregivers or researchers - is critically important. Positive change is made when marginalized persons and groups are humanized in the press. Further, it's important to speak to someone informed about developments and what that means to them. Whenever possible, reach out to the networks of people living with HIV for comment or analysis. The organizations are listed on page 28 of this guide.**

→ We appreciate GLAAD recognized the importance of making this point and take it as confirmation of the good intentions we know are behind GLAAD's interest in producing this guide.

→ This entire page is good, but we would suggest that a note be added for journalists to be cautious about law enforcement making claims about "public health"; they should seek input from public health professionals before framing a story in public health terms.

Page 10

> **Avoid inaccurate sources of HIV diagnosis. Do not rely on hearsay. If someone's HIV status is relevant to the story, make sure the source knows with certainty the person's diagnosis.**

→ This should note that just because a law enforcement official or agency says someone has HIV doesn't mean it is true. Journalists should not rely on statements of law enforcement to reveal a persons' alleged HIV status, unless explicitly noting it is an allegation.

Page 11

> **With the variety of scientific research that has gone into the prevention and treatment of HIV, the bulk of media attention has gone into PrEP (pre-exposure prophylaxis).**

→ Should be "much recent"…

> **Much of the media attention has been focused on myths, rumors, or speculation around the drugs, usage, and implications for the future. It is important to note that myths and misinformation around PrEP are based on long-existing, harmful stereotypes about the LGBT community, communities of color, and historical stigma attached to HIV.**

→ There certainly are many myths, rumors and speculation in the community discussion about Prep. But by framing the concerns or criticism about or of Prep almost solely in terms of "myths, rumors or speculation" and "myths and misinformation around Prep… based on long-existing, harmful stereotypes about the LGBT communities, communities of color, and historical stigma attached to HIV" is to ignore legitimate concerns that have been raised about unintended consequences that may arise from the implementation and promotion of Prep by leading researchers, public health professionals, clinicians and advocates.

PrEP is a drug treatment for HIV-negative people that protects against exposure to HIV. In 2012, the federal government recommended that PrEP be prescribed for people who are HIV-negative and at substantial risk of contracting HIV.

→ The most recent federal guidelines (released in 2014, not 2012) recommend that Prep be prescribed for *some* people who are HIV-negative, at substantial risk of acquiring HIV and have access to the required healthcare support and are able to adhere properly to the treatment regimen.

→ Prescribing Prep for those who are unwilling, unable or incapable of taking Prep properly, or who do not have access to the healthcare support and monitoring that is required for it to be safe and effective, is not advised.

The only drug approved for this use as of this writing (February 2015) is Truvada, which was previously approved as a treatment for people already infected with HIV.

→ "already infected with HIV" is better stated as "living with HIV."

Truvada has been effective in clinical trials. According to a study reported at the 6th IAS Conference on HIV Pathogenesis, Treatment, and Prevention, Truvada "reduced new infections among men who have sex with men and transgender women by more than 90 percent." This study was performed by iPrex, a network of communication agencies working across the spectrum of industry sectors and practice disciplines. Initially, PrEP was recommended to be taken daily, but the iPrEx study found it to be effective when taken four or more days a week.

→ The iPrex study's 90 percent statistic refers to a subset of those enrolled in the Truvada-receiving arm of the trial, who were found to have detectable levels of Truvada in their blood. Among all those enrolled in the Truvada arm of the trial, the reduction was, because of poor adherence, only 42 percent, versus those in the trial's placebo arm.

Outlets should keep in mind that PrEP is not the only method to reduce the spread of HIV. Some methods have been around for a long time: regular testing, condom use, access to clean needles, and monogamy, among them. Others are still in development. PrEP should be presented along with other methods to present a complete arsenal of tools for prevention of HIV.

→ There are many people with HIV—especially women—who were monogamous, but still acquired HIV from their partners. "Mutual monogamy" would be the appropriate phrase.

The emergence of PrEP has sparked a broad discussion among the LGBT and HIV advocacy communities.

→ More than a discussion, it has been a highly controversial topic, but that isn't suggested anywhere in the guide (the word "controversy" isn't used in the guide once).

→ Moreover, to limit the reference to a discussion to just the "LGBT and HIV advocacy communities" is misleading; there are highly-respected researchers, scientists, clinicians, public health officials and others who have been central to the "discussion." By solely citing the "LGBT and HIV advocacy communities" it implies that the rest of those informed about or interested in HIV are not interested in or are "past" the discussion stage. That isn't true.

News stories looking for reaction will find a range of views around PrEP. It's important for outlets to keep in mind that HIV has been a virus with a high level of stigma and misunderstanding, and many of the comments will reflect that stigma. Inflammatory comments are more often designed to create salacious headlines, rather than reflect the scientific data around the drug.

→ This reads as though any concerns or criticisms among the "range of views" journalists might find are likely to be driven by the stigma and misunderstanding referenced, or by an intent to "create salacious headlines." Those are important considerations and certainly present in the public discussion, but to only reference those scenarios diminishes the potential relevance of other informed critical voices.

Since Gilead is not marketing Truvada in a widespread way, supporters are creating grassroots campaigns to fight stigma around the drug, as well as educate others of its use and effectiveness.

→ Gilead does not place direct-to-consumer advertising promoting Truvada for its Prep indication, like they do for Truvada's indication for treatment of HIV. That is not the same as "not marketing" it; marketing is more than direct-to-consumer advertising.

Stories covering the use of PrEP are encouraged to explore some of the following questions:

Why is there not a wider marketing and education campaign targeted at doctors about the use of PrEP? Who bears responsibility for leading such a campaign?

→ It is peculiar that this is presented as the first story GLAAD suggests

journalists explore concerning Prep, instead of "how will Prep help people with limited healthcare access" or "will Prep be effective as a public health intervention" or perhaps "what are researchers and scientists saying about the potential unintended consequences of Prep."

> **Because PEP is reactive as opposed to proactive, it is easier to get a prescription for PEP than it is for PrEP.**

→ It is highly debatable whether or not it is easier to get a prescription for PEP than for Prep; getting a prescription is a function of awareness and access, not just whether or not a doctor will write a prescription when presented with the need for one.

> **Someone who has reason to believe that they have been infected…**

This should read "Someone who has reason to believe they have been exposed…" Exposure, or potential exposure, does not equal infection.

> **… can receive begin PEP treatment simply by visiting their doctor or any emergency room.**

→ This is a fantasy; it is not that simple.

Page 13

> **HIV-specific criminalization laws do not differentiate between sex with and without condoms, …**

→ Should read "typically do not differentiate," (some do).

Page 14

> **Most of those laws were passed in the late 1980s and early 1990s; the bulk of them were based on model legislation proposed by the right-wing think tank American Legislative Exchange Council (ALEC).**

→ Should read "some" not "the bulk.

Page 15

> **When reporting on HIV criminalization laws, be clear about the difference between exposure and transmission.**

→ This should read "between *perceived* exposure, exposure and transmission" or "between perceived or potential exposure, exposure and transmission." Do not equate sex with someone with HIV with "exposure."

> **During sexual contact with a person who is HIV- positive, the other partner may be exposed to** HIV, but the virus is not transmitted every time someone is exposed to it.

→ This should read "the other partner may or may not be exposed..."

> **In many cases, no transmission takes place.**

→ Instead of suggesting that in "many cases" there is no transmission, this should make it clear that in the *vast majority* of instances where someone with HIV has sex with another person, HIV is not transmitted.

> **Often, media coverage implies transmission has occurred. Sometimes these laws are even described as "laws that criminalize the transmission of HIV," but in reality, people are often prosecuted under these laws even if no transmission has taken place.**

→ Actually, people are not "often prosecuted" when there is no transmission, but the overwhelming majority of HIV criminalization prosecutions do not involve HIV transmission.

> **Several people prosecuted for HIV-related crimes have had undetectable viral loads.**

→ Several implies that it is relatively rare, when it is possibly more often the case than not. It should read "many people…"

> **When reporting on HIV criminal charges or investigations, media should inquire into the specific allegations of consensual adult noncommercial sexual activity involving HIV criminalization.**

→ Why is this important with just "noncommercial" sexual activity? Prosecutions of commercial sexual activity can and often do increase stigma as well.

> **Such reporting can increase unfounded stigma against people living with HIV.**

→ "Unfounded" is an insult, as it implies some stigma is appropriate when stigma is defined as "a mark of disgrace or infamy; a stain or reproach, as on one's reputation. A mental or physical mark that is characteristic of a defect or disease."

The CDC study that gives us the HIV rates among Black men also stated that African-American MSM tend to have fewer partners, are less likely to do IV drugs, and are no more likely to have anal intercourse than other gay men.

→ This should also note that studies have shown that African American youth overall are *more likely* to use condoms.

Page 19

Outlets could focus on cultural factors that influence HIV rates among Latinos, including immigrant status, cultural stigma, and discrimination around HIV in the Latino population. Other possible leads socioeconomic factors such as poverty, language barriers, and limited access to healthcare for the Latino population.

→ The socioeconomic factors should be cited first, before the cultural factors.

American Indians and Alaska Natives

American Indians and Alaska Natives (AI/AN) are impacted by HIV proportional to their US population size, with lower rates than in blacks/ African Americans and Hispanics/Latinos, but higher rates than in Asians and whites.

→ "AI/AN are impacted by HIV proportional to their US population size." What an odd thing to choose to say, when in fact, according to the latest CDC surveillance report, AI/AN are the ONLY racial/ethnic group among whom the RATE of new HIV diagnoses increased.

