Fenway Institute at Fenway Health comments on sexual orientation questions proposed for National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930—0334)--Revision issued March 1, 2013

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Sent to summer.king@samhsa.hhs.gov on April 30, 2013.

Dear Ms. King,

We write to comment on the two proposed sexual orientation questions for the National Survey on Drug Use and Health. We commend SAMHSA for considering adding these questions to the NSDUH.

We support the addition of a sexual orientation identity question, and strongly recommend that you ask a sexual behavior question as well. Ideally you can add this to the two questions already proposed. However, if you limit the number of sexual orientation questions to two, we believe that a sexual behavior question is more important than the proposed sexual attraction question. We believe that a sexual behavior question—that captures same-sex behavior, regardless of how one self-identifies—is necessary for the proper performance of the functions of the agency, and that replacing the proposed attraction question with a behavior question will enhance the quality, utility, and clarity of the information to be collected. We also encourage you to consider adding a gender identity question as well, to gather critically needed data on substance use issues affecting transgender Americans.

The Fenway Institute works to make life healthier for those who are lesbian, gay, bisexual, and transgender (LGBT), people living with HIV/AIDS, and the larger community. We do this through research and evaluation, education and training, and public health advocacy. Several members of the Fenway Institute faculty have worked for more than a decade to promote adding sexual orientation and gender identity questions to national health surveys. We have also played a leading role in conducting ground-breaking research on sexual orientation and substance use, including research on how to measure sexual orientation on surveys and in clinical settings, and research on the experiences of sexual and gender minorities with crystal methamphetamine, alcohol, and other substances. Much of our research has explored the connection between substance use and sexual risk behavior.

Gathering data on LGBT people's experiences with substance use is important not only because substance use is a structural driver of HIV and other health disparities, but because LGBT people confront barriers to accessing mental health services. Experiences of discrimination among LGBT people can make them less likely to seek needed mental health and substance use services, and "experiences of discrimination may engender negative expectations among stigmatized groups about how they will be treated within larger institutional systems, making them wary of entering those situations" (Burgess, Lee, Tran, & van Ryn, 2007, 11). Compared with heterosexuals,

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LGBT people are more likely to report "that they did not receive mental health services, or that such services were delayed" (Ibid). One study of mental health and substance use services in rural areas found widespread experiences of discrimination among LGBT clients, at the hands of both providers and heterosexual clients. Clients who were LGBT were frequently silenced and told not to raise issues of sexuality or gender identity in group settings. Counselors expressed disapproval of homosexuality and sought to convert clients to heterosexuality. Clients who self-identified as LGBT were often refused entry into programs to "protect" them from discrimination, or placed in isolation from other clients. Of 20 providers interviewed, only one had had formal training in LGBT mental health issues (Willging, Salvador, & Kano, 2006).

There are significant documented physical health disparities affecting LGBT people (Healthy People 2020; Mayer et al., 2008). The exact causes of these health disparities are still understudied and therefore not well understood (Mayer et al., 2008). Meyer and Northridge (2007) suggest that social stigma and systematic discrimination based on sexual orientation and gender identity create a stressful social environment that has a significant negative impact on the overall health of LGBT individuals. Fredriksen-Golden et al. (2011) report that LGBT health disparities correlate with minority stress and experiences of anti-LGBT prejudice. These could be factors in a higher rate of substance use and mental health burden among LGBT people.

Based on our experience and research, we support the inclusion of QD63:

Do you consider yourself to be:

1) *Heterosexual, that is straight;*
2) *Lesbian or gay;*
3) *Bisexual?*

We assume that you are aware that the National Health Interview Survey is asking a different version of this question. Specifically, the NHIS option for heterosexual is:

Straight, that is, not gay

NHIS found that the inclusion of the word "heterosexual" introduced measurement error into the responses. NHIS also offers three other options:

Something else

I don't know the answer

Refused

We urge you to coordinate with NHIS and the National Center for Health Statistics on how to ask about sexual orientation identity. Ideally, to the greatest extent possible, similar questions would be asked across different surveys to allow for comparisons.

While we support asking a sexual orientation self-identifier question, we think that QD62, measuring sexual attraction, is less important than a question on sexual behavior.

The National Survey on Drug Use and Health (formerly the National Household Survey on Drug Abuse) only asked a sexual behavior question in 1996 (Institute of Medicine, 2011, 125). We strongly urge you to add a behavior question back onto the survey in place of the proposed attraction question. While data on attraction are interesting, they are less critical than data on behavior. Behavior data tell us who is homosexually active,

and what differences we see between those who are homosexually active (either exclusively with same-sex partners or with both opposite-sex and same-sex partners) and those who are exclusively heterosexual. One analysis of the 1996 NHSDA data found that:

> There were consistent patterns of elevated drug use in homosexually experienced individuals for life-time drug use… homosexually active men and women were more likely than exclusively heterosexually active respondents to report at least one symptom indicating dysfunctional drug use across all drug classes, and to meet criteria for marijuana dependence syndrome (Cochran, Ackerman, Mays, Ross, 2004).

