Attachment T – Comments on 60-Day Federal Register Notice

THE TREVOR PROJECT
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April 22, 2013

Summer King, SAMHSA Reports Clearance Officer
Room 2-1057
One Choke Cherry Road
Rockville, MD 20857

Re: 2013 National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930-0334)

The Trevor Project greatly appreciates the efforts of the Substance Abuse and Mental Health Services Agency (SAMSHA) to recognize the health disparities faced by LGBTQ communities by incorporating sexual orientation data collection into the proposed Dress Rehearsal for the National Survey on Drug Use and Health (NSDUH). We applaud the proposed amendments to this survey tool, and urge SAMHSA to adopt additional measures that would permit accurate collection of data on all LGBTQ identities. Additionally, recognizing the critical importance of school safety to youth mental health, we strongly encourage the adoption of youth experience questions asking about school safety and suicide prevention measures. We commend SAMHSA's ongoing support of LGBTQ communities, as evidenced by your leadership in addressing LGBTQ health disparities in your resource materials, and through your commitment to collecting data on transgender individuals through your programmatic forms.

The Trevor Project is the leading national organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender, and questioning (LGBTQ) young people under 24. The Trevor Project saves young lives through its free and confidential lifeline, a secure instant messaging service providing live help, in-school workshops, educational materials, online resources, and advocacy. The Trevor Project is a leader and innovator in suicide prevention.

Accurate data collection is critically important to identifying and ending the health disparities facing LGBTQ communities. This need is recognized in the Affordable Care Act, which prioritizes data collection and directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors deemed relevant to reducing disparities.[1] In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[2] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys. This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBTQ individuals are more likely to be uninsured and report poorer health outcomes than the general population.

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[1] Affordable Care Act Section 1302.
[2] Department of Health and Human Services, "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations" (2011) Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209.

Federal sources such as the Institute of Medicine,[3] Healthy People 2020,[4] the Substance Abuse and Mental Health Services Administration,[5] and the National Healthcare Disparities Report[6] indicate that LGBTQ individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[7] As a result, the LGBTQ population experiences significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental and behavioral health concerns, and HIV infection. Data collection is crucial to understanding and addressing these disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

In recognition of this need, the Williams Institute convened two groups of scientists, experts, and researchers to study gender- and sexual orientation-related measurement in survey instruments. The Gender Identity in U.S. Surveillance (GenIUSS) group and the Sexual Minority Assessment Research Team (SMART) have compiled an overview of current measures in use to collect accurate information about lesbian, gay, bisexual, and transgender respondents to federally supported surveys.[8] These comments are drawn in part from protocols discussed by SMART and the GenIUSS group.

Given the large sample size of the NSDUH, this is a critically important opportunity to collect meaningful data on LGBTQ people, and many of our recommendations reflect that priority. We appreciate the opportunity to comment on these proposed revisions to the NSDUH, and we make the following recommendations:

1. **Preliminary segregation of respondents by gender**
   A. **QD01 and QD01a:** Respondents should be asked to provide answers to these questions; interviewers should not be asked to make assumptions about sex or gender.
   B. **QD01 and QD01a:** These questions should be revised to capture information about sex assigned at birth.
2. **Accurately capturing information about gender identity and expression**
   A. Adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.
   B. Adopt the amended YRBS/GLSEN single-question protocol to allow for the collection of gender expression information on all respondents.
3. **Accurately capturing information about sexual orientation and attraction**
   A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.
   B. Adopt QD62 as proposed and track according to gender identity.
4. **Expanding youth-related questions to better understand youth mental health needs**

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[3] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx
[4] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25
[5] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBTQ Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBTQ-Populations/SMA12-4684
[6] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf
[7] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf
[8] For more information on these groups, please visit http://williamsinstitute.law.ucla.edu/wp-content/uploads/GenIUSS-Gender-related-Question-Overview.pdf for the GenIUSS group, and http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf for SMART.

A. Amend the Youth Experience section of the proposed survey instrument to include questions relating to bullying.
B. Amend the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.

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1. PRELIMINARY SEGREGATION OF RESPONDENTS BY GENDER:

In order to capture accurate physiological and sociological information about respondents, it is important to ask precise questions about sex and gender. To that end we recommend two revisions to the current initial collection of this information. First (A), respondents should be asked to provide an answer to QD01, rather than asking an interviewer to make assumptions about the respondent's sex or gender.

Second (B), gender identity, gender expression, and sex assigned at birth are distinct concepts, which do not always relate to physiological characteristics.[9] QD01 and QD02 should be rewritten to capture information about "sex assigned at birth" rather than gender. Complete information about gender identity, gender expression, and sex assigned at birth is particularly important to capture in a survey like NSDUH, where physiological and sociological questions are tracked separately based on a respondent's demographic characteristics. It is essential for the accuracy of information collected that the distinct concepts of sex assigned at birth and gender identity not be conflated.

A. Respondents should self-identify gender and sex assigned at birth.

Currently, interviewers administering the NSDUH are asked to record a respondent's gender and then verify that they have entered it correctly:

QD01 *The first few questions are for statistical purposes only, to help us analyze the results of the study.*

INTERVIEWER: RECORD RESPONDENT'S GENDER.

5 MALE
9 FEMALE

QD01a *INTERVIEWER: YOU HAVE ENTERED THAT THE RESPONDENT IS* ***[FILL QD01]****. IS THIS CORRECT?*

4 YES
6 NO

This formulation is problematic for several reasons. First, neither sex assigned at birth nor gender is a characteristic that can be reliably deduced solely through appearance or physical characteristics, and as a result, interviewer error may result in inaccurate data.[10] Because of the gender-segregated nature of this survey, accuracy in assessment of gender and sex is especially critical for all respondents. For example, if an interviewer incorrectly assesses a respondent's sex, it reduces the data integrity of questions relating to

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[9] *See, e.g.,* American Psychological Association, Task Force on Gender Identity and Gender Variance (2009). Report of the Task Force on Gender Identity and Gender Variance. Washington, DC: Author. Available online at www.apa.org/pi/lgbc/transgender/2008TaskForceReport.html

[10] The California LGBT Tobacco Use Survey, in recognition of this, instructs phone interviewers to explicitly ask about gender and to "not assume [they] know gender based on voice qualities." Bye L, Gruskin E, Greenwood, G, Albright V, Krotki K. California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey – 2004, page 112. Sacramento, CA: California Department of Health Services, 2005.

pregnancy, cervical and prostate cancer, and alcohol consumption, among many others. In addition, transgender and gender non-conforming individuals should have the opportunity to self-identify their sex assigned at birth to provide accurate data, and also to avoid potential misidentification. **We therefore recommend that all NSDUH respondents be asked for a response to question QD01, rather have gender or sex be assumed by the interviewer.**

B. QD01 and QD01a should be rewritten to capture information about sex assigned at birth rather than gender.

As written, QD01 and QD01a would result in inaccurate information being collected about transgender respondents. For example, a transgender man respondent who was assigned female at birth would likely indicate "male" as his gender. As a result of the separate survey tracks for gender in the NSDUH, the respondent would follow a male track in which he would not be given the opportunity to respond to relevant questions about pregnancy, cervical cancer, and other health-related questions generally associated with people assigned female at birth. However, if the question were revised to ask about sex assigned at birth rather than gender, a transgender man would most likely indicate "female." As a result, he would be tracked as "female" and would be presented with relevant physiological questions. While adopting this approach alone does not solve all discrepancies relating to gender-based tracking (see below), this revision of the current question relating to gender would at least result in more accurate collection of medical history information for all respondents. The primary tracking in this survey relates to medical history and physiological concerns, and sex assigned at birth is the best measure by which accurate responses to those questions can be captured. **Therefore, we recommend that "sex assigned at birth" replace the current initial question regarding gender.**

The Center of Excellence for Transgender Health at the University of California at San Francisco (UCSF) advocates for a two-question protocol to assess current gender identity and assigned sex at birth.[11] As applies to the NSDUH, QD01 and QD01a would be rewritten to follow the second part of the two-question protocol, as follows:

QD01: What sex were you assigned at birth, meaning on your original birth certificate?

- *Male*
- *Female*

QD01a: You have entered that your sex assigned at birth is [FILL QD01], is that correct?[12]

We recommend that SAMHSA collect data regarding sex assigned at birth rather than gender in QD01, and amend questions QD01 and QD01a accordingly. Physiological questions that are currently tracked based on responses to QD01 should continue to be tracked by this revised question.[13]

2. ACCURATELY CAPTURING INFORMATION ABOUT GENDER IDENTITY AND EXPRESSION

A. Gender identity should be collected as part of a two-step gender and sex protocol, and should be used to track sociological questions throughout the survey.

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[11] *Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services,* Center of Excellence for Transgender Health (2009). http://transhealth.ucsf.edu/pdf/data-recommendation.pdf.

[12] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[13] We also encourage SAMHSA to pursue research into whether the benefits of segregating studies based on gender outweigh the difficulties that arise in accurately tracking the physiological and sociological characteristics of all respondents in such surveys.

Independent of sex assigned at birth, collecting gender identity data will help ensure that accurate and complete information about all respondents is obtained. Currently, the NSDUH conflates sex and gender, and tracks both sociological and physiological questions based on a single characteristic. This model is inaccurate for transgender respondents, and it will therefore result in conflicting and flawed data. Where collecting sex assigned at birth will result in more accurate information with regard to medical history and other physiological questions, it is necessary to also collect gender identity information in order to accurately capture sociological information about transgender respondents.

In addition to questions about medical history, the proposed revisions to the NSDUH include sociological questions, such as questions about sexual orientation and sexual attraction, and numerous questions relating to gendered family relationship. Many of these questions are currently tracked in the proposed survey based on a respondent's presumed sex as determined in QD01. For transgender respondents, to track the answers to sociological questions based on sex assigned at birth (rather than gender identity) would result in inappropriate response options, inverse data collection, and misuse of pronouns and family relationship identifiers. For example, under the current proposed system, a transgender man would be identified as female in the introduction to questions about income, and "her" would be designated as the appropriate pronoun to describe his relationship with his family (e.g. "These next questions are about the kinds and amounts of income received by [transgender man] and her family.")

Questions relating to medical history and other physiological characteristics should be tracked according to sex assigned at birth in order to accurately and appropriately capture information about transgender respondents. Other questions, which relate to gendered social characteristics (such as sexual orientation and family interactions), should be tracked according to a respondent's gender identity. Trans men and other men should be tracked together, as should trans women and other women.[14]

Recommendation: if the NSDUH is segregated by gender and sex, then sex assigned at birth should be used to track physiological questions, and gender identity should be used to track sociological questions.

Collecting gender identity is the recommended first question of the two-step protocol for assessing current gender identity and assigned sex at birth that is discussed in the GenIUSS group's overview of gender-related survey measures. This question has already been federally adopted for use in national health surveys: in 2011, the U.S. Centers for Disease Control and Prevention (CDC) adopted this question protocol for use in its Adult Case Report Form as well as its electronic surveillance system, the Enhanced HIV/AIDS Reporting System (eHARS).[15]

Research suggests that more accurate and complete data will be collected through the adoption of a two-step protocol in which gender identity is asked first. According to the GenIUSS group,

> *Asking gender identity first emphasizes that this parameter tends to be much more important than assigned sex at birth for transgender people. A 2012 study by Tate, Ledbetter, and Youssef has shown that this technique provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single-item method (i.e., a single question asking respondents' gender with*

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[14] For example, ALCC30, HLTH02, HLTH26, AD26c2, YD26c2, CA10, CA11, and other similar questions should be tracked according to sex assigned a birth. Sociological questions, such as QD62, QD63, [R GENDER] (NSDUH Dress Rehearsal pages 707 and 710), DEFINE SAMPLE MEMBER (NSDUH Dress Rehearsal pages 727-731), INTROINC, and others, should be tracked according to gender identity.

[15] CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. 2011. *HIV Infection among Transgender People*. Washington, DC: Centers for Disease Control and Prevention, available at http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf.; see also, *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

choices of "male," "female," "transgender," or "other" only).[16] It also minimizes confusion among and misclassification of non-transgender people, who may be unfamiliar with the concept of gender identity.[17]

The two-step protocol is a best practice because simply adding a "transgender" to a demographic question as part of a single-question protocol may under-report transgender respondents; research has shown that 75% of transgender survey respondents, when given the option of self-identifying as transgender, male, or female, will not identify as transgender.[18] However, by identifying respondents whose sex assigned at birth is at variance with their gender identity in addition to individuals who self-identify as transgender, researchers will be better able to identify the entire population of transgender survey participants.

We recommend that gender identity be asked as follows. This question should precede the sex assigned at birth question:

What is your current gender identity?

- *Male*
- *Female*
- *Trans male/Trans man*
- *Trans female/Trans woman*[19]

Recommendation: adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.[20]

B. Adopt a single question protocol querying gender expression via appearance and mannerisms

In addition to gender identity and sex assigned at birth, how a person's gender expression is perceived can have important health implications. Gender nonconforming youth often face victimization in school, which can result in increased risk of suicidality, depression, and post-traumatic stress disorder, as well as poor academic achievement.[21] Gender nonconforming adults can face increased workplace harassment,

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[16] Tate, C.C., J.N. Ledbetter, and C.P. Youssef. 2012. A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences. *Journal of Sex Research*. 18:1–10.
[17] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.
[18] Schilt, Kristen and Jenifer Bratter. 2010. *From Multiracial to Multigender? Assessing Attitudes toward a Transgender Category on the Census*. Presented at the 2010 Annual Meeting of the American Sociological Association, Atlanta, GA.
[19] In addition to these four response choices, the question in the GenIUSS group's overview also includes "genderqueer" and "different identity: ____" as available responses. The NSDUH currently segregates certain physiological and sociological questions by gender. Because sociological questions would most appropriately be tracked by gender identity, and because there is no consistent structure for question responses that would accurately and reliably reflect a genderqueer or "different identity ____" response, we have removed them from the recommended question.
[20] As an alternative, if SAMHSA is not prepared to move forward with a gender identity question at this time, we strongly urge you to adopt a combined sexual orientation and gender identity question, adding "transgender" to the proposed QD63, and changing the question so that multiple options may be checked at once. This would at least allow SAMHSA to capture information about transgender respondents, and know for which respondents other questions are likely to be incorrectly coded.
[21] Roberts, A.L., M. Rosario, N. Slopen, J.P. Calzo, and S.B. Austin. 2013. Childhood Gender Nonconformity, Bullying Victimization, and Depressive Symptoms Across Adolescence and Early Adulthood: An 11-Year Longitudinal Study. *Journal of the American Academy of Child & Adolescent Psychiatry*. (forthcoming, accepted November 16, 2012); Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Childhood Gender Nonconformity: A Risk Indicator for Childhood Abuse and Posttraumatic Stress in Youth. *Pediatrics*. 129(3): 571-573; Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Elevated Risk of Posttraumatic Stress in Sexual Minority Youths: Mediation by Childhood Abuse and Gender Nonconformity. *American Journal of Public Health*. 102(8): 1587-1593. See also, *Gender-Related Measures Overview*, 5, The GenIUSS Group. The Williams Institute, February 2013, and *Including a Gender Expression Question on the YRBS Can Help Assess Disparities and Achieve Better Outcomes for Gender Nonconforming Students*, All Students Count Coalition,

discrimination and negative employment actions. Both one- and two-question protocols for surveying gender expression have been successfully tested. In 2010, Wylie et al. tested the following two-question protocol on young adults in New England, which queries both appearance and mannerisms:[22]

Gender Expression

1. A person's appearance, style, or dress may affect the way people think of them. On average, how do you think people would describe your appearance, style, or dress?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

3. *A person's mannerisms (such as the way they walk or talk) may affect the way people think of them. On average, how do you think people would describe your mannerisms?*
    - *Very feminine*
    - *Mostly feminine*
    - *Somewhat feminine*
    - *Equally feminine and masculine*
    - *Somewhat masculine*
    - *Mostly masculine*
    - *Very masculine*

In 2012, the Gay, Lesbian & Straight Education Network (GLSEN) merged this two-question protocol into one question querying both mannerisms and appearance to fit the requirements of the Youth Risk Behavior Survey (YRBS). GLSEN then conducted cognitive testing and pilot testing of this item with a sample of school-age adolescents. Cognitive testing indicated that the item was understandable to a diverse range of 14-18 year-old youth, including cisgender[23] youth (heterosexual, lesbian, gay, and bisexual) and transgender youth. The CDC subsequently approved this question as an optional question for state and local agencies to add to the 2013 YRBS:[24]

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people at school would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*

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available at http://amplifyyourvoice.org/wp-content/uploads/2012/10/ASC-Gender-Expression-FAQ3.pdf [hereinafter *All Students Count*].