Stories on HIV could explore prevention challenges, such as cultural and language diversity among tribes, mistrust of government and its healthcare facilities, and culturally based stigma and confidentiality concerns, especially among gay and bisexual men living in rural communities or on reservations.

→ "Stories could explore... mistrust of government"? How about the lack of healthcare, infrastructure, extreme poverty and stolen land?

→ Should note that National Native HIV/AIDS Awareness Day is observed on the first day of spring of each year.

Despite growth of the Asian population in the United States, the number of HIV diagnoses among Asians has remained stable and the rate of new infections has decreased.

→ This doesn't make sense. Why would an increase in a population lead to an increase in the *rate* of infection? The sentence should end with "the number of HIV diagnoses has remained stable" (assuming that is true).

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One study showed that a majority of transgender men did not use condoms consistently during receptive sex with non-trans male partners.

→ This implies transgender men engaging in receptive sex without condoms is necessarily a risk, when it may or may not.

It is important that these statistics are used to frame a harrowing reality, not further stigmatize transgender people.

→ "Harrowing reality" is neither helpful or appropriate language in this context.

It is also important to recognize disparities within the transgender population. Among transgender people in 2010, the highest percentages of newly identified HIV-positive test results were among racial and ethnic minorities: blacks/African Americans comprised 4.1% of newly identified HIV-positive test results, followed by Latinos (3.0%), American Indians/ Alaska Natives and Native Hawaiians/Other Pacific Islanders (both 2.0%), and whites (1.0%).

→ The point is about racial disparities, so why not say that upfront? Is the statistic cited asserting that among new diagnoses of transgender people in 2010 4.1% were black/African American, 3% Latino, etc.? This doesn't sound accurate, but the citation provided could not be found on the web.

→ Why keep referring to people of color as "racial and ethnic minorities"?

Page 21

Coverage for HIV and AIDS Prevention and Treatment

→ Take out "and AIDS" in the headline.

Page 25

Many may believe that a parent's HIV positive status should not factor

into custody cases unless the parent is sick to the point that it may be hard to care for their child.

→ To suggest that there are legitimate or understandable differences of opinion concerning whether or not a person's HIV status should be considered in a custody case is offensive. GLAAD should state clearly that a parent's HIV status should have no role in custody cases. The question should be a parent's ability to properly parent, not the parent's HIV status.

However, stigma, discrimination, and ignorance still impact guardianship and custody cases for parents, particularly when involved parties are ignorant

→ This should be "ignorant to how HIV is transmitted" or "ignorant of HIV transmission risk."

Page 26

Due to a number of societal factors, correctional facilities are often the first place incarcerated men and women are diagnosed with HIV and provided treatment.

→ It should be stated that the vast majority of people who are HIV positive in prison did not contract the virus while incarcerated. The idea that HIV is frequently transmitted in prison is a common misconception that media can help work against.

However, there are challenges associated with the implementation of testing, which isn't required in all facilities

→ This sentence could imply that GLAAD thinks testing should be required in all correctional facilities. HIV testing should be routine and available to everyone, but always an option, not a requirement.

While discrimination can occur within facilities regarding HIV status, some institutions also have peer-educator systems to provide support for HIV positive inmates.

→ This minimizes discrimination by saying it "can occur" when there is overwhelming evidence that it is widespread.

→ HIV education is needed to break down stigma among those incarcerated as well as those who work in correctional facilities, not just as support for HIV positive people.

Alabama prisons ended segregation for HIV-positive females who were

incarcerated after an inmate advocated for herself with help…

→ This should use word "women" not "females"

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Further questions to explore might include:

→ Prison guards and medical staff frequently violate confidentiality and perpetuate HIV stigma.

→ People with HIV sometimes don't get their medications on time in prisons, jails, and detention centers, which puts them at risk for drug resistance.

→ Incarcerated people have the constitutional right to health care while in the custody of the state, even if it's expensive.

If they test positive, they are evaluated intensively to determine whether they are "fit for duty.

→ HIV+ personnel are automatically restricted and limited to what jobs they can perform and where they may be stationed.

Additionally, the Department of Defense is attempting to reduce new HIV infections through education and training and increasing access to healthcare for HIV positive personnel, in coordination with the White House National HIV and AIDS Strategy.

→ DOD has done nothing new to reduce HIV in the military in any substantive way, other than implementing mandatory testing every two years. There is no new funding allocated to any education or training programs.

→ As an example of the military's non-standard approach to care, the Army does not provide any clinical social work "counseling" services for HIV+ soldiers, while the Navy does.

In 2013, fewer recruits tested positive for HIV than in any year since the Pentagon begin pre-service screening in 1985.

→ DOD has nothing to do with recruits before they join; this reduction is a result of civilian public health initiatives.

→ It should be noted that the Uniform Code of Military Justice allows for Aggravated Assault charges to be filed against service members for behaviors which, for members of the military who are not HIV positive, would be unremarkable.

Other

→ There are multiple corrections on the resource guide, which can be provided at a later date.