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Public Comment on the National Institutes of Health FY 2016-2020 Strategic Plan on the Health and Well-Being of Sexual and Gender Minorities (SGM) Request for Comments

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Dear colleagues,

We write to provide comment for the Request for Comments regarding the National Institutes of Health FY 2016-2020 Strategic Plan on the Health and Well-Being of Sexual and Gender Minorities (SGM).

The Fenway Institute works to make life healthier for those who are lesbian, gay, bisexual, and transgender (LGBT), as well as people living with HIV/AIDS and the larger community. We do this through research and evaluation, education and training, policy analysis, and public health advocacy. We are the research division of Fenway Health, a federally qualified health center that serves about 26,000 patients each year.

Goal 1 Objective 1: Encourage extramural and intramural investigators to conduct SGM research in priority areas

The Fenway Institute commends NIH on its goal of prioritizing SGM health research. There is a dearth of data on the health care needs and experiences of sexual and gender minority (SGM) populations, as well as the LGBT health disparities in disease burden, access to care, risk behaviors, and insurance coverage that they experience. We believe that top priority areas of research should include the following:

- Behavioral health: Behavioral health issues such as minority stress, depression, and substance use disproportionately burden SGM populations. For example, studies have shown higher rates of mental health burden, including depression, anxiety, and suicidality, in lesbian, gay, and bisexual people compared to heterosexual people.[1] Studies have also shown that LGBT populations have the highest rates of tobacco,[2] alcohol,[3] and other drug use.[4] Research should focus on

[1] King, M, Semlyen, J, Tai, SS, Killaspy, H, Osborn, D, Popelyuk, D, Nazareth, I. "A systematic review of mental disorder, suicide, and deliberate self harm in lesbian, gay and bisexual people. *BMC Psychiatry*." 2008; 8:70. Cited in Committee on LGBT Health Issues (IOM), 2011, 190.
[2] Lee GL, Griffin GK, Melvin CL. "Tobacco use among sexual minorities in the USA: 1987 to May 2007: A systematic review." *Tob Control*. 2009;18:275-82.

creating and implementing successful behavioral health and substance use interventions and cessation programs that can reduce the behavioral health burden on the LGBT population.

- Resiliency factors: Much research has been done on factors that contribute to LGBT people's vulnerability, but more research needs to be done focusing on resiliency factors, such as family acceptance, community affirmation, and Positive Youth Development approaches to working with LGBT youth. There is a need for more research on interventions that strengthen resiliency among the LGBT population. What are protective, nurturing factors that can be promoted to LGBT youth to counter the effects of social stigma, prejudice, and social isolation? What are the correlates of success in school and adolescence and young adulthood for LGBT youth? How do youth avoid health risk behaviors?[5]
- Adult survivors of child abuse: Rates of childhood sexual abuse among men who have sex with men have been estimated to be as high as 46%.[6] Studies have suggested that childhood sexual abuse can lead to patterns of vulnerability in adult men who have sex with men, including PTSD, substance use, and sexual risk taking.[7] Further research is needed to develop and test detailed assessments of childhood sexual abuse in men who have sex with men and the development of HIV interventions that integrate childhood sexual abuse assessments in addressing mental health and substance use comorbidities.
- Chronic disease and disability: LGBT older adults are more likely to have a disability than older adults in general.[8] This is especially true for transgender older adults. In a study of 2,560 LGBT older adults aged 50-95, 62% of the transgender respondents had a physical disability.[9] Due to the disproportionate burden of HIV on gay and bisexual men and transgender women, attention to older adults living with HIV is also warranted. About half of the HIV-positive population in the United States is now age 50 or older.[10] Older adults living with HIV are more

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[3] Hughes TL. "Alcohol use and alcohol-related problems among lesbians and gay men." *Ann Rev of Nurs Res*. 2005;23:283-325.

[4] Lyons T, Chandra G, Goldstein J. "Stimulant use and HIV risk behavior: The influence of peer support." *AIDS Ed and Prev*. 2006;18(5):461-73.

[5] Cianciotto & Cahill, 168-172.

[6] Boroughs, M.S., O'Cleirigh, C. et al. "Complexity of Childhood Sexual Abuse: Predictors of Current Post-Traumatic Stress Disorder, Mood Disorders, Substance Use, and Sexual Risk Behavior Among Adult Men Who Have Sex with Men." *Arch Sex Behav*. 2015. 44(7): 1891-902.

[7] *Ibid*.

[8] Fredriksen-Goldsen, K.I., H.J. Kim, C. Emlet et al. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual and Transgender Older Adults*. 2011. Seattle, WA: Institute for Multigenerational Health.

[9] *Ibid*.

[10] Effros, R.B., C.V. Fletcher, K. Gebo et al. "Aging and Infectious Diseases: Workshop on HIV Infection and Aging: What Is Known and Future Research Directions." *Clinical Infectious Diseases.* 2008. 47(4):542–53. (Cited in Cahill, S., and R. Valadez. 2013. "Growing Older with HIV/AIDS: New Public Health Challenges." *American Journal of Public Health* 103(3):e7–e15. doi:10.2105/AJPH.2012.301161.)

likely to have comorbidities than other older adults.[11] As people grow older with HIV, their ability to metabolize antiretroviral medications is diminished, resulting in increased toxicity.[12] Taking antiretrovirals for a long time may increase the risk of heart attack[13] and heart disease.[14] HIV infection and antiretroviral therapy are associated with obesity,[15] which presents additional risk factors for heart disease.[16] Preexisting cardiovascular, hepatic, and metabolic complications can be exacerbated by HIV infection itself, immunodeficiency, and by metabolic syndrome and other adverse effects of antiretroviral therapy.[17] Research into disability and chronic disease issues affecting long-term survivors of HIV living into old age is needed.

- Evaluate the effectiveness of school-based interventions to support LGBT and questioning youth: Research is needed to understand whether school-based interventions and policies aimed at supporting LGBTQ youth, such as Gay-Straight Alliances (GSAs), staff training, and nondiscrimination/anti-bullying policies, actually improve the climate for LGBTQ youth.
- Race, ethnicity, and culture in LGBT youth: Research is needed to examine the differences among the experiences of LGBT youth of color from different racial and ethnic groups.[18] How do race, ethnicity, and culture influence LGBT identity development and disclosure of sexual orientation and gender identity?[19]
- Out-of-home LGBT youth: Research is needed on LGBT out-of-home youth, i.e. youth who are homeless, in foster care, in juvenile detention, or in a congregate living facility related to mental health and/or substance use. Most LGBT youth research is school-based, such as the Youth Risk Behavior Survey. While some out-of-home youth are in school, many are not. The disparities in health risk behaviors among LGB youth documented in YRBS data from seven states and six cities[20]

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[11] Deeks, S.G., and A.N. Philips. "HIV Infection, Antiretroviral Treatment, Aging, and Non-AIDS Related Morbidity." *BMJ.* 2009. 338(7689):288–92. (Cited in Cahill and Valadez. 2013. "Growing Older with HIV/AIDS.")

[12] Gebo, K.A. "HIV and Aging: Implications for Patient Management." *Drugs and Aging*. 2006. 23(11):897–913. (Cited in Cahill and Valadez. 2013. "Growing Older with HIV/AIDS.")

[13] Bhavan, K., V. Kampalath, and E.T. Overton. "The Aging of the HIV Epidemic." *Current HIV/AIDS Reports*. 2008. 5(3):150–8. (Cited in Cahill and Valadez. 2013. "Growing Older with HIV/AIDS.")

[14] Deeks and Phillips. "HIV Infection." 2009.

[15] Bhavan et al. "The Aging of the HIV Epidemic." 2008.

[16] Simone, M., and J. Appelbaum. "HIV in Older Adults." *Geriatrics*. 2008. 63(12):6–12. (Cited in Cahill and Valadez. 2013. "Growing Older with HIV/AIDS.")

[17] Kirk, J.B., and M.B. Goetz. "Human Immunodeficiency Virus in an Aging Population, a Complication of Success." *Journal of the American Geriatrics Society*. 2009. 57:2129–38. (Cited in Cahill and Valadez. 2013. "Growing Older with HIV/AIDS.")

[18] Many of these youth research recommendations were first made in Cianciotto, J. & Cahill, S. (2012), 155-172.

[19] Ibid.

[20] CDC *Morbidity and Mortality Weekly Report*, June 6, 2011

may understate the risks facing LGB youth who are not living in their homes of origin.