[22] Wylie, S.A., H.C. Corliss, V. Boulanger, L.A. Prokop, and S.B. Austin. 2010. *Socially assigned gender nonconformity: a brief measure for use in surveillance and investigation of health disparities*. Sex Roles. 63(3-4): 264-276.

[23] Cisgender is a term that refers a person whose gender identity and sex assigned at birth are congruent.

[24] Greytak, EA (2012). Asking about gender: *A report on the development and testing of gender-related constructs for population-based surveys of adolescents.* New York, NY: GLSEN. See also, *All Students Count.*

- *Very masculine*

We recommend adopting the YRBS/GLSEN single-question protocol, but eliminating the words “at school” from the question to allow for the collection of gender expression information on all respondents. Our recommended question reads as follows:

> *A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people would describe you?*
> - *Very feminine*
> - *Mostly feminine*
> - *Somewhat feminine*
> - *Equally feminine and masculine*
> - *Somewhat masculine*
> - *Mostly masculine*
> - *Very masculine*

This question can be used in conjunction with either sex assigned at birth or gender identity in order to gauge gender nonconformity, although it is preferred to measure it against gender identity. When measured against sex assigned at birth, transgender respondents who are gender nonconforming would be coded erroneously as gender conforming. For example, a transgender man who is “somewhat feminine”, but who has indicated “female” as his sex assigned at birth would be coded as a “somewhat feminine female.” Although he is in reality gender nonconforming, he will not be coded as such. This issue would not arise if gender expression were matched against gender identity. As with other sociological questions in the NSDUH, it would be appropriate to track this question based on gender identity, and to reverse the order of response options accordingly.

3. ACCURATELY CAPTURING INFORMATION ABOUT SEXUAL ORIENTATION AND ATTRACTION

We welcome the addition of questions relating to sexual orientation and attraction to the NSDUH, and strongly encourage SAMHSA to adopt these proposed revisions, with slight amendment in order to ensure data accuracy and integrity.

A. Adopt proposed QD63 with “gay or lesbian” as a static response choice, and do not alter this question based on gender or sex assigned at birth.

Currently, QD63 is proposed to read as follows:

> ***QD63*** *Do you consider yourself to be*:
> *1 Heterosexual, that is straight;*
> *2 [IF QD01=9 THEN “Lesbian or] Gay*
> *3 Bisexual?*

Sexual orientation, along with several other sociological questions, is currently being tracked in reference to gender. It would actually be simpler to not track this question in reference to gender identity or sex at all, and to have “gay or lesbian” be consistently available as a static item. In doing so, every respondent who identifies as lesbian, gay, or bisexual would be able to accurately respond to the question, regardless of whatever decisions are made with regard to the gender tracking of the survey. Moreover, many women who are attracted to other women identify as gay, so even if the question were tracked by

gender identity, it would be appropriate to have a static response including both options. Additionally, SMART best practices for adoption of this question include "gay or lesbian" as a static response choice.[25]

Recommendation: Adopt the proposed question on sexual orientation, but do not alter the question based on the gender or sex of the respondent. "Both gay" and "lesbian" should both be visible for all respondents.[26]

B. Adopt QD62 as proposed and track according to gender identity.

Question QD62 currently reads as follows:

QD62 *People are different in their sexual attraction to other people. Which best describes your feelings? Are you:*
[IF QD01=5]
1 Only attracted to females?
2 Mostly attracted to females?
3 Equally attracted to females and males?
4 Mostly attracted to males?
5 Only attracted to males?
6 Not sure?
DK/REF

[IF QD01=9]
1 Only attracted to males?
2 Mostly attracted to males?
3 Equally attracted to males and females?
4 Mostly attracted to females?
5 Only attracted to females
6 Not sure?

Unlike QD63, this question should be tracked with other sociological questions according to gender identity. Because of gender tracking of the proposed question, a coded response of "1" from both genders surveyed indicates sole attraction to individuals of the same gender. Under a system where only one marker of gender (or, as amended, sex assigned at birth) is tracked, this could result in inverse data collection for transgender respondents. For example, a transgender woman who was being tracked as "male" per her sex at birth, would be presented with "Only attracted to males" as the option meant to represent sole attraction to the same gender. If she identifies as a lesbian, and solely experiences attraction to other women, she will select "5, solely attracted to females." This will then be coded, erroneously, as heterosexuality. Therefore, in order to accurately capture information about sexual attraction for all respondents, it is important to adopt a question asking about gender identity and then track QD63 based on gender identity.

Recommendation: adopt the proposed question on sexual attraction and track the order of the response options in reference to gender identity.

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[25] *Best Practices for Asking Questions about Sexual Orientation on Surveys*, the Sexual Minority Assessment Research Team (SMART), November 2009, 8. http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf.
[26] As noted in *supra* n. 20, a possible alternative means of collecting information about transgender respondents would add "transgender" to the question options, and respondents would be able to check multiple responses. This option is less ideal for this survey than a two-step approach for identifying transgender respondents because it will underreport transgender people who identify as simply "male" or "female." This alternative question would also continue to result in inaccurate data collection with regard to transgender people and sociological information.

4. More effectively addressing student health through assessing school climate

Effectively addressing the behavioral health impact of bullying that affects young people requires data that accurately reflects the safety of our nation's schools.[27] The NSDUH is an ideal survey instrument to collect data on student experiences with bullying and associated health outcomes. Currently, the Youth Experience section of the proposed survey instrument does not ask youth to report on experiences of bullying in school. **We recommend the addition of questions relating to bullying because of the important health outcomes associated with it.**

Data about safe schools is enormously important because it gives us a better picture of school climate issues as a whole, and allows us to implement more effective and efficient interventions. Research has shown that school climate is a nation-wide issue, and that marginalized populations face increased bullying and harassment in schools. In a 2011 GLSEN School Climate Survey, 81.9% of LGBT students reported being verbally harassed, 38.3% reported being physically harassed and 18.3% reported being physically assaulted at school because of their sexual orientation in 2011.[28] GLSEN also found in their national survey that LGBT students faced increased rates of depression, lower self-esteem, and lower school-connectedness.[29] According to the CDC, one in five high school students report that they were bullied on school property in 2009.[30] Technology has increased the means and ways for bullying to occur in our school system. In 2010, one in five adolescents said that they had been cyber-bullied at some point in their lives, and about the same number admits to having been a cyber-bully. One in ten adolescents had been both a cyber-bully and a victim.[31]

School safety can have a tremendous impact on a youth's ability to study and graduate. According to the Department of Health and Human Services bullying can lead to decreased academic achievement—GPA and standardized test scores—and school participation.[32] Students who are bullied are more likely to miss, skip, or drop out of school.[33] Information about bullying must be consistently tracked and studied in order to effectively reduce youth dropout rates and prevent negative health outcomes.

We recommend amending the Youth Experience section of the proposed survey instrument to include the following two questions, which were taken from the CDC's 2013 YRBS:

> *The next 2 questions ask about bullying. Bullying is when 1 or more students tease, threaten, spread rumors about, hit, shove, or hurt another student over and over again. It is not bullying when 2 students of about the same strength or power argue or fight or tease each other in a friendly way.*
>
> *During the past 12 months, have you ever been bullied on school property?*
> *A. Yes*
> *B. No*

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[27] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf (detailing high rates of bullying in American schools).
[28] GLSEN, The 2011 National School Climate Survey (2011), http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2106-1.pdf.
[29] Id.
[30] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.
[31] Hinduja, S. and Patchin, J.W., Overview on Cyberbullying (2011), http://www.stopbullying.gov/references/white_house_conference/white_house_conference_materials.pdf#overview_of_cyberbullying.
[32] U.S. Dep't of Health and Human Services, Effects of Bullying (Last Visited March 25, 2013), http://www.stopbullying.gov/at-risk/effects/index.html.
[33] Id.

During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites, or texting.)
A. Yes
B. No

Given the relative burden associated with participating in the survey, we believe there are a number of questions that could be replaced by a new safe schools question. There are several questions in the Youth Experience section that may be outdated and no longer collect useful data; we recommend that SAMHSA reevaluate the utility of these and other questions: YE10[34], YE11[35], YE13.[36] Each of these questions asks for student sentiment about school, but they may not sufficiently address the link between safety and student mental health and wellbeing.

5. COLLECTING INFORMATION ABOUT THE PRESENCE OF SUICIDE PREVENTION PROGRAMS IN ELEMENTARY AND SECONDARY SCHOOLS.

The statistics relating to youth suicidality are staggering, and clearly indicate a public health need to collect better information on suicide prevention efforts. Suicide is the 2nd leading cause of death among young people ages 10 to 24.[37] A nationwide survey by the CDC found that 16% of students reported seriously considering suicide, 13% reported creating a plan, and 8% reporting trying to take their own life in the previous 12 months.[38] Each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at Emergency Departments across the United States.[39] 1 out of 6 students' nationwide (grades 9-12) have seriously considered suicide in the past year.[40] These statistics are even more devastating within LGBTQ communities: research has shown that LGB youth are 4 times more likely to attempt suicide as their straight peers, and questioning youth are 3 times more likely.[41] Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.[42]

Reducing youth suicidality should be one of our highest public health priorities. In order to adequately assess the need for greater suicide prevention funding, research, and outreach for suicide prevention measures, such as the National Suicide Hotline and available Campus Suicide Prevention programs, we should collect information about what programs are successfully reaching youth. **We therefore recommend amending the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.**

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[34] "Which of the statements below best describes how you felt overall about going to school during the past 12 months? You liked going to school a lot; You kind of liked going to school; You didn't like going to school very much; You hated going to school." NSDUH Dress Rehearsal at 599.
[35] "During the past 12 months, how often did you feel that the school work you were assigned to do was meaningful and important? Always, Sometimes, Seldom, Never." NSDUH Dress Rehearsal at 599.
[36] "How interesting do you think most of your courses at school during the past 12 months have been? Very interesting, Somewhat interesting, Somewhat boring, Very boring." NSDUH Dress Rehearsal at 600.
[37] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Available from www.cdc.gov/ncipc/wisqars.
[38] CDC, Injury Center: Violence Prevention, (2012), http://www.cdc.gov/violenceprevention/pub/youth_suicide.html
[39] Id.
[40] CDC, Youth Risk Behavior Surveillance – United States, 2011, (2011), http://www.cdc.gov/mmwr/pdf/ss/ss6104.pdf
[41] Kann, L, et al. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12 – Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009." MMWR 60(SS07): 1-133. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm
[42] Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) SUICIDE LIFE THREAT BEHAV. 527 (2007).

This question should mirror YE23c,[43] YE23g,[44] and YE23o,[45] all of which ask about youth prevention programs for negative mental and physical health outcomes. Given the high rates of youth suicide, particularly among at-risk youth populations, amending the NSDUH to include a question about suicide prevention is a natural and necessary extension.

Conclusion

We commend SAMHSA for recognizing the importance of data collection to begin to eliminate the health disparities facing lesbian, gay, bisexual, and questioning individuals. We strongly encourage you to continue to revise the National Survey on Drug Use and Health to allow for targeted and evidence-based solutions to ending the disparities facing transgender people as well. We also urge you to amend the Youth Experience section of the proposed survey instrument to collect better information about suicide prevention programs and school bullying.

The Trevor Project appreciates the opportunity to provide suggestions for improving the National Survey on Drug Use and Health. If you should have any questions regarding these comments, please contact myself or Elliot Kennedy, Government Affairs Counsel, at 202-380-1181 or by email at Elliot.Kennedy@thetrevorproject.org.

Sincerely,

Abbe Land
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[43] **During the past 12 months** have you participated in a violence prevention program, where you learn ways to avoid fights and control anger?

[44] **During the past 12 months** have you participated in an alcohol, tobacco or drug prevention program outside of school, where you learn about the dangers of using, and how to resist using, alcohol, tobacco, or drugs?

[45] **During the past 12 months** have you participated in pregnancy or sexually transmitted disease prevention programs?

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Re: 2013 National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930-0334)

The National Center for Transgender Equality (NCTE) greatly appreciates the efforts of the Substance Abuse and Mental Health Services Agency (SAMSHA) to recognize the health disparities faced by LGBTQ communities by incorporating sexual orientation data collection into the proposed Dress Rehearsal for the National Survey on Drug Use and Health (NSDUH). We applaud the proposed amendments to this survey tool, and urge SAMHSA to adopt additional measures that would permit accurate collection of data on all LGBTQ identities. Additionally, recognizing the critical importance of school safety to youth mental health, we strongly encourage the adoption of youth experience questions asking about school safety and suicide prevention measures. We commend SAMHSA's ongoing support of LGBTQ communities, as evidenced by your leadership in addressing LGBTQ health disparities in your resource materials, and through your commitment to collecting data on transgender individuals through your programmatic forms.

NCTE is a national social justice organization, founded in 2003, that seeks to promote justice, opportunity and empowerment for transgender people through education and policy advocacy. NCTE has identified health equity and health data collection as major priorities within its mission. In 2008-2011, in response to the lack of national data on transgender populations, NCTE collaborated with the National Gay and Lesbian Task Force to conduct and report the National Transgender Discrimination Survey, the largest survey to date of transgender people.

Accurate data collection is critically important to identifying and ending the health disparities facing LGBTQ communities. This need is recognized in the Affordable Care Act, which prioritizes data collection and directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors deemed relevant to reducing disparities.[1] In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[2] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys. This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBTQ individuals are more likely to be uninsured and report poorer health outcomes than the general population.

[1] Affordable Care Act Section 1302.
[2] Department of Health and Human Services, "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations" (2011) Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209.

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Federal sources such as the Institute of Medicine,[3] Healthy People 2020,[4] the Substance Abuse and Mental Health Services Administration,[5] and the National Healthcare Disparities Report[6] indicate that LGBTQ individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[7] As a result, the LGBTQ population experiences significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental and behavioral health concerns, and HIV infection. Data collection is crucial to understanding and addressing these disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

In recognition of this need, the Williams Institute convened two groups of scientists, experts, and researchers to study gender- and sexual orientation-related measurement in survey instruments. The Gender Identity in U.S. Surveillance (GenIUSS) group and the Sexual Minority Assessment Research Team (SMART) have compiled an overview of current measures in use to collect accurate information about lesbian, gay, bisexual, and transgender respondents to federally supported surveys.[8] These comments are drawn in part from protocols discussed by SMART and the GenIUSS group.

Given the large sample size of the NSDUH, this is a critically important opportunity to collect meaningful data on LGBTQ people, and many of our recommendations reflect that priority. We appreciate the opportunity to comment on these proposed revisions to the NSDUH, and we make the following recommendations:

1. **Preliminary segregation of respondents by gender**
   A. **QD01 and QD01a:** Respondents should be asked to provide answers to these questions; interviewers should not be asked to make assumptions about sex or gender.
   B. **QD01 and QD01a:** These questions should be revised to capture information about sex assigned at birth.
2. **Accurately capturing information about gender identity and expression**
   A. Adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.
   B. Adopt the amended YRBS/GLSEN single-question protocol to allow for the collection of gender expression information on all respondents.
3. **Accurately capturing information about sexual orientation and attraction**

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[3] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

[4] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[5] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBTQ Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBTQ-Populations/SMA12-4684

[6] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[7] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

[8] For more information on these groups, please visit http://williamsinstitute.law.ucla.edu/wp-content/uploads/GenIUSS-Gender-related-Question-Overview.pdf for the GenIUSS group, and http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf for SMART.

A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.
B. Adopt QD62 as proposed and track according to gender identity.

4. Expanding youth-related questions to better understand youth mental health needs

A. Amend the Youth Experience section of the proposed survey instrument to include questions relating to bullying.
B. Amend the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.

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1. PRELIMINARY SEGREGATION OF RESPONDENTS BY GENDER:

In order to capture accurate physiological and sociological information about respondents, it is important to ask precise questions about sex and gender. To that end we recommend two revisions to the current initial collection of this information. First (A), respondents should be asked to provide an answer to QD01, rather than asking an interviewer to make assumptions about the respondent's sex or gender.

Second (B), gender identity, gender expression, and sex assigned at birth are distinct concepts, which do not always relate to physiological characteristics.[9] QD01 and QD02 should be rewritten to capture information about "sex assigned at birth" rather than gender. Complete information about gender identity, gender expression, and sex assigned at birth is particularly important to capture in a survey like NSDUH, where physiological and sociological questions are tracked separately based on a respondent's demographic characteristics. It is essential for the accuracy of information collected that the distinct concepts of sex assigned at birth and gender identity not be conflated.

A. Respondents should self-identify gender and sex assigned at birth.

Currently, interviewers administering the NSDUH are asked to record a respondent's gender and then verify that they have entered it correctly:

QD01 *The first few questions are for statistical purposes only, to help us analyze the results of the study.*

INTERVIEWER: RECORD RESPONDENT'S GENDER.

5 MALE
9 FEMALE

QD01a *INTERVIEWER: YOU HAVE ENTERED THAT THE RESPONDENT IS **[FILL QD01]**. IS THIS CORRECT?*

4 YES
6 NO

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[9] *See, e.g.,* American Psychological Association, Task Force on Gender Identity and Gender Variance (2009). Report of the Task Force on Gender Identity and Gender Variance. Washington, DC: Author. Available online at www.apa.org/pi/lgbc/transgender/2008TaskForceReport.html

This formulation is problematic for several reasons. First, neither sex assigned at birth nor gender is a characteristic that can be reliably deduced solely through appearance or physical characteristics, and as a result, interviewer error may result in inaccurate data.[10] Because of the gender-segregated nature of this survey, accuracy in assessment of gender and sex is especially critical for all respondents. For example, if an interviewer incorrectly assesses a respondent's sex, it reduces the data integrity of questions relating to pregnancy, cervical and prostate cancer, and alcohol consumption, among many others. In addition, transgender and gender non-conforming individuals should have the opportunity to self-identify their sex assigned at birth to provide accurate data, and also to avoid potential misidentification. **We therefore recommend that all NSDUH respondents be asked for a response to question QD01, rather have gender or sex be assumed by the interviewer.**

B. QD01 and QD01a should be rewritten to capture information about sex assigned at birth rather than gender.

As written, QD01 and QD01a would result in inaccurate information being collected about transgender respondents. For example, a transgender man respondent who was assigned female at birth would likely indicate "male" as his gender. As a result of the separate survey tracks for gender in the NSDUH, the respondent would follow a male track in which he would not be given the opportunity to respond to relevant questions about pregnancy, cervical cancer, and other health-related questions generally associated with people assigned female at birth. However, if the question were revised to ask about sex assigned at birth rather than gender, a transgender man would most likely indicate "female." As a result, he would be tracked as "female" and would be presented with relevant physiological questions. While adopting this approach alone does not solve all discrepancies relating to gender-based tracking (see below), this revision of the current question relating to gender would at least result in more accurate collection of medical history information for all respondents. The primary tracking in this survey relates to medical history and physiological concerns, and sex assigned at birth is the best measure by which accurate responses to those questions can be captured. **Therefore, we recommend that "sex assigned at birth" replace the current initial question regarding gender.**

The Center of Excellence for Transgender Health at the University of California at San Francisco (UCSF) advocates for a two-question protocol to assess current gender identity and assigned sex at birth.[11] As applies to the NSDUH, QD01 and QD01a would be rewritten to follow the second part of the two-question protocol, as follows:

QD01: What sex were you assigned at birth, meaning on your original birth certificate?

- *Male*
- *Female*

QD01a: You have entered that your sex assigned at birth is [FILL QD01], is that correct?[12]

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[10] The California LGBT Tobacco Use Survey, in recognition of this, instructs phone interviewers to explicitly ask about gender and to "not assume [they] know gender based on voice qualities." Bye L, Gruskin E, Greenwood, G, Albright V, Krotki K. California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey – 2004, page 112. Sacramento, CA: California Department of Health Services, 2005.

[11] *Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services,* Center of Excellence for Transgender Health (2009). http://transhealth.ucsf.edu/pdf/data-recommendation.pdf.

[12] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

We recommend that SAMHSA collect data regarding sex assigned at birth rather than gender in QD01, and amend questions QD01 and QD01a accordingly. Physiological questions that are currently tracked based on responses to QD01 should continue to be tracked by this revised question.[13]

2. ACCURATELY CAPTURING INFORMATION ABOUT GENDER IDENTITY AND EXPRESSION

A. Gender identity should be collected as part of a two-step gender and sex protocol, and should be used to track sociological questions throughout the survey.

Independent of sex assigned at birth, collecting gender identity data will help ensure that accurate and complete information about all respondents is obtained. Currently, the NSDUH conflates sex and gender, and tracks both sociological and physiological questions based on a single characteristic. This model is inaccurate for transgender respondents, and it will therefore result in conflicting and flawed data. Where collecting sex assigned at birth will result in more accurate information with regard to medical history and other physiological questions, it is necessary to also collect gender identity information in order to accurately capture sociological information about transgender respondents.

In addition to questions about medical history, the proposed revisions to the NSDUH include sociological questions, such as questions about sexual orientation and sexual attraction, and numerous questions relating to gendered family relationship. Many of these questions are currently tracked in the proposed survey based on a respondent's presumed sex as determined in QD01. For transgender respondents, to track the answers to sociological questions based on sex assigned at birth (rather than gender identity) would result in inappropriate response options, inverse data collection, and misuse of pronouns and family relationship identifiers. For example, under the current proposed system, a transgender man would be identified as female in the introduction to questions about income, and "her" would be designated as the appropriate pronoun to describe his relationship with his family (e.g. "These next questions are about the kinds and amounts of income received by [transgender man] and her family.")

Questions relating to medical history and other physiological characteristics should be tracked according to sex assigned at birth in order to accurately and appropriately capture information about transgender respondents. Other questions, which relate to gendered social characteristics (such as sexual orientation and family interactions), should be tracked according to a respondent's gender identity. Trans men and other men should be tracked together, as should trans women and other women.[14]

Recommendation: if the NSDUH is segregated by gender and sex, then sex assigned at birth should be used to track physiological questions, and gender identity should be used to track sociological questions.

Collecting gender identity is the recommended first question of the two-step protocol for assessing current gender identity and assigned sex at birth that is discussed in the GenIUSS group's overview of gender-related survey measures. This question has already been federally

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[13] We also encourage SAMHSA to pursue research into whether the benefits of segregating studies based on gender outweigh the difficulties that arise in accurately tracking the physiological and sociological characteristics of all respondents in such surveys.

[14] For example, ALCC30, HLTH02, HLTH26, AD26c2, YD26c2, CA10, CA11, and other similar questions should be tracked according to sex assigned a birth. Sociological questions, such as QD62, QD63, [R GENDER] (NSDUH Dress Rehearsal pages 707 and 710), DEFINE SAMPLE MEMBER (NSDUH Dress Rehearsal pages 727-731), INTROINC, and others, should be tracked according to gender identity.

adopted for use in national health surveys: in 2011, the U.S. Centers for Disease Control and Prevention (CDC) adopted this question protocol for use in its Adult Case Report Form as well as its electronic surveillance system, the Enhanced HIV/AIDS Reporting System (eHARS).[15]

Research suggests that more accurate and complete data will be collected through the adoption of a two-step protocol in which gender identity is asked first. According to the GenIUSS group,

> *Asking gender identity first emphasizes that this parameter tends to be much more important than assigned sex at birth for transgender people. A 2012 study by Tate, Ledbetter, and Youssef has shown that this technique provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single-item method (i.e., a single question asking respondents' gender with choices of "male," "female," "transgender," or "other" only).[16] It also minimizes confusion among and misclassification of non-transgender people, who may be unfamiliar with the concept of gender identity.[17]*

The two-step protocol is a best practice because simply adding a "transgender" to a demographic question as part of a single-question protocol may under-report transgender respondents; research has shown that 75% of transgender survey respondents, when given the option of self-identifying as transgender, male, or female, will not identify as transgender.[18] However, by identifying respondents whose sex assigned at birth is at variance with their gender identity in addition to individuals who self-identify as transgender, researchers will be better able to identify the entire population of transgender survey participants.

We recommend that gender identity be asked as follows. This question should precede the sex assigned at birth question:

What is your current gender identity?

- *Male*
- *Female*
- *Trans male/Trans man*
- *Trans female/Trans woman*[19]

Recommendation: adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.[20]

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[15] CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. 2011. *HIV Infection among Transgender People*. Washington, DC: Centers for Disease Control and Prevention, available at http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf.; see also, *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[16] Tate, C.C., J.N. Ledbetter, and C.P. Youssef. 2012. A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences. *Journal of Sex Research*. 18:1–10.

[17] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[18] Schilt, Kristen and Jenifer Bratter. 2010. *From Multiracial to Multigender? Assessing Attitudes toward a Transgender Category on the Census*. Presented at the 2010 Annual Meeting of the American Sociological Association, Atlanta, GA.

[19] In addition to these four response choices, the question in the GenIUSS group's overview also includes "genderqueer" and "different identity: ____" as available responses. The NSDUH currently segregates certain physiological and sociological questions by gender. Because sociological questions would most appropriately be tracked by gender identity, and because there is no consistent structure for question responses that would accurately and reliably reflect a genderqueer or "different identity ____" response, we have removed them from the recommended question.

[20] As an alternative, if SAMHSA is not prepared to move forward with a gender identity question at this time, we strongly urge you to adopt a combined sexual orientation and gender identity question, adding "transgender" to the proposed QD63, and

B. Adopt a single question protocol querying gender expression via appearance and mannerisms

In addition to gender identity and sex assigned at birth, how a person's gender expression is perceived can have important health implications. Gender nonconforming youth often face victimization in school, which can result in increased risk of suicidality, depression, and post-traumatic stress disorder, as well as poor academic achievement.[21] Gender nonconforming adults can face increased workplace harassment, discrimination and negative employment actions. Both one- and two-question protocols for surveying gender expression have been successfully tested. In 2010, Wylie et al. tested the following two-question protocol on young adults in New England, which queries both appearance and mannerisms:[22]

Gender Expression

1. A person's appearance, style, or dress may affect the way people think of them. On average, how do you think people would describe your appearance, style, or dress?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

3. A person's mannerisms (such as the way they walk or talk) may affect the way people think of them. On average, how do you think people would describe your mannerisms?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

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changing the question so that multiple options may be checked at once. This would at least allow SAMHSA to capture information about transgender respondents, and know for which respondents other questions are likely to be incorrectly coded.

[21] Roberts, A.L., M. Rosario, N. Slopen, J.P. Calzo, and S.B. Austin. 2013. Childhood Gender Nonconformity, Bullying Victimization, and Depressive Symptoms Across Adolescence and Early Adulthood: An 11-Year Longitudinal Study. *Journal of the American Academy of Child & Adolescent Psychiatry*. (forthcoming, accepted November 16, 2012); Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Childhood Gender Nonconformity: A Risk Indicator for Childhood Abuse and Posttraumatic Stress in Youth. *Pediatrics*. 129(3): 571-573; Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Elevated Risk of Posttraumatic Stress in Sexual Minority Youths: Mediation by Childhood Abuse and Gender Nonconformity. *American Journal of Public Health*. 102(8): 1587-1593. See also, *Gender-Related Measures Overview*, 5, The GenIUSS Group. The Williams Institute, February 2013, and *Including a Gender Expression Question on the YRBS Can Help Assess Disparities and Achieve Better Outcomes for Gender Nonconforming Students*, All Students Count Coalition, available at http://amplifyyourvoice.org/wp-content/uploads/2012/10/ASC-Gender-Expression-FAQ3.pdf [hereinafter *All Students Count*].

[22] Wylie, S.A., H.C. Corliss, V. Boulanger, L.A. Prokop, and S.B. Austin. 2010. *Socially assigned gender nonconformity: a brief measure for use in surveillance and investigation of health disparities*. Sex Roles. 63(3-4): 264-276.

In 2012, the Gay, Lesbian & Straight Education Network (GLSEN) merged this two-question protocol into one question querying both mannerisms and appearance to fit the requirements of the Youth Risk Behavior Survey (YRBS). GLSEN then conducted cognitive testing and pilot testing of this item with a sample of school-age adolescents. Cognitive testing indicated that the item was understandable to a diverse range of 14-18 year-old youth, including cisgender[23] youth (heterosexual, lesbian, gay, and bisexual) and transgender youth. The CDC subsequently approved this question as an optional question for state and local agencies to add to the 2013 YRBS:[24]

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people at school would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

We recommend adopting the YRBS/GLSEN single-question protocol, but eliminating the words "at school" from the question to allow for the collection of gender expression information on all respondents. Our recommended question reads as follows:

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

This question can be used in conjunction with either sex assigned at birth or gender identity in order to gauge gender nonconformity, although it is preferred to measure it against gender identity. When measured against sex assigned at birth, transgender respondents who are gender nonconforming would be coded erroneously as gender conforming. For example, a transgender man who is "somewhat feminine", but who has indicated "female" as his sex assigned at birth would be coded as a "somewhat feminine female." Although he is in reality gender nonconforming, he will not be coded as such. This issue would not arise if gender expression were matched against gender identity. As with other sociological questions in the NSDUH, it would be appropriate to track this question based on gender identity, and to reverse the order of response options accordingly.

[23] Cisgender is a term that refers a person whose gender identity and sex assigned at birth are congruent.
[24] Greytak, EA (2012). Asking about gender: *A report on the development and testing of gender-related constructs for population-based surveys of adolescents.* New York, NY: GLSEN. See also, *All Students Count.*

3. ACCURATELY CAPTURING INFORMATION ABOUT SEXUAL ORIENTATION AND ATTRACTION

We welcome the addition of questions relating to sexual orientation and attraction to the NSDUH, and strongly encourage SAMHSA to adopt these proposed revisions, with slight amendment in order to ensure data accuracy and integrity.

A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.

Currently, QD63 is proposed to read as follows:

QD63 *Do you consider yourself to be*:
1 Heterosexual, that is straight;
2 [IF QD01=9 THEN "Lesbian or] Gay
3 Bisexual?

Sexual orientation, along with several other sociological questions, is currently being tracked in reference to gender. It would actually be simpler to not track this question in reference to gender identity or sex at all, and to have "gay or lesbian" be consistently available as a static item. In doing so, every respondent who identifies as lesbian, gay, or bisexual would be able to accurately respond to the question, regardless of whatever decisions are made with regard to the gender tracking of the survey. Moreover, many women who are attracted to other women identify as gay, so even if the question were tracked by gender identity, it would be appropriate to have a static response including both options. Additionally, SMART best practices for adoption of this question include "gay or lesbian" as a static response choice.[25]

Recommendation: Adopt the proposed question on sexual orientation, but do not alter the question based on the gender or sex of the respondent. "Both gay" and "lesbian" should both be visible for all respondents.[26]

B. Adopt QD62 as proposed and track according to gender identity.

Question QD62 currently reads as follows:

QD62 *People are different in their sexual attraction to other people. Which best describes your feelings? Are you:*
[IF QD01=5]
1 Only attracted to females?
2 Mostly attracted to females?
3 Equally attracted to females and males?
4 Mostly attracted to males?
5 Only attracted to males?
6 Not sure?

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[25] *Best Practices for Asking Questions about Sexual Orientation on Surveys*, the Sexual Minority Assessment Research Team (SMART), November 2009, 8. http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf.

[26] As noted in *supra* n. 20, a possible alternative means of collecting information about transgender respondents would add "transgender" to the question options, and respondents would be able to check multiple responses. This option is less ideal for this survey than a two-step approach for identifying transgender respondents because it will underreport transgender people who identify as simply "male" or "female." This alternative question would also continue to result in inaccurate data collection with regard to transgender people and sociological information.

DK/REF

[IF QD01=9]
1 *Only attracted to males?*
2 *Mostly attracted to males?*
3 *Equally attracted to males and females?*
4 *Mostly attracted to females?*
5 *Only attracted to females*
6 *Not sure?*

Unlike QD63, this question should be tracked with other sociological questions according to gender identity. Because of gender tracking of the proposed question, a coded response of "1" from both genders surveyed indicates sole attraction to individuals of the same gender. Under a system where only one marker of gender (or, as amended, sex assigned at birth) is tracked, this could result in inverse data collection for transgender respondents. For example, a transgender woman who was being tracked as "male" per her sex at birth, would be presented with "Only attracted to males" as the option meant to represent sole attraction to the same gender. If she identifies as a lesbian, and solely experiences attraction to other women, she will select "5, solely attracted to females." This will then be coded, erroneously, as heterosexuality. Therefore, in order to accurately capture information about sexual attraction for all respondents, it is important to adopt a question asking about gender identity and then track QD63 based on gender identity.

Recommendation: adopt the proposed question on sexual attraction and track the order of the response options in reference to gender identity.

4. MORE EFFECTIVELY ADDRESSING STUDENT HEALTH THROUGH ASSESSING SCHOOL CLIMATE

Effectively addressing the behavioral health impact of bullying that affects young people requires data that accurately reflects the safety of our nation's schools.[27] The NSDUH is an ideal survey instrument to collect data on student experiences with bullying and associated health outcomes. Currently, the Youth Experience section of the proposed survey instrument does not ask youth to report on experiences of bullying in school. **We recommend the addition of questions relating to bullying because of the important health outcomes associated with it.**

Data about safe schools is enormously important because it gives us a better picture of school climate issues as a whole, and allows us to implement more effective and efficient interventions. Research has shown that school climate is a nation-wide issue, and that marginalized populations face increased bullying and harassment in schools. In a 2011 GLSEN School Climate Survey, 81.9% of LGBT students reported being verbally harassed, 38.3% reported being physically harassed and 18.3% reported being physically assaulted at school because of their sexual orientation in 2011.[28] GLSEN also found in their national survey that LGBT students faced increased rates of depression, lower self-esteem, and lower school-connectedness.[29] According to the CDC, one in five high school students report that they were bullied on school property in

[27] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf (detailing high rates of bullying in American schools).
[28] GLSEN, The 2011 National School Climate Survey (2011), http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2106-1.pdf.
[29] Id.

2009.[30] Technology has increased the means and ways for bullying to occur in our school system. In 2010, one in five adolescents said that they had been cyber-bullied at some point in their lives, and about the same number admits to having been a cyber-bully. One in ten adolescents had been both a cyber-bully and a victim.[31]

School safety can have a tremendous impact on a youth's ability to study and graduate. According to the Department of Health and Human Services bullying can lead to decreased academic achievement—GPA and standardized test scores—and school participation.[32] Students who are bullied are more likely to miss, skip, or drop out of school.[33] Information about bullying must be consistently tracked and studied in order to effectively reduce youth dropout rates and prevent negative health outcomes.

We recommend amending the Youth Experience section of the proposed survey instrument to include the following two questions, which were taken from the CDC's 2013 YRBS:

> *The next 2 questions ask about bullying. Bullying is when 1 or more students tease, threaten, spread rumors about, hit, shove, or hurt another student over and over again. It is not bullying when 2 students of about the same strength or power argue or fight or tease each other in a friendly way.*
>
> *During the past 12 months, have you ever been bullied on school property?*
> *A. Yes*
> *B. No*
>
> *During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites, or texting.)*
> *A. Yes*
> *B. No*

Given the relative burden associated with participating in the survey, we believe there are a number of questions that could be replaced by a new safe schools question. There are several questions in the Youth Experience section that may be outdated and no longer collect useful data; we recommend that SAMHSA reevaluate the utility of these and other questions: YE10[34], YE11[35], YE13.[36] Each of these questions asks for student sentiment about school, but they may not sufficiently address the link between safety and student mental health and wellbeing.

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[30] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.
[31] Hinduja, S. and Patchin, J.W., Overview on Cyberbullying (2011), http://www.stopbullying.gov/references/white_house_conference/white_house_conference_materials.pdf#overview_of_cyberbullying.
[32] U.S. Dep't of Health and Human Services, Effects of Bullying (Last Visited March 25, 2013), http://www.stopbullying.gov/at-risk/effects/index.html.
[33] Id.
[34] "Which of the statements below best describes how you felt overall about going to school during the past 12 months? You liked going to school a lot; You kind of liked going to school; You didn't like going to school very much; You hated going to school." NSDUH Dress Rehearsal at 599.
[35] "During the past 12 months, how often did you feel that the school work you were assigned to do was meaningful and important? Always, Sometimes, Seldom, Never." NSDUH Dress Rehearsal at 599.
[36] "How interesting do you think most of your courses at school during the past 12 months have been? Very interesting, Somewhat interesting, Somewhat boring, Very boring." NSDUH Dress Rehearsal at 600.

5. Collecting information about the presence of suicide prevention programs in elementary and secondary schools.

The statistics relating to youth suicidality are staggering, and clearly indicate a public health need to collect better information on suicide prevention efforts. Suicide is the 2nd leading cause of death among young people ages 10 to 24.[37] A nationwide survey by the CDC found that 16% of students reported seriously considering suicide, 13% reported creating a plan, and 8% reporting trying to take their own life in the previous 12 months.[38] Each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at Emergency Departments across the United States.[39] 1 out of 6 students' nationwide (grades 9-12) have seriously considered suicide in the past year.[40] These statistics are even more devastating within LGBTQ communities: research has shown that LGB youth are 4 times more likely to attempt suicide as their straight peers, and questioning youth are 3 times more likely.[41] Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.[42]

Reducing youth suicidality should be one of our highest public health priorities. In order to adequately assess the need for greater suicide prevention funding, research, and outreach for suicide prevention measures, such as the National Suicide Hotline and available Campus Suicide Prevention programs, we should collect information about what programs are successfully reaching youth. **We therefore recommend amending the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.**

This question should mirror YE23c,[43] YE23g,[44] and YE23o,[45] all of which ask about youth prevention programs for negative mental and physical health outcomes. Given the high rates of youth suicide, particularly among at-risk youth populations, amending the NSDUH to include a question about suicide prevention is a natural and necessary extension.

Conclusion

NCTE commends SAMHSA for recognizing the importance of data collection to begin to eliminate the health disparities facing lesbian, gay, bisexual, and questioning individuals. We strongly encourage you to continue to revise the National Survey on Drug Use and Health to allow for targeted and evidence-based solutions to ending the disparities facing transgender people as well. We also urge you to amend the Youth Experience section of the proposed survey instrument to collect better information about suicide prevention programs and school bullying.

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[37] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Available from www.cdc.gov/ncipc/wisqars.

[38] CDC, Injury Center: Violence Prevention, (2012), http://www.cdc.gov/violenceprevention/pub/youth_suicide.html

[39] Id.

[40] CDC, Youth Risk Behavior Surveillance – United States, 2011, (2011), http://www.cdc.gov/mmwr/pdf/ss/ss6104.pdf

[41] Kann, L, et al. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12 – Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009." MMWR 60(SS07): 1-133. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm

[42] Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) SUICIDE LIFE THREAT BEHAV. 527 (2007).

[43] **During the past 12 months** have you participated in a violence prevention program, where you learn ways to avoid fights and control anger?

[44] **During the past 12 months** have you participated in an alcohol, tobacco or drug prevention program outside of school, where you learn about the dangers of using, and how to resist using, alcohol, tobacco, or drugs?

[45] **During the past 12 months** have you participated in pregnancy or sexually transmitted disease prevention programs?

To submit:
Email comments to Summer King (SAMHSA Reports Clearing Officer) at *summer.king@samhsa.hhs.gov* by **April 30, 2013.**

Summer King, SAMHSA Reports Clearance Officer
Room 2-1057
One Choke Cherry Road
Rockville, MD 20857

Re: 2013 National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930-0334)

The American Foundation for Suicide Prevention (AFSP) greatly appreciates the opportunity to comment on the proposed Dress Rehearsal for the National Survey on Drug Use and Health (NSDUH). We applaud the proposed amendments to this survey tool, and urge the Substance Abuse and Mental Health Services Agency (SAMHSA) to adopt additional measures that would permit accurate collection of data on all lesbian, gay, bisexual, transgender, and questioning (LGBTQ) identities. Additionally, recognizing the critical importance of school safety to youth mental health, we strongly encourage the adoption of youth experience questions asking about school safety and suicide prevention measures.

AFSP is the nation's leading organization bringing together people across communities and backgrounds to understand and prevent suicide, and to help heal the pain it causes. Individuals, families, and communities who have been personally touched by suicide are the moving force behind everything we do.

- We strive for a world that is free of suicide.
- We support research, because understanding the causes of suicide is vital to saving lives.
- We educate others in order to foster understanding and inspire action.
- We offer a caring community to those who have lost someone they love to suicide, or who are struggling with thoughts of suicide themselves.
- We advocate to ensure that federal, state, and local governments do all they can to prevent suicide, and to support and care for those at risk.

Accurate data collection is critically important to identifying and ending the health disparities facing LGBTQ communities. This need is recognized in the Affordable Care Act, which prioritizes data collection and directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors deemed relevant to reducing disparities.[1] In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[2] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys. This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBTQ individuals are more likely to be uninsured and report poorer health outcomes than the general population.

Federal sources such as the Institute of Medicine,[3] Healthy People 2020,[4] the Substance Abuse and Mental Health Services Administration,[5] and the National Healthcare Disparities Report[6] indicate that

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[1] Affordable Care Act Section 1302.
[2] Department of Health and Human Services, "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations" (2011) Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209.
[3] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

LGBTQ individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[7] As a result, the LGBTQ population experiences significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental and behavioral health concerns, and HIV infection. Data collection is crucial to understanding and addressing these disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

Given the large sample size of the NSDUH, this is a critically important opportunity to collect meaningful data on LGBTQ people, and many of our recommendations reflect that priority. We appreciate the opportunity to comment on these proposed revisions to the NSDUH, and we make the following recommendations:

1. AMEND THE SURVEY INSTRUMENT TO MORE ACCURATELY CAPTURE DATA ABOUT LGBTQ INDIVIDUALS

In order to capture accurate physiological and sociological information about respondents, it is important to ask precise questions about sex and gender. To that end we recommend several revisions to the current initial collection of this information:

i. **Respondents should be asked to provide an answer to QD01, rather than asking an interviewer to make assumptions about the respondent's sex or gender.**

ii. Gender identity, gender expression, and sex assigned at birth are distinct concepts, which do not always relate to physiological characteristics.[8] **QD01 and QD02 should be rewritten to capture information about "sex assigned at birth" rather than gender**. Complete information about gender identity, gender expression, and sex assigned at birth is particularly important to capture in a survey like NSDUH, where physiological and sociological questions are tracked separately based on a respondent's demographic characteristics. It is essential for the accuracy of information collected that the distinct concepts of sex assigned at birth and gender identity not be conflated.

iii. **Gender identity should be collected as part of a two-step gender identity and sex assigned at birth protocol, and should be used to track sociological questions throughout the survey.**[9] Currently, the NSDUH conflates sex and gender, and tracks both sociological and physiological questions based on a single characteristic. This model is inaccurate for transgender respondents, and it will therefore result in conflicting and flawed data. Where collecting sex assigned at birth will result in more accurate information with

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[4] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[5] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBTQ Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBTQ-Populations/SMA12-4684

[6] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[7] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

[8] *See, e.g.,* American Psychological Association, Task Force on Gender Identity and Gender Variance (2009). Report of the Task Force on Gender Identity and Gender Variance. Washington, DC: Author. Available online at www.apa.org/pi/lgbc/transgender/2008TaskForceReport.html

[9] *See Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services,* Center of Excellence for Transgender Health (2009). Available online at http://transhealth.ucsf.edu/pdf/data-recommendation.pdf

regard to medical history and other physiological questions, it is necessary to also collect gender identity information in order to accurately capture sociological information about transgender respondents.

iv. In addition to gender identity and sex assigned at birth, how a person's gender expression is perceived can have important health implications. Gender nonconforming youth often face victimization in school, which can result in increased risk of suicidality, depression, and post-traumatic stress disorder, as well as poor academic achievement.[10] Gender nonconforming adults can face increased workplace harassment, discrimination and negative employment actions. **We recommend adopting a single question protocol querying gender expression via appearance and mannerisms.[11]**

v. We welcome the addition of questions relating to sexual orientation and attraction to the NSDUH, and strongly encourage SAMHSA to adopt these proposed revisions, with slight amendment in order to ensure data accuracy and integrity. **We recommend adopting proposed QD63 with "gay or lesbian" as a static response choice, and not altering this question based on gender or sex assigned at birth.**[12] **We also recommend adopting QD62, querying sexual attraction, as proposed and tracking it according to gender identity.** Unlike QD63, this question should be tracked with other sociological questions according to gender identity.

2. MORE EFFECTIVELY ADDRESSING STUDENT HEALTH THROUGH ASSESSING SCHOOL CLIMATE

Effectively addressing the behavioral health impact of bullying that affects young people requires data that accurately reflects the safety of our nation's schools.[13] The NSDUH is an ideal survey instrument to collect data on student experiences with bullying and associated health outcomes. Currently, the Youth Experience section of the proposed survey instrument does not ask youth to report on experiences of bullying in school. **We recommend the addition of questions relating to bullying because of the important health outcomes associated with it.**

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[10] Roberts, A.L., M. Rosario, N. Slopen, J.P. Calzo, and S.B. Austin. 2013. Childhood Gender Nonconformity, Bullying Victimization, and Depressive Symptoms Across Adolescence and Early Adulthood: An 11-Year Longitudinal Study. *Journal of the American Academy of Child & Adolescent Psychiatry*. (forthcoming, accepted November 16, 2012); Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Childhood Gender Nonconformity: A Risk Indicator for Childhood Abuse and Posttraumatic Stress in Youth. *Pediatrics*. 129(3): 571-573; Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Elevated Risk of Posttraumatic Stress in Sexual Minority Youths: Mediation by Childhood Abuse and Gender Nonconformity. *American Journal of Public Health*. 102(8): 1587-1593. See also, *Gender-Related Measures Overview*, 5, The GenIUSS Group. The Williams Institute, February 2013, and *Including a Gender Expression Question on the YRBS Can Help Assess Disparities and Achieve Better Outcomes for Gender Nonconforming Students*, All Students Count Coalition, available at http://amplifyyourvoice.org/wp-content/uploads/2012/10/ASC-Gender-Expression-FAQ3.pdf [hereinafter *All Students Count*].

[11] Greytak, EA (2012). Asking about gender: *A report on the development and testing of gender-related constructs for population-based surveys of adolescents.* New York, NY: GLSEN. See also, *All Students Count.* See also, Centers for Disease Control and Prevention, *Youth Risk Behavior Surveillance Survey - United States, 2009* (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.

[12] This recommendation is consistent with a question recommended by the Sexual Minority Assessment Research Team (SMART), which was convened by the Williams Institute convened to study sexual orientation-related measurement in survey instruments For more information on SMART please visit http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf.

[13] Centers for Disease Control and Prevention, *Youth Risk Behavior Surveillance Survey - United States, 2009* (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf (detailing high rates of bullying in American schools).

shown that school climate is a nation-wide issue, and that marginalized populations face increased bullying and harassment in schools. In a 2011 GLSEN School Climate Survey, 81.9% of LGBT students reported being verbally harassed, 38.3% reported being physically harassed and 18.3% reported being physically assaulted at school because of their sexual orientation in 2011.[14] GLSEN also found in their national survey that LGBT students faced increased rates of depression, lower self-esteem, and lower school-connectedness.[15] According to the CDC, one in five high school students report that they were bullied on school property in 2009.[16] Technology has increased the means and ways for bullying to occur in our school system. In 2010, one in five adolescents said that they had been cyber-bullied at some point in their lives, and about the same number admits to having been a cyber-bully. One in ten adolescents had been both a cyber-bully and a victim.[17]

School safety can have a tremendous impact on a youth's ability to study and graduate. According to the Department of Health and Human Services bullying can lead to decreased academic achievement—GPA and standardized test scores—and school participation.[18] Students who are bullied are more likely to miss, skip, or drop out of school.[19] Information about bullying must be consistently tracked and studied in order to effectively reduce youth dropout rates and prevent negative health outcomes.

We recommend amending the Youth Experience section of the proposed survey instrument to include the following two questions, which were taken from the CDC's 2013 YRBS:

> *The next 2 questions ask about bullying. Bullying is when 1 or more students tease, threaten, spread rumors about, hit, shove, or hurt another student over and over again. It is not bullying when 2 students of about the same strength or power argue or fight or tease each other in a friendly way.*
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> *B. No*

3. COLLECTING INFORMATION ABOUT THE PRESENCE OF SUICIDE PREVENTION PROGRAMS IN ELEMENTARY AND SECONDARY SCHOOLS.

The statistics relating to youth suicidality are staggering, and clearly indicate a public health need to collect better information on suicide prevention efforts. Suicide is the 2nd leading cause of death among

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[14] GLSEN, *The 2011 National School Climate Survey* (2011), http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2106-1.pdf.
[15] Id.
[16] Centers for Disease Control and Prevention, *Youth Risk Behavior Surveillance Survey - United States, 2009* (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.
[17] Hinduja, S. and Patchin, J.W., Overview on Cyberbullying (2011), http://www.stopbullying.gov/references/white_house_conference/white_house_conference_materials.pdf#overview_of_cyberbullying.
[18] U.S. Dep't of Health and Human Services, Effects of Bullying (Last Visited March 25, 2013), http://www.stopbullying.gov/at-risk/effects/index.html.
[19] Id.

young people ages 10 to 24.[20] A nationwide survey by the CDC found that 16% of students reported seriously considering suicide, 13% reported creating a plan, and 8% reporting trying to take their own life in the previous 12 months.[21] Each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at Emergency Departments across the United States.[22] 1 out of 6 students' nationwide (grades 9-12) have seriously considered suicide in the past year.[23] This is especially a problem within the LGBTQ community: research has shown that LGB youth are 4 times more likely to attempt suicide as their straight peers, and questioning youth are 3 times more likely.[24] Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.[25]

Reducing youth suicidality is an important public health priority. In order to adequately assess the need for greater suicide prevention funding, research, and outreach for suicide prevention measures, such as the National Suicide Hotline and available Campus Suicide Prevention programs, we should collect information about what programs are successfully reaching youth. **We therefore recommend amending the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.**

This question should mirror YE23c,[26] YE23g,[27] and YE23o,[28] all of which ask about youth prevention programs for negative mental and physical health outcomes. Given the high rates of youth suicide, particularly among at-risk youth populations, amending the NSDUH to include a question about suicide prevention is a natural and necessary extension.

Conclusion

We commend SAMHSA for recognizing the importance of data collection to begin to eliminate the health disparities facing lesbian, gay, bisexual, and questioning individuals. We strongly encourage you to continue to revise the National Survey on Drug Use and Health to allow for targeted and evidence-based solutions to ending the disparities facing transgender people as well. We also urge you to amend the Youth Experience section of the proposed survey instrument to collect better information about suicide prevention programs and school bullying.

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[20] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Available from www.cdc.gov/ncipc/wisqars.
[21] CDC, *Injury Center: Violence Prevention*, (2012), http://www.cdc.gov/violenceprevention/pub/youth_suicide.html
[22] Id.
[23] CDC, *Youth Risk Behavior Surveillance – United States, 2011*, (2011), http://www.cdc.gov/mmwr/pdf/ss/ss6104.pdf
[24] Kann, L, et al. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12 – Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009." MMWR 60(SS07): 1-133. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm
[25] Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) SUICIDE LIFE THREAT BEHAV. 527 (2007).
[26] **During the past 12 months** have you participated in a violence prevention program, where you learn ways to avoid fights and control anger?
[27] **During the past 12 months** have you participated in an alcohol, tobacco or drug prevention program outside of school, where you learn about the dangers of using, and how to resist using, alcohol, tobacco, or drugs?
[28] **During the past 12 months** have you participated in pregnancy or sexually transmitted disease prevention programs?

Summer King, SAMHSA Reports Clearance Officer
Room 2-1057
One Choke Cherry Road
Rockville, MD 20857

Re: 2013 National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930-0334)

The Center for American Progress greatly appreciates the efforts of the Substance Abuse and Mental Health Services Agency (SAMSHA) to recognize the health disparities faced by lesbian, gay, bisexual, and transgender (LGBT) communities by incorporating sexual orientation data collection into the proposed Dress Rehearsal for the National Survey on Drug Use and Health (NSDUH). We applaud the proposed amendments to this survey tool, and urge SAMHSA to adopt additional measures that would permit accurate collection of data on all LGBT identities. Additionally, recognizing the critical importance of school safety to youth mental health, we strongly encourage the adoption of youth experience questions asking about school safety and suicide prevention measures. We commend SAMHSA's ongoing support of LGBT communities, as evidenced by your leadership in addressing LGBT health disparities in resource materials, and through the Agency's commitment to collecting data on transgender individuals through programmatic forms.

Accurate data collection is critically important to identifying and ending the health disparities facing LGBTQ communities. This need is recognized in the Affordable Care Act, which prioritizes data collection and directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors deemed relevant to reducing disparities.[1] In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[2] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys. This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBT individuals are more likely to be uninsured and report poorer health outcomes than the general population.

Federal sources such as the Institute of Medicine,[3] Healthy People 2020,[4] the Substance Abuse and Mental Health Services Administration,[5] and the National Healthcare Disparities Report[6] indicate that LGBT individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[7] As a result, the LGBT population experiences significant disparities in health indicators such as smoking, obesity, experiences of

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[1] Affordable Care Act Section 1302.
[2] Department of Health and Human Services, "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations" (2011) Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209.
[3] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx
[4] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25
[5] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBTQ Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBTQ-Populations/SMA12-4684
[6] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf
[7] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

abuse and violence, mental and behavioral health concerns, and HIV infection. Data collection is crucial to understanding and addressing these disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

In recognition of this need, the Williams Institute convened two groups of scientists, experts, and researchers to study gender- and sexual orientation-related measurement in survey instruments. The Gender Identity in U.S. Surveillance (GenIUSS) group and the Sexual Minority Assessment Research Team (SMART) have compiled an overview of current measures in use to collect accurate information about lesbian, gay, bisexual, and transgender respondents to federally supported surveys.[8] These comments are drawn in part from protocols discussed by SMART and the GenIUSS group.

Given the large sample size of the NSDUH, this is a critically important opportunity to collect meaningful data on LGBT people, and many of our recommendations reflect that priority. We appreciate the opportunity to comment on these proposed revisions to the NSDUH, and we make the following recommendations:

1. **Preliminary segregation of respondents by gender**
   A. **QD01 and QD01a:** Respondents should be asked to provide answers to these questions; interviewers should not be asked to make assumptions about sex or gender.
   B. **QD01 and QD01a:** These questions should be revised to capture information about sex assigned at birth.
2. **Accurately capturing information about gender identity and expression**
   A. Adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.
   B. Adopt the amended YRBS/GLSEN single-question protocol to allow for the collection of gender expression information on all respondents.
3. **Accurately capturing information about sexual orientation and attraction**
   A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.
   B. Adopt QD62 as proposed and track according to gender identity.
4. **Expanding youth-related questions to better understand youth mental health needs**
   A. Amend the Youth Experience section of the proposed survey instrument to include questions relating to bullying.
   B. Amend the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.

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1. PRELIMINARY SEGREGATION OF RESPONDENTS BY GENDER:

In order to capture accurate physiological and sociological information about respondents, it is important to ask precise questions about sex and gender. To that end we recommend two revisions to the current initial collection of this information. First (A), respondents should be asked to provide an answer to QD01, rather than asking an interviewer to make assumptions about the respondent's sex or gender.

[8] For more information on these groups, please visit http://williamsinstitute.law.ucla.edu/wp-content/uploads/GenIUSS-Gender-related-Question-Overview.pdf for the GenIUSS group, and http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf for SMART.

Second (B), gender identity, gender expression, and sex assigned at birth are distinct concepts, which do not always relate to physiological characteristics.[9] QD01 and QD02 should be rewritten to capture information about "sex assigned at birth" rather than gender. Complete information about gender identity, gender expression, and sex assigned at birth is particularly important to capture in a survey like NSDUH, where physiological and sociological questions are tracked separately based on a respondent's demographic characteristics. It is essential for the accuracy of information collected that the distinct concepts of sex assigned at birth and gender identity not be conflated.

A. Respondents should self-identify gender and sex assigned at birth.

Currently, interviewers administering the NSDUH are asked to record a respondent's gender and then verify that they have entered it correctly:

QD01 *The first few questions are for statistical purposes only, to help us analyze the results of the study.*

INTERVIEWER: RECORD RESPONDENT'S GENDER.

5 MALE
9 FEMALE

QD01a *INTERVIEWER: YOU HAVE ENTERED THAT THE RESPONDENT IS **[FILL QD01]**. IS THIS CORRECT?*

4 YES
6 NO

This formulation is problematic for several reasons. First, neither sex assigned at birth nor gender is a characteristic that can be reliably deduced solely through appearance or physical characteristics, and as a result, interviewer error may result in inaccurate data.[10] Because of the gender-segregated nature of this survey, accuracy in assessment of gender and sex is especially critical for all respondents. For example, if an interviewer incorrectly assesses a respondent's sex, it reduces the data integrity of questions relating to pregnancy, cervical and prostate cancer, and alcohol consumption, among many others. In addition, transgender and gender non-conforming individuals should have the opportunity to self-identify their sex assigned at birth to provide accurate data, and also to avoid potential misidentification. **We therefore recommend that all NSDUH respondents be asked for a response to question QD01, rather have gender or sex be assumed by the interviewer.**

B. QD01 and QD01a should be rewritten to capture information about sex assigned at birth rather than gender.

As written, QD01 and QD01a would result in inaccurate information being collected about transgender respondents. For example, a transgender man respondent who was assigned female at birth would likely indicate "male" as his gender. As a result of the separate survey tracks for gender in the NSDUH, the respondent would follow a male track in which he would not be given the opportunity to

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[9] *See, e.g.,* American Psychological Association, Task Force on Gender Identity and Gender Variance (2009). Report of the Task Force on Gender Identity and Gender Variance. Washington, DC: Author. Available online at www.apa.org/pi/lgbc/transgender/2008TaskForceReport.html

[10] The California LGBT Tobacco Use Survey, in recognition of this, instructs phone interviewers to explicitly ask about gender and to "not assume [they] know gender based on voice qualities." Bye L, Gruskin E, Greenwood, G, Albright V, Krotki K. California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey – 2004, page 112. Sacramento, CA: California Department of Health Services, 2005.

respond to relevant questions about pregnancy, cervical cancer, and other health-related questions generally associated with people assigned female at birth. However, if the question were revised to ask about sex assigned at birth rather than gender, a transgender man would most likely indicate "female." As a result, he would be tracked as "female" and would be presented with relevant physiological questions. While adopting this approach alone does not solve all discrepancies relating to gender-based tracking (see below), this revision of the current question relating to gender would at least result in more accurate collection of medical history information for all respondents. The primary tracking in this survey relates to medical history and physiological concerns, and sex assigned at birth is the best measure by which accurate responses to those questions can be captured. **Therefore, we recommend that "sex assigned at birth" replace the current initial question regarding gender.**

The Center of Excellence for Transgender Health at the University of California at San Francisco (UCSF) advocates for a two-question protocol to assess current gender identity and assigned sex at birth.[11] As applies to the NSDUH, QD01 and QD01a would be rewritten to follow the second part of the two-question protocol, as follows:

QD01: What sex were you assigned at birth, meaning on your original birth certificate?

- *Male*
- *Female*

QD01a: You have entered that your sex assigned at birth is [FILL QD01], is that correct?[12]

We recommend that SAMHSA collect data regarding sex assigned at birth rather than gender in QD01, and amend questions QD01 and QD01a accordingly. Physiological questions that are currently tracked based on responses to QD01 should continue to be tracked by this revised question.[13]

2. ACCURATELY CAPTURING INFORMATION ABOUT GENDER IDENTITY AND EXPRESSION

A. Gender identity should be collected as part of a two-step gender and sex protocol, and should be used to track sociological questions throughout the survey.

Independent of sex assigned at birth, collecting gender identity data will help ensure that accurate and complete information about all respondents is obtained. Currently, the NSDUH conflates sex and gender, and tracks both sociological and physiological questions based on a single characteristic. This model is inaccurate for transgender respondents, and it will therefore result in conflicting and flawed data. Where collecting sex assigned at birth will result in more accurate information with regard to medical history and other physiological questions, it is necessary to also collect gender identity information in order to accurately capture sociological information about transgender respondents.

In addition to questions about medical history, the proposed revisions to the NSDUH include sociological questions, such as questions about sexual orientation and sexual attraction, and numerous questions relating to gendered family relationship. Many of these questions are currently tracked in the proposed survey based on a respondent's presumed sex as determined in QD01. For transgender respondents, to track the answers to sociological questions based on sex assigned at birth (rather than gender identity) would result in inappropriate response options, inverse data collection, and misuse of

[11] *Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services,* Center of Excellence for Transgender Health (2009). http://transhealth.ucsf.edu/pdf/data-recommendation.pdf.

[12] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[13] We also encourage SAMHSA to pursue research into whether the benefits of segregating studies based on gender outweigh the difficulties that arise in accurately tracking the physiological and sociological characteristics of all respondents in such surveys.

pronouns and family relationship identifiers. For example, under the current proposed system, a transgender man would be identified as female in the introduction to questions about income, and "her" would be designated as the appropriate pronoun to describe his relationship with his family (e.g. "These next questions are about the kinds and amounts of income received by [transgender man] and her family.")

Questions relating to medical history and other physiological characteristics should be tracked according to sex assigned at birth in order to accurately and appropriately capture information about transgender respondents. Other questions, which relate to gendered social characteristics (such as sexual orientation and family interactions), should be tracked according to a respondent's gender identity. Transgender men and other men should be tracked together, as should transgender women and other women.[14]

Recommendation: if the NSDUH is segregated by gender and sex, then sex assigned at birth should be used to track physiological questions, and gender identity should be used to track sociological questions.

Collecting gender identity is the recommended first question of the two-step protocol for assessing current gender identity and assigned sex at birth that is discussed in the GenIUSS group's overview of gender-related survey measures. This question has already been federally adopted for use in national health surveys: in 2011, the U.S. Centers for Disease Control and Prevention (CDC) adopted this question protocol for use in its Adult Case Report Form as well as its electronic surveillance system, the Enhanced HIV/AIDS Reporting System (eHARS).[15]

Research suggests that more accurate and complete data will be collected through the adoption of a two-step protocol in which gender identity is asked first. According to the GenIUSS group,

> *Asking gender identity first emphasizes that this parameter tends to be much more important than assigned sex at birth for transgender people. A 2012 study by Tate, Ledbetter, and Youssef has shown that this technique provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single-item method (i.e., a single question asking respondents' gender with choices of "male," "female," "transgender," or "other" only).[16] It also minimizes confusion among and misclassification of non-transgender people, who may be unfamiliar with the concept of gender identity.[17]*

The two-step protocol is a best practice because simply adding a "transgender" to a demographic question as part of a single-question protocol may under-report transgender respondents; research has shown that 75% of transgender survey respondents, when given the option of self-identifying as transgender, male, or female, will not identify as transgender.[18] However, by identifying respondents whose sex assigned at birth is at variance with their gender identity in addition to individuals who self-

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[14] For example, ALCC30, HLTH02, HLTH26, AD26c2, YD26c2, CA10, CA11, and other similar questions should be tracked according to sex assigned a birth. Sociological questions, such as QD62, QD63, [R GENDER] (NSDUH Dress Rehearsal pages 707 and 710), DEFINE SAMPLE MEMBER (NSDUH Dress Rehearsal pages 727-731), INTROINC, and others, should be tracked according to gender identity.

[15] CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. 2011. *HIV Infection among Transgender People*. Washington, DC: Centers for Disease Control and Prevention, available at http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf.; see also, *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[16] Tate, C.C., J.N. Ledbetter, and C.P. Youssef. 2012. A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences. *Journal of Sex Research*. 18:1–10.

[17] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[18] Schilt, Kristen and Jenifer Bratter. 2010. *From Multiracial to Multigender? Assessing Attitudes toward a Transgender Category on the Census*. Presented at the 2010 Annual Meeting of the American Sociological Association, Atlanta, GA.

identify as transgender, researchers will be better able to identify the entire population of transgender survey participants.

We recommend that gender identity be asked as follows. This question should precede the sex assigned at birth question:

What is your current gender identity?
- *Male*
- *Female*
- *Trans male/Trans man*
- *Trans female/Trans woman*[19]

Recommendation: adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.[20]

B. Adopt a single question protocol querying gender expression via appearance and mannerisms

In addition to gender identity and sex assigned at birth, how a person's gender expression is perceived can have important health implications. Gender nonconforming youth often face victimization in school, which can result in increased risk of suicidality, depression, and post-traumatic stress disorder, as well as poor academic achievement.[21] Gender nonconforming adults can face increased workplace harassment, discrimination and negative employment actions. Both one- and two-question protocols for surveying gender expression have been successfully tested. In 2010, Wylie et al. tested the following two-question protocol on young adults in New England, which queries both appearance and mannerisms:[22]

Gender Expression

1. A person's appearance, style, or dress may affect the way people think of them. On average, how do you think people would describe your appearance, style, or dress?

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[19] In addition to these four response choices, the question in the GenIUSS group's overview also includes "genderqueer" and "different identity: ____" as available responses. The NSDUH currently segregates certain physiological and sociological questions by gender. Because sociological questions would most appropriately be tracked by gender identity, and because there is no consistent structure for question responses that would accurately and reliably reflect a genderqueer or "different identity ____" response, we have removed them from the recommended question.

[20] As an alternative, if SAMHSA is not prepared to move forward with a gender identity question at this time, we strongly urge you to adopt a combined sexual orientation and gender identity question, adding "transgender" to the proposed QD63, and changing the question so that multiple options may be checked at once. This would at least allow SAMHSA to capture information about transgender respondents, and know for which respondents other questions are likely to be incorrectly coded.

[21] Roberts, A.L., M. Rosario, N. Slopen, J.P. Calzo, and S.B. Austin. 2013. Childhood Gender Nonconformity, Bullying Victimization, and Depressive Symptoms Across Adolescence and Early Adulthood: An 11-Year Longitudinal Study. *Journal of the American Academy of Child & Adolescent Psychiatry*. (forthcoming, accepted November 16, 2012); Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Childhood Gender Nonconformity: A Risk Indicator for Childhood Abuse and Posttraumatic Stress in Youth. *Pediatrics*. 129(3): 571-573; Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Elevated Risk of Posttraumatic Stress in Sexual Minority Youths: Mediation by Childhood Abuse and Gender Nonconformity. *American Journal of Public Health*. 102(8): 1587-1593. See also, *Gender-Related Measures Overview*, 5, The GenIUSS Group. The Williams Institute, February 2013, and *Including a Gender Expression Question on the YRBS Can Help Assess Disparities and Achieve Better Outcomes for Gender Nonconforming Students*, All Students Count Coalition, available at http://amplifyyourvoice.org/wp-content/uploads/2012/10/ASC-Gender-Expression-FAQ3.pdf [hereinafter *All Students Count*].

[22] Wylie, S.A., H.C. Corliss, V. Boulanger, L.A. Prokop, and S.B. Austin. 2010. *Socially assigned gender nonconformity: a brief measure for use in surveillance and investigation of health disparities*. Sex Roles. 63(3-4): 264-276.

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

3. *A person's mannerisms (such as the way they walk or talk) may affect the way people think of them. On average, how do you think people would describe your mannerisms?*
    - *Very feminine*
    - *Mostly feminine*
    - *Somewhat feminine*
    - *Equally feminine and masculine*
    - *Somewhat masculine*
    - *Mostly masculine*
    - *Very masculine*

In 2012, the Gay, Lesbian & Straight Education Network (GLSEN) merged this two-question protocol into one question querying both mannerisms and appearance to fit the requirements of the Youth Risk Behavior Survey (YRBS). GLSEN then conducted cognitive testing and pilot testing of this item with a sample of school-age adolescents. Cognitive testing indicated that the item was understandable to a diverse range of 14-18 year-old youth, including cisgender[23] youth (heterosexual, lesbian, gay, and bisexual) and transgender youth. The CDC subsequently approved this question as an optional question for state and local agencies to add to the 2013 YRBS:[24]

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people at school would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

We recommend adopting the YRBS/GLSEN single-question protocol, but eliminating the words "at school" from the question to allow for the collection of gender expression information on all respondents. Our recommended question reads as follows:

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*

[23] Cisgender is a term that refers a person whose gender identity and sex assigned at birth are congruent.
[24] Greytak, EA (2012). Asking about gender: *A report on the development and testing of gender-related constructs for population-based surveys of adolescents.* New York, NY: GLSEN. See also, *All Students Count.*

- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

This question can be used in conjunction with either sex assigned at birth or gender identity in order to gauge gender nonconformity, although it is preferred to measure it against gender identity. When measured against sex assigned at birth, transgender respondents who are gender nonconforming would be coded erroneously as gender conforming. For example, a transgender man who is "somewhat feminine", but who has indicated "female" as his sex assigned at birth would be coded as a "somewhat feminine female." Although he is in reality gender nonconforming, he will not be coded as such. This issue would not arise if gender expression were matched against gender identity. As with other sociological questions in the NSDUH, it would be appropriate to track this question based on gender identity, and to reverse the order of response options accordingly.

3. ACCURATELY CAPTURING INFORMATION ABOUT SEXUAL ORIENTATION AND ATTRACTION

We welcome the addition of questions relating to sexual orientation and attraction to the NSDUH, and strongly encourage SAMHSA to adopt these proposed revisions, with slight amendment in order to ensure data accuracy and integrity.

A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.

Currently, QD63 is proposed to read as follows:

QD63 *Do you consider yourself to be*:
1 Heterosexual, that is straight;
2 [IF QD01=9 THEN "Lesbian or] Gay
3 Bisexual?

Sexual orientation, along with several other sociological questions, is currently being tracked in reference to gender. It would actually be simpler to not track this question in reference to gender identity or sex at all, and to have "gay or lesbian" be consistently available as a static item. In doing so, every respondent who identifies as lesbian, gay, or bisexual would be able to accurately respond to the question, regardless of whatever decisions are made with regard to the gender tracking of the survey. Moreover, many women who are attracted to other women identify as gay, so even if the question were tracked by gender identity, it would be appropriate to have a static response including both options. Additionally, SMART best practices for adoption of this question include "gay or lesbian" as a static response choice.[25]

Recommendation: Adopt the proposed question on sexual orientation, but do not alter the question based on the gender or sex of the respondent. "Both gay" and "lesbian" should both be visible for all respondents.[26]

B. Adopt QD62 as proposed and track according to gender identity.

[25] *Best Practices for Asking Questions about Sexual Orientation on Surveys*, the Sexual Minority Assessment Research Team (SMART), November 2009, 8. http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf.
[26] As noted in *supra* n. 20, a possible alternative means of collecting information about transgender respondents would add "transgender" to the question options, and respondents would be able to check multiple responses. This option is less ideal for this survey than a two-step approach for identifying transgender respondents because it will underreport transgender people who identify as simply "male" or "female." This alternative question would also continue to result in inaccurate data collection with regard to transgender people and sociological information.

Question QD62 currently reads as follows:

QD62 *People are different in their sexual attraction to other people. Which best describes your feelings? Are you:*
[IF QD01=5]
1 Only attracted to females?
2 Mostly attracted to females?
3 Equally attracted to females and males?
4 Mostly attracted to males?
5 Only attracted to males?
6 Not sure?
DK/REF

[IF QD01=9]
1 Only attracted to males?
2 Mostly attracted to males?
3 Equally attracted to males and females?
4 Mostly attracted to females?
5 Only attracted to females
6 Not sure?

Unlike QD63, this question should be tracked with other sociological questions according to gender identity. Because of gender tracking of the proposed question, a coded response of "1" from both genders surveyed indicates sole attraction to individuals of the same gender. Under a system where only one marker of gender (or, as amended, sex assigned at birth) is tracked, this could result in inverse data collection for transgender respondents. For example, a transgender woman who was being tracked as "male" per her sex at birth, would be presented with "Only attracted to males" as the option meant to represent sole attraction to the same gender. If she identifies as a lesbian, and solely experiences attraction to other women, she will select "5, solely attracted to females." This will then be coded, erroneously, as heterosexuality. Therefore, in order to accurately capture information about sexual attraction for all respondents, it is important to adopt a question asking about gender identity and then track QD63 based on gender identity.

Recommendation: adopt the proposed question on sexual attraction and track the order of the response options in reference to gender identity.

4. MORE EFFECTIVELY ADDRESSING STUDENT HEALTH THROUGH ASSESSING SCHOOL CLIMATE

Effectively addressing the behavioral health impact of bullying that affects young people requires data that accurately reflects the safety of our nation's schools.[27] The NSDUH is an ideal survey instrument to collect data on student experiences with bullying and associated health outcomes. Currently, the Youth Experience section of the proposed survey instrument does not ask youth to report on experiences of bullying in school. **We recommend the addition of questions relating to bullying because of the important health outcomes associated with it.**

Data about safe schools is enormously important because it gives us a better picture of school climate issues as a whole, and allows us to implement more effective and efficient interventions. Research has

[27] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf (detailing high rates of bullying in American schools).

shown that school climate is a nation-wide issue, and that marginalized populations face increased bullying and harassment in schools. In a 2011 GLSEN School Climate Survey, 81.9% of LGBT students reported being verbally harassed, 38.3% reported being physically harassed and 18.3% reported being physically assaulted at school because of their sexual orientation in 2011.[28] GLSEN also found in their national survey that LGBT students faced increased rates of depression, lower self-esteem, and lower school-connectedness.[29] According to the CDC, one in five high school students report that they were bullied on school property in 2009.[30] Technology has increased the means and ways for bullying to occur in our school system. In 2010, one in five adolescents said that they had been cyber-bullied at some point in their lives, and about the same number admits to having been a cyber-bully. One in ten adolescents had been both a cyber-bully and a victim.[31]

School safety can have a tremendous impact on a youth's ability to study and graduate. According to the Department of Health and Human Services bullying can lead to decreased academic achievement—GPA and standardized test scores—and school participation.[32] Students who are bullied are more likely to miss, skip, or drop out of school.[33] Information about bullying must be consistently tracked and studied in order to effectively reduce youth dropout rates and prevent negative health outcomes.

We recommend amending the Youth Experience section of the proposed survey instrument to include the following two questions, which were taken from the CDC's 2013 YRBS:

> *The next 2 questions ask about bullying. Bullying is when 1 or more students tease, threaten, spread rumors about, hit, shove, or hurt another student over and over again. It is not bullying when 2 students of about the same strength or power argue or fight or tease each other in a friendly way.*
>
> *During the past 12 months, have you ever been bullied on school property?*
> *A. Yes*
> *B. No*
>
> *During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites, or texting.)*
> *A. Yes*
> *B. No*

Given the relative burden associated with participating in the survey, we believe there are a number of questions that could be replaced by a new safe schools question. There are several questions in the Youth Experience section that may be outdated and no longer collect useful data; we recommend that SAMHSA reevaluate the utility of these and other questions: YE10[34], YE11[35], YE13.[36] Each of these questions asks

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[28] GLSEN, The 2011 National School Climate Survey (2011), http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2106-1.pdf.
[29] Id.
[30] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.
[31] Hinduja, S. and Patchin, J.W., Overview on Cyberbullying (2011), http://www.stopbullying.gov/references/white_house_conference/white_house_conference_materials.pdf#overview_of_cyberbullying.
[32] U.S. Dep't of Health and Human Services, Effects of Bullying (Last Visited March 25, 2013), http://www.stopbullying.gov/at-risk/effects/index.html.
[33] Id.
[34] "Which of the statements below best describes how you felt overall about going to school during the past 12 months? You liked going to school a lot; You kind of liked going to school; You didn't like going to school very much; You hated going to school." NSDUH Dress Rehearsal at 599.
[35] "During the past 12 months, how often did you feel that the school work you were assigned to do was meaningful and important? Always, Sometimes, Seldom, Never." NSDUH Dress Rehearsal at 599.

for student sentiment about school, but they may not sufficiently address the link between safety and student mental health and wellbeing.

5. **COLLECTING INFORMATION ABOUT THE PRESENCE OF SUICIDE PREVENTION PROGRAMS IN ELEMENTARY AND SECONDARY SCHOOLS.**

The statistics relating to youth suicidality are staggering, and clearly indicate a public health need to collect better information on suicide prevention efforts. Suicide is the 2nd leading cause of death among young people ages 10 to 24.[37] A nationwide survey by the CDC found that 16% of students reported seriously considering suicide, 13% reported creating a plan, and 8% reporting trying to take their own life in the previous 12 months.[38] Each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at Emergency Departments across the United States.[39] 1 out of 6 students' nationwide (grades 9-12) have seriously considered suicide in the past year.[40] These statistics are even more devastating within LGBT communities: research has shown that LGB youth are 4 times more likely to attempt suicide as their straight peers, and questioning youth are 3 times more likely.[41] Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.[42]

Reducing youth suicidality should be one of our highest public health priorities. In order to adequately assess the need for greater suicide prevention funding, research, and outreach for suicide prevention measures, such as the National Suicide Hotline and available Campus Suicide Prevention programs, we should collect information about what programs are successfully reaching youth. **We therefore recommend amending the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.**

This question should mirror YE23c,[43] YE23g,[44] and YE23o,[45] all of which ask about youth prevention programs for negative mental and physical health outcomes. Given the high rates of youth suicide, particularly among at-risk youth populations, amending the NSDUH to include a question about suicide prevention is a natural and necessary extension.

