Fighting the Current Epidemic, Not the Past One

January 13, 2014 By Sean Strub

Writing a memoir is, necessarily, about revisiting the past. In Body Counts, I've covered quite a lot of the past, from my 1976 arrival in Washington, as a fresh-faced 17-year-old from Iowa, to running an elevator in the U.S. Senate, up through the decades to my current HIV advocacy.

My work today, with the Sero Project, fighting HIV-related stigma, discrimination and criminalization, is about the future, but is necessarily informed by the past. I wish the Centers for Disease Control and Prevention could learn a bit more from the past and let it properly inform their plans for the future.

Instead, they sometimes seem mired in the past, addressing the epidemic that was, rather than the epidemic as it currently is. Sero recently joined with several other groups to send an open letter to the CDC to challenge their misleading depictions of gay/bi/MSM sexuality and HIV prevention practices.

It is deeply troubling that in 2014 community groups still need to point out the issues raised in this letter. It is indicative of how far off the mark the federal response has so often been. The letter is wonky, but when it comes to changing policy, the part that isn't about leadership is all about the wonk.

Open Letter to the Centers for Disease Control and Prevention (CDC) on 2013 MMWR Report on HIV Testing and Risk of US Gay, Bisexual and other MSM[1]:

A call to re-evaluate language, methods and recommendations ?in order to support men's health and HIV resiliency:[2]

* CDC urged to reduce its own risk of misleading depictions of Gay/Bi/MSM sexuality, HIV prevention practices

Seeking the spotlight of World AIDS Day, CDC released a report in their Morbidity and Mortality Weekly Report (MMWR) focused on gay, bisexual and other MSM (men who have sex with men) in the United States -- the population that remains both disproportionately affected by HIV and drastically underserved by federal HIV/AIDS prevention resources.

The press release for the report, headlined “Sexual risk lower among U.S. gay and bisexual men who accurately know their HIV status,”[3] provides a constructive and accurate emphasis on the success of gay and bisexual men who know their HIV status. Thus, it delivers an encouraging message about the importance of HIV testing.

However, the full MMWR article is quite different in its messaging and emphasis, skewing sharply to language that could encourage sexual stigma and blaming.

Both documents use increasingly antiquated language on risk, miss the opportunity to take a bold and scientifically-validated stance on systems change to facilitate more frequent HIV testing for bisexual and gay men, and does not clarify if transgender women are included in the historically-confusing category of MSM.

We urge CDC to take this opportunity to re-evaluate language, methods and recommendations regarding the sexuality and HIV prevention practices of gay, and bisexual men and other MSM.

We look forward to further dialogue with you on these and other issues:

1) “Unprotected anal sex” and “unprotected discordant anal sex” are the key terms for looking at sexual behavior across the three years of the NHBS cohort.

However, these terms have grown increasingly non-specific, or even inaccurate, in the current landscape of HIV prevention and the parameters of sexual decision-making by gay men, other MSM and their partners.

Insertive anal sex and receptive anal sex are distinct acts with very different levels of risk -- a spectrum of risk that is further broadened through widespread sero-adaptive practices. In addition, the use of virally-suppressive HIV treatment is a relevant factor in accurate risk assessment and sexual decision-making.

In the report, unprotected is used to refer to the non-use of condoms. However it does not mean that sex occurred in an environment of heightened HIV risk. Although much of this data was collected before PrEP licensure, reports emerging today should use clearer language -- such as “sex without condoms,” rather than “unprotected.”

These distinctions are neither political nor semantic. They are integral to reaching the goals of the National HIV/AIDS Strategy and curtailing the epidemic.

Gay, bisexual and other men who have sex with men and their partners need accurate information for sexual risk reduction. There are noted methodological models for data collection that effectively clarify and refine descriptions of sexual behavior that should be adopted across research conducted or supported by CDC.

2) We agree that increased HIV testing is a priority, and that “the data suggest that some men may benefit from more frequent testing.”

However, we believe that “at least annual HIV testing” that is only to happen more frequently at provider discretion is insufficient in the current environment.

Once again, CDC has missed the opportunity to take a bold and data-supported stand in favor of more frequent HIV testing for all gay and bisexual men and other MSM. Sticking to the once-a-year standard, leaving it at providers’ discretion to advocate for more frequent testing (which many do), is not warranted given the strong -- and historically consistent -- findings of behavior change by those who test positive as well as the recognized role of treatment as a prevention modality.

By formally recommending testing on a quarterly basis, CDC will encourage systemic changes that will result in more men learning earlier if they are infected and allowing them to make informed decisions about their health care and sexual practices. Individuals who tend to lag behind in testing with the recommended interval will be prompted to test more frequently.

A system that is set up to facilitate more frequent HIV testing is a resource not only for case-finding and entry into care, but also to support the use of PrEP, which requires testing every 3 months.

In addition, we support efforts at the time of testing that would help identify HIV negative men who would benefit from access to PrEP and other prevention interventions, and increased vigilance in opposing the stigma,

discrimination and criminalization of those who test positive.