- Children of LGBT parents: How many school-age youth have LGBT parents? What are their experiences? Studies have shown that children of LGBT parents experience homophobia, violence, victimization, and discrimination at the hands of other youth and school staff.[21,22] Research to better understand how anti-LGBT prejudice affects the children of LGBT parents, and how to reduce this phenomenon, is needed.
- Family acceptance interventions: Family acceptance has been shown protective of LGB youth; family rejection is a risk factor for unprotected sex, substance use, and other behaviors.[23] City health departments are promoting family acceptance as a resiliency factor for LGBT youth. Parents who exhibit a strong degree of religiosity may reject their children for being LGBT. Research is needed to evaluate interventions promoting family acceptance in order to develop effective interventions that can be scaled up to shift social norms toward family acceptance of LGBT youth.
- Racial/ethnic and geographical differences: There is a dearth of research on LGBT people from racial and ethnic minority backgrounds and LGBT people living in rural areas. For example, how are social support networks and experiences of anti-LGBT discrimination different in various racial/ethnic groups and across geographical differences? What are the unique health care needs and priorities of Two Spirit Native Americans and American Indians, as well as Black, Latino, and Asian Pacific Islander LGBT people?
- Gerontological research: Gerontologists distinguish among the "young-old" (ages 65 to 74), the "old-old" (ages 75-84), and the "oldest-old" (age 85 and older). In general, frequency of illnesses and chronic conditions increases with age.[24] The majority of research on LGBT elders looks at the young-old LGBT cohort. More research is needed on the old-old and oldest-old LGBT people.
- Resiliency factors among LGBT elders: It would be useful to better understand resiliency factors among LGBT people of all ages, including elders. What are the factors that can reduce the likelihood of behavioral health burdens, risk behaviors, comorbidities, social isolation, and support healthy aging in place?

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[21] Russell, S., Seif, H., & Truong, N. School outcomes of sexual minority youth in the United States: Evidence from a national study. *Journal of Adolescence*. 2001. *24*, 111–27.

[22] Kosciw, J. G. & Diaz, E. M. *Involved, invisible, ignored: The experiences of lesbian, gay, bisexual and transgender parents and their children in our nation's K–12 schools*. 2008. New York: Gay, Lesbian and Straight Education Network. Retrieved September 25, 2010, from http://www.glsen.org/binary-data/GLSEN_ATTACHMENTS/file/000/001/1104-1.pdf.

[23] Ryan, C., Huebner, D. and Sanchez, J. Family rejection as a predictor of negative health outcomes in white and Latino lesbian, gay, and bisexual young adults. *Pediatrics*. 2009. 123(1): 346-352.

[24] McMahan, S., and R. Lutz. "Alternative Therapy Use among the Young-Old (Ages 65 to 74): An Evaluation of the MIDUS Database." *Journal of Applied Gerontology*. 2004. 23(2):91–103.

- Research on the impact of sexual orientation and gender identity nondiscrimination laws and policies on LGBT health: Reisner et al. (2015) found widespread discrimination against transgender people had negative physical and mental health consequences, and that experiencing discrimination in health care makes transgender people less likely to seek preventive and emergent care.[25] Frederiksen-Goldsen et al. (2009) found that discrimination and relationship quality were associated with depression among chronically ill lesbian, gay, and bisexual (LGB) older adults and their caregivers.[26] These and other studies indicate that nondiscrimination policies, regulations, and laws that reduce LGBT individuals' perceived discrimination could have a positive effect on mental health, including depression and social anxiety, as well as physical health and access to health care among LGBT people. What are the public health effects of institutional practices that affirm LGBT identities and laws and policies that prohibit discrimination on the basis of real or perceived sexual orientation and gender identity and recognize LGBT families?
- Bisexuality research: The Massachusetts Behavioral Risk Factor Surveillance Survey found poorer physical health among bisexual respondents compared with gay, lesbian, and heterosexual respondents, as well as higher rates of mental health issues and smoking.[27] Often bisexual respondents are combined with gay male and lesbian respondents; this can skew results, as often bisexual health outcomes and risk behaviors are significantly worse than those of gay men and lesbians.[28] NIH should fund research to understand bisexual health disparities related to risk behaviors and mental health, and encourage existing health surveys to add questions that would capture information about bisexual identity and same-sex behavior.

Transgender health research: We support the NIH's prioritization of transgender health research. However, in addition to research on the safety and efficacy of hormone use or gender affirmation surgery, which are prioritized in the draft plan, there are other issues requiring more research and investigation. While hormones and surgery are important areas of research, studies have already been done showing the safety and efficacy of hormone

[25] Reisner, S., Hughto, J., Dunham, E., Heflin, K., Begenyi, J., Coffey-Esquivel, J., & Cahill, S. Legal Protections in Public Accommodations Settings: A Critical Public Health Issue for Transgender and Gender-Nonconforming People. *Milbank Quarterly*. 2015. 0(0), 1-32. Retrieved August 11, 2015, from www.milbank.org

[26] Fredriksen-Goldsen, K.I., H.J. Kim, A. Muraco et al. "Chronically Ill Midlife and Older Lesbians, Gay Men, and Bisexuals and Their Informal Caregivers: The Impact of the Social Context." *Sexuality Research and Social Policy Journal of NSRC*. 2009. 6(4):52–64.

[27] Conron, KJ, Mimiaga, MJ, Landers, SJ. "A population-based study of sexual orientation identity and gender differences in adult health." *Am J Pub Health*. 2010; 100(10); 1953-1960.

[28] Matthews D., Blosnich J., Farmer G., & Adams B. "Operational definitions of sexual orientation and estimates of adolescent health risk behaviors." *LGBT Health*. 2013. 1(1). 42-59.

treatment and gender affirmation surgery for transgender people in general.[29] There are many understudied areas of transgender health research that are unrelated to hormones or gender affirmation surgery that the NIH should emphasize, including:

- Behavioral health of transgender people: Transgender people suffer disproportionately from mental health issues such as depression, suicidality, and minority stress that often stem from the widespread discrimination that transgender people face in their everyday lives.[30] More research is needed on behavioral health issues of transgender people to inform interventions that can relieve the disproportionate behavioral health burden currently affecting transgender people. This is especially important in lesser studied transgender populations, such as transgender people of color.
- Transgender children and adolescents: More research needs to be done on how to create an affirmative and healthy environment for transgender children and adolescents. Best practices for surgical and non-surgical gender affirmation treatments in transgender children and adolescents need to be developed.
- PrEP and other HIV prevention needs of transgender women: Transgender women have 49 times the odds of being infected with HIV compared with all adults of reproductive age.[31] This glaring disparity is even more apparent in transgender women of color.[32] Transgender people also experience widespread discrimination, including discrimination in health care settings, which contributes to lack of access to current HIV prevention methods, including PrEP. Furthermore, previous large clinical studies of PrEP have only included a small percentage of transgender women within their study samples despite the disproportionate burden of HIV on transgender women. Because of this, there is a strong need for more research in the area of PrEP and HIV prevention interventions for transgender women.
- Evaluate the impact of nondiscriminatory access to health coverage and care: Research is needed to understand the impact of healthcare discrimination and denial of care on the behavioral and physical health of transgender patients, as well as the effectiveness of interventions

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[29] Coleman, Eli et al. *Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People*. The World Professional Association for Transgender Health. Version 7. 2012.

[30] Keatley, J., Deutsch, M., Sevelius, J., Gutierrez-Mock, L. "Creating a Foundation for Improving Trans Health: Understanding Trans Identities and Health Care Needs." In Makadon, H. et al. *Fenway Guide to Lesbian, Gay Bisexual, and Transgender Health*. 2nd Edition. Pp. 459-479.

[31] Baral, S. D., Poteat, T., Stromdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. "Worldwide burden of HIV in transgender women: A systematic review and meta-analysis." *The Lancet Infectious Diseases*. 2013. 13, 214–222. doi:10.1016/S1473-3099(12)70315-8

[32] The Foundation for AIDS Research. "Trans population and HIV: Time to end the neglect." 2014. Accessed at: http://www.amfar.org/issue-brief-trans-populations-and-hiv-time-to-end-the-neglect/

designed to improve meaningful access to health care and insurance coverage, including nondiscrimination policies, cultural competency training and coverage of transition-related care.

Goal 1 Objective 2: Promote the development and implementation of appropriate measures, methods, and resources to facilitate research relevant to SGM populations

We support the NIH's goal of developing consistent terminology and common research data elements in order to facilitate research relevant to SGM populations. In order to achieve this goal, NIH should promote best practices for collecting and analyzing sexual orientation and gender identity (SO/GI) data, both in clinical settings and on health surveys. In terms of collecting SO/GI data in Electronic Health Records and in clinical settings, we recommend the following standard questions and answer options for use in clinical settings and surveys. The questions and answers below were found acceptable in a diverse set of community health centers across the United States.[33]

1. Do you think of yourself as:
   - ☐ Lesbian, gay, or homosexual
   - ☐ Straight or heterosexual
   - ☐ Bisexual
   - ☐ Something else, please describe: _____
   - ☐ Don't know

2. What is your current gender identity? (Check all that apply.)
   - ☐ Male
   - ☐ Female
   - ☐ Female-to-male (FTM)/transgender male/trans man
   - ☐ Male-to-female (MTF)/transgender female/trans woman
   - ☐ Genderqueer, neither exclusively male nor female
   - ☐ Additional gender category (or other), please specify: _____
   - ☐ Decline to answer