Conclusion

We commend SAMHSA for recognizing the importance of data collection to begin to eliminate the health disparities facing lesbian, gay, bisexual, and questioning individuals. We strongly encourage continued revision to the National Survey on Drug Use and Health to allow for targeted and evidence-based solutions to ending the disparities facing transgender people as well. We also recommend amendment of

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[36] "How interesting do you think most of your courses at school during the past 12 months have been? Very interesting, Somewhat interesting, Somewhat boring, Very boring." NSDUH Dress Rehearsal at 600.
[37] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Available from www.cdc.gov/ncipc/wisqars.
[38] CDC, Injury Center: Violence Prevention, (2012), http://www.cdc.gov/violenceprevention/pub/youth_suicide.html
[39] Id.
[40] CDC, Youth Risk Behavior Surveillance – United States, 2011, (2011), http://www.cdc.gov/mmwr/pdf/ss/ss6104.pdf
[41] Kann, L, et al. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12 – Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009." MMWR 60(SS07): 1-133. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm
[42] Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) SUICIDE LIFE THREAT BEHAV. 527 (2007).
[43] **During the past 12 months** have you participated in a violence prevention program, where you learn ways to avoid fights and control anger?
[44] **During the past 12 months** have you participated in an alcohol, tobacco or drug prevention program outside of school, where you learn about the dangers of using, and how to resist using, alcohol, tobacco, or drugs?
[45] **During the past 12 months** have you participated in pregnancy or sexually transmitted disease prevention programs?

the Youth Experience section of the proposed survey instrument to collect better information about suicide prevention programs and school bullying.

Sincerely,

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Re: 2013 National Survey on Drug Use and Health (NSDUH) Dress Rehearsal (OMB No. 0930-0334)

The Gay, Lesbian & Straight Education Network (GLSEN) greatly appreciates the efforts of the Substance Abuse and Mental Health Services Agency (SAMSHA) to recognize the health disparities faced by lesbian, gay, bisexual, transgender, and questioning (LGBTQ) communities by incorporating sexual orientation data collection into the proposed Dress Rehearsal for the National Survey on Drug Use and Health (NSDUH). We applaud the proposed amendments to this survey tool, and urge SAMHSA to adopt additional measures that would permit accurate collection of data on all LGBTQ identities. Additionally, recognizing the critical importance of school safety to youth mental health, we strongly encourage the adoption of youth experience questions asking about school safety and suicide prevention measures. We commend SAMHSA's ongoing support of LGBTQ communities, as evidenced by your leadership in addressing LGBTQ health disparities in your resource materials, and through your commitment to collecting data on transgender individuals through your programmatic forms.

GLSEN strives to ensure that each member of every school community is valued and respected regardless of sexual orientation or gender identity/expression.

We believe that such an atmosphere engenders a positive sense of self, which is the basis of educational achievement and personal growth. Since homophobia, transphobia and heterosexism undermine a healthy school climate, we work to educate teachers, students and the public at large about the damaging effects these forces have on youth and adults alike.

Accurate data collection is critically important to identifying and ending the health disparities facing LGBTQ communities. This need is recognized in the Affordable Care Act, which prioritizes data collection and directs the U.S. Secretary of Health and Human Services to collect a range of data on the health disparities associated with race, ethnicity, sex, disability status, and primary language, as well as any other factors deemed relevant to reducing disparities.[1] In June 2011, Secretary Sebelius drew on this authority in the new LGBT Data Progression Plan,[2] which commits the Department of Health and Human Services to developing sexual orientation and gender identity questions for federally supported health surveys. This plan recognizes that, like other underserved populations such as communities of color and rural populations, LGBTQ individuals are more likely to be uninsured and report poorer health outcomes than the general population.

Federal sources such as the Institute of Medicine,[3] Healthy People 2020,[4] the Substance Abuse and Mental Health Services Administration,[5] and the National Healthcare Disparities Report[6] indicate that

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[1] Affordable Care Act Section 1302.
[2] Department of Health and Human Services, "Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations" (2011) Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209.
[3] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx
[4] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25
[5] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBTQ Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBTQ-Populations/SMA12-4684

LGBTQ individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[7] As a result, the LGBTQ population experiences significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental and behavioral health concerns, and HIV infection. Data collection is crucial to understanding and addressing these disparities because it allows for accurate assessment of how the various components of each individual's identity and background affect health status, access to health care and insurance, and health care outcomes.

In recognition of this need, the Williams Institute convened two groups of scientists, experts, and researchers to study gender- and sexual orientation-related measurement in survey instruments. The Gender Identity in U.S. Surveillance (GenIUSS) group and the Sexual Minority Assessment Research Team (SMART) have compiled an overview of current measures in use to collect accurate information about lesbian, gay, bisexual, and transgender respondents to federally supported surveys.[8] These comments are drawn in part from protocols discussed by SMART and the GenIUSS group.

Given the large sample size of the NSDUH, this is a critically important opportunity to collect meaningful data on LGBTQ people, and many of our recommendations reflect that priority. We appreciate the opportunity to comment on these proposed revisions to the NSDUH, and we make the following recommendations:

1. **Preliminary segregation of respondents by gender**
   A. **QD01 and QD01a:** Respondents should be asked to provide answers to these questions; interviewers should not be asked to make assumptions about sex or gender.
   B. **QD01 and QD01a:** These questions should be revised to capture information about sex assigned at birth.
2. **Accurately capturing information about gender identity and expression**
   A. Adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.
   B. Adopt the amended Youth Risk Behavior Survey (YRBS) single-question protocol to allow for the collection of gender expression information on all respondents.
3. **Accurately capturing information about sexual orientation and attraction**
   A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.
   B. Adopt QD62 as proposed and track according to gender identity.
4. **Expanding youth-related questions to better understand youth health needs**
   A. Amend the Youth Experience section of the proposed survey instrument to include questions relating to bullying.
   B. Amend the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.

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1. PRELIMINARY SEGREGATION OF RESPONDENTS BY GENDER:

[6] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[7] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

[8] For more information on these groups, please visit http://williamsinstitute.law.ucla.edu/wp-content/uploads/GenIUSS-Gender-related-Question-Overview.pdf for the GenIUSS group, and http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf for SMART.

In order to capture accurate physiological and sociological information about respondents, it is important to ask precise questions about sex and gender. To that end we recommend two revisions to the current initial collection of this information. First (A), respondents should be asked to provide an answer to QD01, rather than asking an interviewer to make assumptions about the respondent's sex or gender.

Second (B), gender identity, gender expression, and sex assigned at birth are distinct concepts, which do not always relate to physiological characteristics.[9] QD01 and QD02 should be rewritten to capture information about "sex assigned at birth" rather than gender. Complete information about gender identity, gender expression, and sex assigned at birth is particularly important to capture in a survey like NSDUH, where physiological and sociological questions are tracked separately based on a respondent's demographic characteristics. It is essential for the accuracy of information collected that the distinct concepts of sex assigned at birth and gender identity not be conflated.

A. Respondents should self-identify gender and sex assigned at birth.

Currently, interviewers administering the NSDUH are asked to record a respondent's gender and then verify that they have entered it correctly:

QD01 *The first few questions are for statistical purposes only, to help us analyze the results of the study.*

INTERVIEWER: RECORD RESPONDENT'S GENDER.

5 MALE
9 FEMALE

QD01a *INTERVIEWER: YOU HAVE ENTERED THAT THE RESPONDENT IS **[FILL QD01]**. IS THIS CORRECT?*

4 YES
6 NO

This formulation is problematic for several reasons. First, neither sex assigned at birth nor gender is a characteristic that can be reliably deduced solely through appearance or physical characteristics, and as a result, interviewer error may result in inaccurate data.[10] Because of the gender-segregated nature of this survey, accuracy in assessment of gender and sex is especially critical for all respondents. For example, if an interviewer incorrectly assesses a respondent's sex, it reduces the data integrity of questions relating to pregnancy, cervical and prostate cancer, and alcohol consumption, among many others. In addition, transgender and gender non-conforming individuals should have the opportunity to self-identify their sex assigned at birth to provide accurate data, and also to avoid potential misidentification. **We therefore recommend that all NSDUH respondents be asked for a response to question QD01, rather have gender or sex be assumed by the interviewer.**

B. QD01 and QD01a should be rewritten to capture information about sex assigned at birth rather than gender.

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[9] *See, e.g.,* American Psychological Association, Task Force on Gender Identity and Gender Variance (2009). Report of the Task Force on Gender Identity and Gender Variance. Washington, DC: Author. Available online at www.apa.org/pi/lgbc/transgender/2008TaskForceReport.html

[10] The California LGBT Tobacco Use Survey, in recognition of this, instructs phone interviewers to explicitly ask about gender and to "not assume [they] know gender based on voice qualities." Bye L, Gruskin E, Greenwood, G, Albright V, Krotki K. California Lesbians, Gays, Bisexuals, and Transgender (LGBT) Tobacco Use Survey – 2004, page 112. Sacramento, CA: California Department of Health Services, 2005.

As written, QD01 and QD01a would result in inaccurate information being collected about transgender respondents. For example, a transgender man respondent who was assigned female at birth would likely indicate "male" as his gender. As a result of the separate survey tracks for gender in the NSDUH, the respondent would follow a male track in which he would not be given the opportunity to respond to relevant questions about pregnancy, cervical cancer, and other health-related questions generally associated with people assigned female at birth. However, if the question were revised to ask about sex assigned at birth rather than gender, a transgender man would most likely indicate "female." As a result, he would be tracked as "female" and would be presented with relevant physiological questions. While adopting this approach alone does not solve all discrepancies relating to gender-based tracking (see below), this revision of the current question relating to gender would at least result in more accurate collection of medical history information for all respondents. The primary tracking in this survey relates to medical history and physiological concerns, and sex assigned at birth is the best measure by which accurate responses to those questions can be captured. **Therefore, we recommend that "sex assigned at birth" replace the current initial question regarding gender.**

The Center of Excellence for Transgender Health at the University of California at San Francisco (UCSF) advocates for a two-question protocol to assess current gender identity and assigned sex at birth.[11] As applies to the NSDUH, QD01 and QD01a would be rewritten to follow the second part of the two-question protocol, as follows:

QD01: What sex were you assigned at birth, meaning on your original birth certificate?

- *Male*
- *Female*

QD01a: You have entered that your sex assigned at birth is [FILL QD01], is that correct?[12]

We recommend that SAMHSA collect data regarding sex assigned at birth rather than gender in QD01, and amend questions QD01 and QD01a accordingly. Physiological questions that are currently tracked based on responses to QD01 should continue to be tracked by this revised question.[13]

2. ACCURATELY CAPTURING INFORMATION ABOUT GENDER IDENTITY AND EXPRESSION

A. Gender identity should be collected as part of a two-step gender and sex protocol, and should be used to track sociological questions throughout the survey.

Independent of sex assigned at birth, collecting gender identity data will help ensure that accurate and complete information about all respondents is obtained. Currently, the NSDUH conflates sex and gender, and tracks both sociological and physiological questions based on a single characteristic. This model is inaccurate for transgender respondents, and it will therefore result in conflicting and flawed data. Where collecting sex assigned at birth will result in more accurate information with regard to medical history and other physiological questions, it is necessary to also collect gender identity information in order to accurately capture sociological information about transgender respondents.

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[11] *Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services,* Center of Excellence for Transgender Health (2009). http://transhealth.ucsf.edu/pdf/data-recommendation.pdf.

[12] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[13] We also encourage SAMHSA to pursue research into whether the benefits of segregating studies based on gender outweigh the difficulties that arise in accurately tracking the physiological and sociological characteristics of all respondents in such surveys.

In addition to questions about medical history, the proposed revisions to the NSDUH include sociological questions, such as questions about sexual orientation and sexual attraction, and numerous questions relating to gendered family relationship. Many of these questions are currently tracked in the proposed survey based on a respondent's presumed sex as determined in QD01. For transgender respondents, to track the answers to sociological questions based on sex assigned at birth (rather than gender identity) would result in inappropriate response options, inverse data collection, and misuse of pronouns and family relationship identifiers. For example, under the current proposed system, a transgender man would be identified as female in the introduction to questions about income, and "her" would be designated as the appropriate pronoun to describe his relationship with his family (e.g. "These next questions are about the kinds and amounts of income received by [transgender man] and her family.")

Questions relating to medical history and other physiological characteristics should be tracked according to sex assigned at birth in order to accurately and appropriately capture information about transgender respondents. Other questions, which relate to gendered social characteristics (such as sexual orientation and family interactions), should be tracked according to a respondent's gender identity. Trans men and other men should be tracked together, as should trans women and other women.[14]

Recommendation: if the NSDUH is segregated by gender and sex, then sex assigned at birth should be used to track physiological questions, and gender identity should be used to track sociological questions.

Collecting gender identity is the recommended first question of the two-step protocol for assessing current gender identity and assigned sex at birth that is discussed in the GenIUSS group's overview of gender-related survey measures. This question has already been federally adopted for use in national health surveys: in 2011, the U.S. Centers for Disease Control and Prevention (CDC) adopted this question protocol for use in its Adult Case Report Form as well as its electronic surveillance system, the Enhanced HIV/AIDS Reporting System (eHARS).[15]

Research suggests that more accurate and complete data will be collected through the adoption of a two-step protocol in which gender identity is asked first. According to the GenIUSS group,

> *Asking gender identity first emphasizes that this parameter tends to be much more important than assigned sex at birth for transgender people. A 2012 study by Tate, Ledbetter, and Youssef has shown that this technique provides more detailed and accurate demographic information and also increases overall rates of identification of transgender individuals as compared to a single-item method (i.e., a single question asking respondents' gender with choices of "male," "female," "transgender," or "other" only).[16] It also minimizes confusion among and misclassification of non-transgender people, who may be unfamiliar with the concept of gender identity.[17]*

The two-step protocol is a best practice because simply adding a "transgender" to a demographic question as part of a single-question protocol may under-report transgender respondents; research has

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[14] For example, ALCC30, HLTH02, HLTH26, AD26c2, YD26c2, CA10, CA11, and other similar questions should be tracked according to sex assigned a birth. Sociological questions, such as QD62, QD63, [R GENDER] (NSDUH Dress Rehearsal pages 707 and 710), DEFINE SAMPLE MEMBER (NSDUH Dress Rehearsal pages 727-731), INTROINC, and others, should be tracked according to gender identity.

[15] CDC National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention. 2011. *HIV Infection among Transgender People*. Washington, DC: Centers for Disease Control and Prevention, available at http://www.cdc.gov/hiv/transgender/pdf/transgender.pdf.; see also, *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

[16] Tate, C.C., J.N. Ledbetter, and C.P. Youssef. 2012. A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences. *Journal of Sex Research*. 18:1–10.

[17] *Gender-Related Measures Overview*, 3, The GenIUSS Group. The Williams Institute, February 2013.

shown that 75% of transgender survey respondents, when given the option of self-identifying as transgender, male, or female, will not identify as transgender.[18] However, by identifying respondents whose sex assigned at birth is at variance with their gender identity in addition to individuals who self-identify as transgender, researchers will be better able to identify the entire population of transgender survey participants.

We recommend that gender identity be asked as follows. This question should precede the sex assigned at birth question:

What is your current gender identity?

- *Male*
- *Female*
- *Trans male/Trans man*
- *Trans female/Trans woman*[19]

Recommendation: adopt the GenIUSS group two-step protocol, and ask gender identity immediately prior to sex assigned at birth.[20]

B. Adopt a single question protocol querying gender expression via appearance and mannerisms

In addition to gender identity and sex assigned at birth, how a person's gender expression is perceived can have important health implications. Gender nonconforming youth often face victimization in school, which can result in increased risk of suicidality, depression, and post-traumatic stress disorder, as well as poor academic achievement.[21] Gender nonconforming adults can face increased workplace harassment, discrimination and negative employment actions. Both one- and two-question protocols for surveying

[18] Schilt, Kristen and Jenifer Bratter. 2010. *From Multiracial to Multigender? Assessing Attitudes toward a Transgender Category on the Census*. Presented at the 2010 Annual Meeting of the American Sociological Association, Atlanta, GA.

[19] In addition to these four response choices, the question in the GenIUSS group's overview also includes "genderqueer" and "different identity: ____" as available responses. The NSDUH currently segregates certain physiological and sociological questions by gender. Because sociological questions would most appropriately be tracked by gender identity, and because there is no consistent structure for question responses that would accurately and reliably reflect a genderqueer or "different identity ____" response, we have removed them from the recommended question. However, it is important to note that by not allowing for gender identities beyond the exclusive options of male, trans male, female , and trans female, individuals whose gender identity does not conform to the gender binary options of male or female may have difficulty selecting a response to the gender identity item and their gender and in turn, due to the gender segregated nature of the instrument, their experiences and characteristics, may not inaccurately assessed.