Self-identity as gay, lesbian, or bisexual and same-sex behavior sometimes overlap, but not always. Therefore a sexual behavior question is essential to capture data on people who are homosexually active but don't identify as gay, lesbian, or bisexual. A 2006 study of more than 4,000 men in New York City found that 9.4% of men who identified as "straight" reported having sex with another man in the past year (Pathela, 2006). A recent survey of sexually active adolescents showed that 76% of lesbians and 96% of bisexual women reported having had sex with a man at some point during their lives (Goodenow, Szalacha, Robin et al, 2008).

We recommend the following sexual behavior question:

During the past 12 months, have you had sex with only males, only females, or both males and females?

This question is asked on the Massachusetts and Vermont Behavioral Risk Factor Surveillance System (http://www.lgbtdata.com/recommend.html).

We also encourage you to add a question about gender identity to NSDUH. Here are two possible ways to ask about gender identity:

The Massachusetts Behavioral Risk Factor Surveillance Survey asks the following question:

Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?

__ *Yes, transgender, male to female*

__ *Yes, transgender, female to male*

__ *Yes, transgender, gender non-conforming*

__ *No*

The Center of Excellent for Transgender Health at the University of California San Francisco recommends the following two-part question:

1. What is your current gender identity?
__ *Male*

__ *Female*

__ *Trans male/Trans man*

__ *Trans female/Trans woman*

__ *Genderqueer/Gender non-conforming*

__ *Different identity (please state): _____*

2. What sex were you assigned at birth, meaning on your original birth certificate?
__ *Male*

__ *Female*

(GenIUSS Group, 2013)

Thank you for proposing to add sexual orientation questions to the NSDUH, and thank you for considering the suggestions contained in these comments. We urge you to keep the proposed sexual orientation identity question, but to replace the attraction question with a behavior question as outlined above. This will greatly increase our understanding of substance use and mental health issues affecting lesbian, gay and bisexual people. Adding a gender identity question will also increase our understanding of substance use issues affecting transgender people as well, another population that bears a disproportionate substance use and mental health burden. Please contact Sean Cahill with any questions, or to discuss further, at scahill@fenwayhealth.org, or 617-927-6016.

Sincerely,

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Cc: Kathleen Sebelius, Secretary, U.S. Department of Health and Human Services

Dr. Howard Koh, Assistant Secretary for Health, U.S. Department of Health and Human Services, Co-chair, HHS LGBT Coordinating Committee

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Dr. Grant Colfax, Director, White House Office of National AIDS Policy

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References

Burgess, D, Lee, R, Tran, A, van Ryn, M. (2007). Effects of perceived discrimination on mental health and mental health services utilization among gay, lesbian, bisexual and transgender persons. *Journal of LGBT Health Researc*h. 3: 1-14.

Cochran SD, Ackerman D, Mays VM, Ross MW. Prevalence of non-medical drug use and dependence among homosexually active men and women in the US population. Addiction. 2004 Aug;99(8):989-98.

Fredriksen-Golden, K., Kim, H., Emlet, C., Muraco, A., Erosheva, E., Hoy-Ellis, C., Goldsen, J., Petry, H., (2011). *The aging and health report: Disparities and resilience among LGBT older adults*. Seattle: Institute for Multigenerational Health, University of Washington.

GenIUSS Group (2013). Gender-related measures overview. Los Angeles: Williams Institute. http://williamsinstitute.law.ucla.edu/wp-content/uploads/GenIUSS-Gender-related-Question-Overview.pdf. Accessed April 26, 2013.

Goodenow C, Szalacha LA, Robin LE, Westheimer K. Dimensions of sexual orientation and HIV-related risk among adolescent females: Evidence from a statewide survey. *Am J Public Health*. 2008;98(6):1051.

Healthy People 2020 (2010). Lesbian, gay, bisexual, and transgender health. http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25. Accessed September 16, 2011.

Mayer K, Bradford J, Makadon H, Stall R, Goldhammer H, Landers S. (2008) Sexual and gender minority health: What we know and what needs to be done. *Am J Public Health*. 98: 989-995.

Meyer, I., and Northridge, M. (2007). *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual and transgender populations*. Springer Science + Business Media LLC.

Pathela et al. (2006). Discordance Between Sexual Behavior and Self-Reported Sexual Identity: A Population-Based Survey of New York City Men. *Annals of Internal Medicine*, v. 145, pp. 416-425.

Willging, CE, Salvador, M, Kano, M. (2006). Unequal treatment: Mental health care for sexual and gender minorities in a rural state. *Psychiatric Services*. 57: 867-870.