3. What sex were you assigned at birth on your original birth certificate? (Check one.)
   - ☐ Male
   - ☐ Female
   - ☐ Decline to answer

<u>Best practices for analyzing SO/GI data:</u> It is also important to promote best practices for analyzing the SO/GI data after it is collected. The Fenway Institute

[33] Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, Makadon H. "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." *PLOS One.* 2014. 9(9). doi:10.1371/journal.pone.0107104

recommends that data for gay men and lesbians not be lumped together into one category for analysis, as this can obscure important differences between the two distinct populations. For example, studies have shown that sexual minority adolescent males are at significantly greater odds of engaging in unhealthy weight management behaviors, such as fasting for greater than 24 hours, using diet pills, or vomiting/using laxatives, compared to heterosexual males.[34] In contrast, sexual minority adolescent females were found to be more likely to be overweight or obese, and almost twice as likely to perceive themselves as being healthy or underweight despite being overweight or obese compared to heterosexual females.[35] These important differences in weight management and perception could be obscured if gay and lesbian people are analyzed as a single group instead of as distinct groups.

Fund a research network of community health centers, research hospitals to track an ongoing clinical cohort of LGBT patients and improve understanding of LGBT health: In order to best facilitate sharing of SO/GI data for research relevant to SGM populations, we recommend the formation of a research network of teaching hospitals and community health centers for collecting and sharing clinical data from a large and diverse population of LGBT patients. We envision this research network to function similarly to the CFAR Network of Integrated Clinical Systems (CNICS) Research Network. The CNICS Research Network is the first electronic medical records-based network poised to integrate clinical data from a large, diverse population of HIV-infected people. This research network provides the critical infrastructure and data necessary to support HIV clinical outcomes and comparative effectiveness research because CNICS is able to capture a broader range of information associated with the rapidly changing course of HIV disease management than data provided by structured interviews or retrospective medical review. Similarly, an LGBT health research network would be able to provide an ongoing clinical cohort to understand the health care needs of LGBT patients. Such a research network could play a transformative role in SGM health research and inform improvements to care that can reduce LGBT health disparities.

Community-based participatory research: We also encourage continued support and funding for CBPR that includes communities in the development of research questions and methodologies, and in the translation and communication of research findings.

Goal 2 Objective 4: Encourage cultural competency training and opportunities on the specific characteristics of SGM-specific research to NIH-funded extramural and intramural clinical research trainees and researchers

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[34] Hadland, S., Austin, S., Goodenow, C., and Calzo, J. "Weight Misperception and Unhealthy Weight Control Behaviors Among Sexual Minorities in the General Adolescent Population." *Journal of Adolescent Health*. 2014 March; 54(3): 296-303. doi:10.1016/j.jadohealth.2013.08.021.

[35] *Ibid*.

Evaluate cultural competency training: We commend NIH for including cultural competency training in the Strategic Plan. There are several resources already available for cultural competency training for LGBT issues in health care settings. For example, the National LGBT Health Education Center, based at the Fenway Institute, is a multi-disciplinary team of clinicians, educators, and public health professionals with expertise in LGBT health care and research. They provide educational programs, resources, training, and technical assistance to health centers, hospitals, health departments and providers across the US with the goal of optimizing high quality and culturally competent care for LGBT people. In addition to increasing cultural competence training using resources like the National LGBT Health Education Center, there is a strong need for systematic evaluation research of existing LGBT cultural competency trainings. This evaluation research would be helpful in measuring the effectiveness of cultural competency training and technical assistance programs and resources by measuring outcomes among staff and among LGBT patients in institutions that have completed cultural competency training.

Expand upon programs proven successful in training racial and ethnic minority researchers in LGBT and Two Spirit health issues: The Indigenous HIV/AIDS Research Training Program and the Indigenous Substance Abuse, Medicines, and Addictions Research Training Program are two successful efforts to support the development of American Indian/Alaska Native researchers, many of them Two Spirit and/or LGBT. We encourage NIH to learn from the successes of these efforts and expand these projects to address other health issues affecting Two Spirit people and other LGBT people.

The Fenway Institute commends NIH on its thorough approach to increasing SGM health research to improve the health and well-being of SGM populations. We thank you for the opportunity to provide comment. Should you have any questions or concerns regarding the suggestions provided, please feel free to contact Sean Cahill, PhD, Director of Health Policy Research, at scahill@fenwayhealth.org or Tim Wang, MPH, LGBT Health Policy Analyst, at twang@fenwayhealth.org.

Sincerely,

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