[20] As an alternative, if SAMHSA is not prepared to move forward with a gender identity question at this time, we strongly urge you to adopt a combined sexual orientation and gender identity question, adding "transgender" to the proposed QD63, and changing the question so that multiple options may be checked at once. This would at least allow SAMHSA to capture information about transgender respondents, and know for which respondents other questions are likely to be incorrectly coded.

[21] Roberts, A.L., M. Rosario, N. Slopen, J.P. Calzo, and S.B. Austin. 2013. Childhood Gender Nonconformity, Bullying Victimization, and Depressive Symptoms Across Adolescence and Early Adulthood: An 11-Year Longitudinal Study. *Journal of the American Academy of Child & Adolescent Psychiatry*. (forthcoming, accepted November 16, 2012); Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Childhood Gender Nonconformity: A Risk Indicator for Childhood Abuse and Posttraumatic Stress in Youth. *Pediatrics*. 129(3): 571-573; Roberts, A.L., M. Rosario, H.L. Corliss, K.C. Koenen, and S.B. Austin. 2012. Elevated Risk of Posttraumatic Stress in Sexual Minority Youths: Mediation by Childhood Abuse and Gender Nonconformity. *American Journal of Public Health*. 102(8): 1587-1593. See also, *Gender-Related Measures Overview*, 5, The GenIUSS Group. The Williams Institute, February 2013, and *Including a Gender Expression Question on the YRBS Can Help Assess Disparities and Achieve Better Outcomes for Gender Nonconforming Students*, All Students Count Coalition, available at http://amplifyyourvoice.org/wp-content/uploads/2012/10/ASC-Gender-Expression-FAQ3.pdf [hereinafter *All Students Count*].

gender expression have been successfully tested. In 2010, Wylie et al. tested the following two-question protocol on young adults in New England, which queries both appearance and mannerisms:[22]

Gender Expression

1. A person's appearance, style, or dress may affect the way people think of them. On average, how do you think people would describe your appearance, style, or dress?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

3. A person's mannerisms (such as the way they walk or talk) may affect the way people think of them. On average, how do you think people would describe your mannerisms?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

In 2012, the Gay, Lesbian & Straight Education Network (GLSEN) merged this two-question protocol into one question querying both mannerisms and appearance to fit the requirements of the Youth Risk Behavior Survey (YRBS). GLSEN then conducted cognitive testing and pilot testing of this item with a sample of school-age adolescents. Cognitive testing indicated that the item was understandable to a diverse range of 14-18 year-old youth, including cisgender[23] youth (heterosexual, lesbian, gay, and bisexual) and transgender youth. The CDC subsequently slightly amended and then approved the question as an optional question for state and local agencies to add to the 2013 YRBS.[24] The final YRBS question appears below:

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people at school would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

[22] Wylie, S.A., H.C. Corliss, V. Boulanger, L.A. Prokop, and S.B. Austin. 2010. *Socially assigned gender nonconformity: a brief measure for use in surveillance and investigation of health disparities*. Sex Roles. 63(3-4): 264-276.

[23] Cisgender is a term that refers a person whose gender identity and sex assigned at birth are congruent.
[24] *All Students Count.*

We recommend adopting the YRBS single-question protocol, but eliminating the words "at school" from the question to allow for the collection of gender expression information on all respondents. Our recommended question reads as follows:

A person's appearance, style, dress, or the way they walk or talk may affect how people describe them. How do you think other people would describe you?

- *Very feminine*
- *Mostly feminine*
- *Somewhat feminine*
- *Equally feminine and masculine*
- *Somewhat masculine*
- *Mostly masculine*
- *Very masculine*

This question can be used in conjunction with either sex assigned at birth or gender identity in order to gauge gender nonconformity, although it is preferred to measure it against gender identity. When measured against sex assigned at birth, transgender respondents who are gender nonconforming would be coded erroneously as gender conforming. For example, a transgender man who is "somewhat feminine", but who has indicated "female" as his sex assigned at birth would be coded as a "somewhat feminine female." Although he is in reality gender nonconforming, he will not be coded as such. This issue would not arise if gender expression were matched against gender identity. As with other sociological questions in the NSDUH, it would be appropriate to track this question based on gender identity, and to reverse the order of response options accordingly.

3. Accurately Capturing Information About Sexual Orientation and Attraction

We welcome the addition of questions relating to sexual orientation and attraction to the NSDUH, and strongly encourage SAMHSA to adopt these proposed revisions, with slight amendment in order to ensure data accuracy and integrity.

A. Adopt proposed QD63 with "gay or lesbian" as a static response choice, and do not alter this question based on gender or sex assigned at birth.

Currently, QD63 is proposed to read as follows:

QD63 *Do you consider yourself to be*:
1 Heterosexual, that is straight;
2 [IF QD01=9 THEN "Lesbian or] Gay
3 Bisexual?

Sexual orientation, along with several other sociological questions, is currently being tracked in reference to gender. It would actually be simpler to not track this question in reference to gender identity or sex at all, and to have "gay or lesbian" be consistently available as a static item. In doing so, every respondent who identifies as lesbian, gay, or bisexual would be able to accurately respond to the question, regardless of whatever decisions are made with regard to the gender tracking of the survey. Moreover, many women who are attracted to other women identify as gay, so even if the question were tracked by gender identity, it would be appropriate to have a static response including both options. Additionally, SMART best practices for adoption of this question include "gay or lesbian" as a static response choice.[25]

[25] *Best Practices for Asking Questions about Sexual Orientation on Surveys*, the Sexual Minority Assessment Research Team (SMART), November 2009, 8. http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf.

Recommendation: Adopt the proposed question on sexual orientation, but do not alter the question based on the gender or sex of the respondent. "Both gay" and "lesbian" should both be visible for all respondents.[26]

B. Adopt QD62 as proposed and track according to gender identity.

Question QD62 currently reads as follows:

QD62 *People are different in their sexual attraction to other people. Which best describes your feelings? Are you:*
[IF QD01=5]
1 Only attracted to females?
2 Mostly attracted to females?
3 Equally attracted to females and males?
4 Mostly attracted to males?
5 Only attracted to males?
6 Not sure?
DK/REF

[IF QD01=9]
1 Only attracted to males?
2 Mostly attracted to males?
3 Equally attracted to males and females?
4 Mostly attracted to females?
5 Only attracted to females
6 Not sure?

Unlike QD63, this question should be tracked with other sociological questions according to gender identity. Because of gender tracking of the proposed question, a coded response of "1" from both genders surveyed indicates sole attraction to individuals of the same gender. Under a system where only one marker of gender (or, as amended, sex assigned at birth) is tracked, this could result in inverse data collection for transgender respondents. For example, a transgender woman who was being tracked as "male" per her sex at birth, would be presented with "Only attracted to males" as the option meant to represent sole attraction to the same gender. If she identifies as a lesbian, and solely experiences attraction to other women, she will select "5, solely attracted to females." This will then be coded, erroneously, as heterosexuality. Therefore, in order to accurately capture information about sexual attraction for all respondents, it is important to adopt a question asking about gender identity and then track QD63 based on gender identity.

Recommendation: adopt the proposed question on sexual attraction and track the order of the response options in reference to gender identity.

4. MORE EFFECTIVELY ADDRESSING STUDENT HEALTH THROUGH ASSESSING BULLYING

[26] As noted in *supra* n. 20, a possible alternative means of collecting information about transgender respondents would add "transgender" to the question options, and respondents would be able to check multiple responses. This option is less ideal for this survey than a two-step approach for identifying transgender respondents because it will underreport transgender people who identify as simply "male" or "female." This alternative question would also continue to result in inaccurate data collection with regard to transgender people and sociological information.

Effectively addressing the behavioral health impact of bullying that affects young people requires data that accurately reflects the safety of our nation's schools.[27] The NSDUH is an ideal survey instrument to collect data on student experiences with bullying and associated health outcomes. Currently, the Youth Experience section of the proposed survey instrument does not ask youth to report on experiences of bullying in school. **We recommend the addition of questions relating to bullying because of the important health outcomes associated with it.**

Data about safe schools is enormously important because it gives us a better picture of school climate issues as a whole, and allows us to implement more effective and efficient interventions. Research has shown that school climate is a nation-wide issue, and that marginalized populations face increased bullying and harassment in schools. In GLSEN's2011 National School Climate Survey, 81.9% of LGBT students reported being verbally harassed, 38.3% reported being physically harassed and 18.3% reported being physically assaulted at school because of their sexual orientation in 2011.[28] GLSEN also found in their national survey that LGBT students who were victimized at school faced increased rates of depression, lower self-esteem, and lower school-connectedness.[29] According to the CDC, one in five high school students report that they were bullied on school property in 2009.[30] Technology has increased the means and ways for bullying to occur in our school system. In 2010, one in five adolescents said that they had been cyber-bullied at some point in their lives, and about the same number admits to having been a cyber-bully. One in ten adolescents had been both a cyber-bully and a victim.[31]

School safety can have a tremendous impact on a youth's ability to study and graduate. According to the Department of Health and Human Services bullying can lead to decreased academic achievement—GPA and standardized test scores—and school participation.[32] Students who are bullied are more likely to miss, skip, or drop out of school.[33] Information about bullying must be consistently tracked and studied in order to effectively reduce youth dropout rates and prevent negative health outcomes.

We recommend amending the Youth Experience section of the proposed survey instrument to include the following two questions, which were taken from the CDC's 2013 YRBS:

> *The next 2 questions ask about bullying. Bullying is when 1 or more students tease, threaten, spread rumors about, hit, shove, or hurt another student over and over again. It is not bullying when 2 students of about the same strength or power argue or fight or tease each other in a friendly way.*
>
> *During the past 12 months, have you ever been bullied on school property?*
> *A. Yes*
> *B. No*
>
> *During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites, or texting.)*
> *A. Yes*

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[27] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf (detailing high rates of bullying in American schools).
[28] GLSEN, The 2011 National School Climate Survey (2011), http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/002/2106-1.pdf.
[29] Id.
[30] Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance Survey - United States, 2009 (2010), http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf.
[31] Hinduja, S. and Patchin, J.W., Overview on Cyberbullying (2011), http://www.stopbullying.gov/references/white_house_conference/white_house_conference_materials.pdf#overview_of_cyberbullying.
[32] U.S. Dep't of Health and Human Services, Effects of Bullying (Last Visited March 25, 2013), http://www.stopbullying.gov/at-risk/effects/index.html.
[33] Id.

B. No

5. Collecting information about the presence of suicide prevention programs in elementary and secondary schools.

The statistics relating to youth suicidality are staggering, and clearly indicate a public health need to collect better information on suicide prevention efforts. Suicide is the 2nd leading cause of death among young people ages 10 to 24.[34] A nationwide survey by the CDC found that 16% of students reported seriously considering suicide, 13% reported creating a plan, and 8% reporting trying to take their own life in the previous 12 months.[35] Each year, approximately 157,000 youth between the ages of 10 and 24 receive medical care for self-inflicted injuries at Emergency Departments across the United States.[36] 1 out of 6 students' nationwide (grades 9-12) have seriously considered suicide in the past year.[37] These statistics are even more devastating within LGBTQ communities: research has shown that LGB youth are 4 times more likely to attempt suicide as their straight peers, and questioning youth are 3 times more likely.[38] There is less research on experiences of transgender youth, but one study of 31 New York City transgender youth found that nearly half of them had seriously thought about taking their lives and one quarter reported having made a suicide attempt.[39]

Reducing youth suicidality should be one of our highest public health priorities. In order to adequately assess the need for greater suicide prevention funding, research, and outreach for suicide prevention measures, such as the National Suicide Hotline and available Campus Suicide Prevention programs, we should collect information about what programs are successfully reaching youth. **We therefore recommend amending the Youth Experience section of the proposed survey instrument to include a question about recent participation in a suicide prevention program.**

This question should mirror YE23c,[40] YE23g,[41] and YE23o,[42] all of which ask about youth prevention programs for negative mental and physical health outcomes. Given the high rates of youth suicide, particularly among at-risk youth populations, amending the NSDUH to include a question about suicide prevention is a natural and necessary extension.

Conclusion

We commend SAMHSA for recognizing the importance of data collection to begin to eliminate the health disparities facing lesbian, gay, bisexual, and questioning individuals. We strongly encourage you to continue to revise the National Survey on Drug Use and Health to allow for targeted and evidence-based solutions to ending the disparities facing transgender people as well. We also urge you to amend the

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[34] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS). Available from www.cdc.gov/ncipc/wisqars.
[35] CDC, Injury Center: Violence Prevention, (2012), http://www.cdc.gov/violenceprevention/pub/youth_suicide.html
[36] Id.
[37] CDC, Youth Risk Behavior Surveillance – United States, 2011, (2011), http://www.cdc.gov/mmwr/pdf/ss/ss6104.pdf
[38] Kann, L, et al. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12 – Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009." MMWR 60(SS07): 1-133. Available from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm
[39] Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) Suicide Life Threat Behav. 527 (2007).
[40] **During the past 12 months** have you participated in a violence prevention program, where you learn ways to avoid fights and control anger?
[41] **During the past 12 months** have you participated in an alcohol, tobacco or drug prevention program outside of school, where you learn about the dangers of using, and how to resist using, alcohol, tobacco, or drugs?
[42] **During the past 12 months** have you participated in pregnancy or sexually transmitted disease prevention programs?

Youth Experience section of the proposed survey instrument to collect better information about suicide prevention programs and bullying.

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

Summer King
SAMHSA Reports Clearance Officer
Room 2—1057
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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*

__ *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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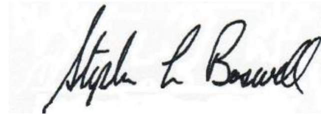
Fenway Institute

Kenneth Mayer, M.D.
Co-Director
Fenway Institute
Professor, Harvard Medical School



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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

Caya Lewis, Director of Outreach and Public Health Policy, Office of Health Reform, DHHS

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

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April 30, 2013

Ms. Summer King
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Dear Ms. King,

We appreciate the opportunity to comment on SAMHSA's National Survey on Drug Use and Health (NSDUH). We are writing to strongly encourage SAMHSA to continue collecting and disseminating the important data it collects on tobacco use behavior.

The tobacco use data collected as part of NSDUH, particularly the initiation data on cigarettes, smokeless tobacco and cigars, are critical to monitoring tobacco use initiation among youth and young adults and to understanding emerging use patterns. These data have been essential in helping the tobacco control and public health communities develop targeted interventions to reduce tobacco use.

NSDUH also provides important data on tobacco brands used most often among population subgroups. NSDUH is currently the only survey that collects this information on an annual basis. These data provide information on how youth and adult smokers respond to tobacco marketing and promotions, and allow the tobacco control community to better understand who is using the various tobacco products and how tobacco use patterns may be changing over time. For instance, it is notable that less than one percent of 12-17 year olds reported using discount moist snuff tobacco brand Grizzly in 2002, but by 2007, it was the top brand among this age group, where it has remained. Having this information helps tobacco control practitioners identify strategies and tactics employed by the tobacco industry to promote the use of particular products and brands.

Finally, we would like to encourage SAMHSA to continue to develop tobacco-related special reports such as "Use of Menthol Cigarettes" and more recently "Smokeless Tobacco Use, Initiation, and Relationship to Cigarette Smoking: 2002 to 2007". Compiling and summarizing data in reports such as these are invaluable to tobacco control advocates and practitioners because they bring to light important trends and information that otherwise might not be known.

The current environment in tobacco control is an especially critical one for continuing this important data collection. There is more happening in terms of tobacco policy change and tobacco industry product and

marketing innovation than perhaps ever before. It is essential that we have data collected in the rigorous fashion employed by NSDUH so it can inform our efforts as we work to reduce tobacco use.

Thank you for your efforts on this important issue.

Sincerely,

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Vice President, Research
Campaign for Tobacco-Free Kids