3) We urge a reconsideration of the reliability of venue-based sampling for the gay, bisexual and MSM cohort of the NHBS. CDC’s own research, as well as that of others, has pointed to the significant shift of sexual networking and social structures to finding partners online, and to greater integration of young LGBT people in networks that are less segregated in terms of sexual orientation. Venues, if used, must be interpreted broadly to include a wide range of non-commercial and commercial spaces, and even digital space. Further, the highly urban-based sample continues to under-power for potential differences in rural and Southern populations of gay, bisexual and MSM, despite rising incidence and prevalence in the South and potentially significant differences in social and sexual structures in non-urban areas.

4) We continue to recommend that CDC clarify the inclusion or exclusion of transgender people in the NHBS, including the MSM cohort, and all other population research and HIV/AIDS cohorts and studies. While we anticipate and commend significant improvements in the collection and reporting of data on transgender people[4] -- including transgender women who evidence high rates of HIV where data is available -- the press, policy-makers and the HIV/AIDS community must have clear information on how to interpret the conclusions of all data vis a vis transgender populations.

5) While we recognize that CDC does not control how the press communicates its policies and findings, we are concerned (though not surprised) that major news stories on the MMWR did not reflect the messaging of the press release. We encourage a coordinated and clear press

strategy, including op-eds by top CDC officials and HIV/AIDS leaders, press briefings and other modalities, to eschew the biases that can come up in these stories. However, it is most important that CDC avail itself of all opportunities to ensure that the source documents, such as the MMWR itself, are free from overt or covert stigmatizing language in its descriptions, findings and areas of emphasis.

6) In an era of expanding prevention options, it is nonetheless imperative to continue to make condoms (and safe, condom-compatible lube) accessible and invest in prevention education for gay and bisexual men and other MSM to increase their capacity to meet their own goals for sexual health and safety.

While many gay men continue to use condoms frequently and consistently, we may be seeing gay men feeling more comfortable being honest about the challenges of condom use (which are reflected in effectiveness rates cited by CDC) -- and must do whatever is possible to encourage this honesty and rejecting the stigma that may come towards those who speak up.

CDC must supply and encourage respectful, unbiased, and accurate data and messaging not only on male condoms but all HIV prevention technologies and practices, including sero-sorting and sero-positioning, that people are using to mitigate risk.

Increased knowledge and uptake of PrEP and PEP, sero-adaptation, and the development of integrated systems of care to facilitate their use will take significant resources and coordination, including education and training of primary care physicians.

7) The MMWR releases was a missed opportunity for CDC, along with federal partners, to reinforce the importance of essential services to support individuals who test positive across the HIV care continuum, and to articulate a cogent HHS-wide strategic approach to ensure that gay, bisexual and other MSM achieve viral suppression.

As you know, the HIV Care Continuum is a planning model that identifies issues and opportunities for improving the service delivery of services and health outcomes for people living with HIV. As such, it is increasingly used by both government and non-governmental stakeholders.
Helping individuals across the continuum of care achieve requires attention to psychosocial issues; identification, prevention and treatment of mental health and substance use disorder; provision of housing; efforts to mitigate HIV stigma, discrimination and criminalization; and employment opportunities and work force re-entry support for of HIV+ persons.

8) Finally, we stress that continued rigor is needed on the part of CDC, and its federal partners, to assure greater concordance between resource allocations and the populations most affected by HIV, including robust and up-to-date and affirming HIV prevention efforts by and for gay and bisexual men.

We come to you as partners for constructive dialogue and change. We look forward to engaging with you on these and other issues in order to ensure significant, necessary shifts in language, funding, research and communication practices in the year ahead.

Sincerely, the undersigned (list in formation)*

- ACT UP
- AIDS Foundation of Chicago
- Gay Men’s Health Crisis (GMHC)
- Global Network of People Living with HIV, North America (GNP+NA)
- HIV Prevention Justice Alliance (HIV PJA)
- Housing Works
- International Rectal Microbicide Advocates (IRMA)
- National Center for Transgender Equality (NCTE)
- Positive Women’s Network - USA (PWN-USA)
- Sero Project
- Transgender Law Center
- Treatment Action Group
- US People Living with HIV Caucus
- Visual AIDS

* To join the list of endorsers, go to http://bit.ly/1kmeVPg

[1] Centers for Disease Control and Prevention. HIV Testing and Risk Behaviors Among Gay, Bisexual, and Other Men Who Have Sex with Men -- United States. MMWR 2013;62(47); 958-962

[2] Please direct correspondence to Julie Davids of the HIV Prevention Justice Alliance (HIV PJA) and AIDS Foundation of Chicago: jdavids@aidschicago.org

[3] www.cdc.gov/media/releases/2013/p1127-World-HIV-AIDS-day.html, accessed 12/10/13

[4] http://www.cdc.gov/hiv/risk/transgender/ accessed December 17, 2013

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