

July 24, 2017

Heather Menne

U.S. Department of Health and Human Services
Administration for Community Living
Washington, D.C. 20201

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RE: Agency Information Collection Activities; Submission for OMB
Review; Comment Request; Revision of a Currently Approved
Collection (ICR Rev); National Survey of Older Americans Act
Participants (NSOAAP)

Dear Dr. Menne,

The Fenway Institute submits this comment in response to the Notice posted by the Administration for Community Living (ACL) regarding the National Survey of Older Americans Act Participants (NSOAAP) on June 22, 2017. We are pleased to see that the question regarding sexual orientation was added back in for the proposed 2017 NSOAAP survey. However, the transgender status question was not added back in. We urge the ACL to keep both the sexual orientation question and the follow-up transgender status question for the proposed NSOAAP survey.

The NSOAAP has included a sexual orientation question and a follow-up question to measure transgender status since 2014. Collecting data on lesbian, gay, bisexual, and transgender (LGBT) older adults and the extent to which they access elder services is critically important for reducing the health disparities that this population experiences. Studies have shown that older LGBT adults are more likely to report being physically disabled or have poor mental health outcomes compared to the general population.¹ LGBT elders are also more likely to be isolated than their peers.² As such, many LGBT older adults may be in need of elder services. However, research indicates that they may be less likely to access formal caregiving support and other elder services.³ Experiences of discrimination or anticipatory fear based on negative experiences of friends in mainstream elder service settings causes many LGBT elders to not seek the support services they need to age in place and thrive in older adulthood.⁴

¹ Fredriksen-Goldsen, K.I., H.J. Kim, C. Emlet et al. 2011. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health.

² MetLife Mature Market Institute and American Society on Aging. 2010. *Still Out, Still Aging: The MetLife Study of Lesbian, Gay, Bisexual and Transgender Baby Boomers*. Westport, CT: MetLife. <http://www.lgbtagingcenter.org/resources/pdfs/StillOutStillAging.pdf>

³ U.S. Administration on Aging. 2001. Fact sheet: The many faces of aging. Washington, DC.

⁴ Stein G, Beckerman N, Sherman P. 2010. Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *J Gerontol Soc Work*. 2010;53(5):421-35.

Transgender people in particular experience high rates of economic instability, disability, and mental health burden. The 2015 United States Transgender survey of nearly 28,000 transgender respondents found that nearly one third of participants (29%) were living in poverty, which is twice the rate of the general population. The survey also found that 39% of respondents had one or more disabilities as described by the American Community Survey, compared to 15% of the general population. Furthermore, 39% of respondents reported experiencing serious psychological distress in the month prior to completing the survey, compared to 5% of the general population, and 40% of respondents had attempted suicide in their lifetime. Respondents also indicated that they commonly experienced discrimination in accessing healthcare services, with 33% of respondents reporting at least one negative experience, such as being verbally harassed or refused treatment.⁵

Older Americans are more likely to hold anti-gay views than younger age cohorts,⁶ and they are also more likely to hold inaccurate beliefs about the casual transmission of HIV.⁷ These can both contribute to creating a more hostile environment toward LGBT older adults in mainstream elder service facilities. Due to the high rates of disability and mental health burden, LGBT older adults may be in greater need of elder services, but they may forego accessing these services due to past experiences of discrimination.

In order to better understand the needs and experiences of older LGBT adults, and especially the needs of older transgender adults, it is critical to collect population-level sexual orientation and gender identity (SOGI) data. SOGI data collection questions are also now included in many public health surveys, such as the Behavioral Risk Factor Surveillance System. While we are pleased that the sexual orientation question was added back in to the proposed 2017 NSO AAP survey, in order to better understand the needs and improve the health and well-being of older transgender adults, it is critical that a transgender status or other gender identity question also be restored to the proposed NSO AAP survey. We encourage ACL to consider adding a two-step question, first asking current gender identity, and then asking for sex assigned at birth.⁸ It could also use the transgender question asked on many state BRFSS surveys.⁹

Some may say that the gender identity question should be removed due to the small number of older adults who identify as transgender. We do not believe this is a legitimate reason to remove this question, as other surveys of older Americans have also found lower percentages of participants that identified as

⁵ James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.

⁶ Anderson, R., Fetner, T. 2008. Cohort Differences in Tolerance of Homosexuality: Attitudinal Change in Canada and the United States, 1981-2000. *Public Opinion Quarterly* 72(2): 311-330.

⁷ 2012 Survey of Americans on HIV/AIDS. Washington, DC: Kaiser Family Foundation; 2012.

Available at: <http://www.kff.org/hivaids/poll-finding/2012-survey-of-americans-on-hivoids/>

⁸ Cahill S, Makadon H, Baker K. 2014. *Do Ask, Do Tell: A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings*. Boston: Fenway Institute, Center for American Progress

⁹ Centers for Disease Control and Prevention. 2014. 2014 Behavioral Risk Factor Surveillance System Questionnaire. https://www.cdc.gov/brfss/questionnaires/pdf-ques/2014_brfss.pdf

transgender. In addition, often response rates to SOGI questions are low when new questions are first added to a survey. The small number of older adults who identified as transgender on the NSOAAP survey is also in line with small number of people who identify as transgender in the general population, with an estimated 0.6% of adults identifying as transgender in the United States.¹⁰ It is essential that ACL follow the growing consensus among federal agencies and professional health organizations that SOGI data should be collected to better understand LGBT people's experiences in elder services and other settings. Collecting SOGI data in the NSOAAP is especially important, as LGBT older adults, and especially transgender older adults, experience high rates of economic insecurity, social isolation, health disparities, and discrimination. We therefore strongly urge you to restore a gender identity question to the 2017 NSOAAP.

Should you have any questions, please contact Sean Cahill at scahill@fenwayhealth.org or Tim Wang at twang@fenwayhealth.org. Thank you for considering this comment.

Sincerely,

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¹⁰ Flores, A., Herman, J., Gates, G., Brown, T. 2016. How many adults identify as transgender in the United States? The Williams Institute. Available at: <https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf>