



HUMAN
RIGHTS
CAMPAIGN®

July 24, 2017

Heather Menne
U.S. Department of Health and Human Services
Administration for Community Living
Washington, DC 20201

**RE: Public Comment Request; Revision of a Currently Approved Collection
(ICR Rev); National Survey of Older Americans Act Participants (NSOAAP)**

To Whom It May Concern:

On behalf of the Human Rights Campaign's nearly two million members and supporters nationwide, I write in response to the request for public comment regarding the revised draft of the National Survey of Older Americans Act Participants (NSOAAP) published June 22, 2017. As the nation's largest organization working to achieve equal rights for the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community, HRC strongly supports comprehensive federal data collection efforts that directly address sexual orientation and gender identity. We were deeply concerned to learn that the Administration for Community Living (ACL) proposed a single change to the 2017 National Survey of Older Americans Act Participants (NSOAAP)—the removal of a question relating to sexual orientation. We are pleased that in response to a large number of public comments the revised draft includes this important and necessary question. In addition to the re-incorporation of the question pertaining to sexual orientation, HRC also urges ACL to include specific information gathering regarding transgender status and gender identity. The continued exclusion of transgender older Americans from this critical survey continues to ignore known health and service disparities, and signals federal indifference toward and neglect of the experiences and needs of this already vulnerable population.

The exclusion of transgender respondents is inconsistent with the National Academy of Sciences (formerly the Institute of Medicine) report on LGBT health.

In 2010 in response to the lack of data available on the healthcare needs of the LGBTQ community, the Department of Health and Human Services (HHS) commissioned a report from the National Academy of Sciences (formerly the Institute of Medicine, or IOM) to assess the health status of LGBTQ people.¹ The report's findings were clear and telling. It specifically addresses the health disparities and unique needs facing older LGBTQ adults including barriers to healthcare services – like those provided under the Older Americans Act. The report highlights several areas of concern regarding transgender older adults including high rates of sexual assault and violence,² a general absence of data and invisibility in research and surveys,³ and rates of family rejection and isolation higher than any other population within the LGBTQ community.⁴ The report also finds that “the combined stigma of being elderly and transgender can serve as a strong traumatizing force, potentially exacerbating both forms of discrimination and stigma.”⁵

The report specifically addresses transportation, isolation, and the failure of federal government programs to meet the needs of LGBTQ older adults as factors that undermine the health status of this population. Finally, the report also concludes that data collection –specifically data collected through federal funded surveys like the NSOAAP must include questions directly addressing both sexual orientation and gender identity. More specifically the authors note that, “including variables to measure sexual orientation and gender identity in a variety of studies (e.g., through the addition of appropriate questions on gender identity and sexual orientation to the demographic section of questionnaires) would generate much-needed data on LGBT populations that could assist in assembling a reliable body of evidence regarding their health status.”⁶

The NSOAAP purports to directly assess several areas that speak directly to barriers identified by the National Academy including caregiver support, case management, nutrition and homemaker support, and transportation.⁷ ACL's decision to exclude transgender respondents from the 2017 survey ignores these critical findings and unnecessarily forfeits a valuable research opportunity as described by the National Academy.

¹ IOM (Institute of Medicine). 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press.

² *Id.* at 271 (Noting that a 2001 study found 58% of transgender people over the age of 60 had experienced sexual assault before age 19).

³ *Id.* at 270.

⁴ *Id.* at 149 (Referencing a 2005 study that found higher rates of family rejection for LGBTQ led to an increased risk of suicide, depression, and risk taking).

⁵ *Id.* at 270.

⁶ *Id.* at 300.

⁷ Administration on Community Living, *Welcome to the National Survey of Older American Act Participants*, available at: <https://aoasurvey.org/default.asp>.

Gender identity has been uniformly considered a health disparity population by HHS.

For almost a decade, HHS has consistently considered transgender people to be a health disparity population for purposes of HHS-funded programs and services. Healthy People 2020 provides that, “Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or ***gender identity***; geographic location; or other characteristics historically linked to discrimination or exclusion.”⁸ The Healthy People report provides science-based national objectives designed to improve the health of every American. One of the five core missions detailed by the initiative is to identify critical research areas and data collection needs and opportunities. Healthy People 2020 specifically provides that recognizing the impact on health of social determinants – which include factors like sexual orientation and gender identity – is essential to improving the health and well-being of the nation.

The National Institutes of Health has also formally designated sexual and gender minorities as a health disparity population for purposes of NIH research. The term "sexual and gender minorities" includes lesbian, gay, bisexual, transgender, and queer people. This designation recognizes the devastating health disparities facing LGBTQ people across the nation and the need for a concerted federal research response. In announcing this designation NIH provided that, “mounting evidence indicates that SGM populations have less access to health care and higher burdens of certain diseases, such as depression, cancer, and HIV/AIDS. But the extent and causes of health disparities are not fully understood, and research on how to close these gaps is lacking.”⁹ The continued exclusion of gender identity from the NSOAAP places the survey and ACL a decade behind consistently stated research and data collection goals relating to LGBTQ older adults created by our nation’s most respected institutions.

The NSOAAP must include a specific question regarding gender identity to ensure compliance with the mission of the Older Americans Act.

The current gender question included in the survey (DE1) provides the following response choices: “male”, “female”, “refused”, and “don’t know.” This question fails to capture data regarding the gender identity of respondents and subsequently does not identify transgender elders in survey analysis and reporting. It also fails to provide elders with the opportunity to self-identify – a general best practice. We urge ACL to look to other federal surveys that

⁸ U.S. Department of Health and Human Services. The Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020 [Internet]. Section IV: Advisory Committee findings and recommendations. Available from: http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf.

⁹ National Institutes of Health, National Institute on Minority Health and Health Disparities, *Directors Message: Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes*, available at: <https://www.nimhd.nih.gov/about/directors-corner/message.html>.

actively engage gender identity and transgender status. For example, the Centers for Disease Control and Prevention’s Behavioral Risk Factor Surveillance System (“BRFSS”), which is the largest ongoing health survey system in the world, and its state partners, provide a number of examples of how ACL can successfully identify transgender individuals.¹⁰ The Gender Identity in U.S. Surveillance (GenIUSS) Group provides another, particularly effective, and well-vetted two-step approach to collecting information about gender identity.¹¹

We appreciate the steps that ACL has taken to remedy the harmful revisions made to the 2017 NSOAAP relating to sexual orientation, but we urge ACL to recognize that these changes are far from complete. ACL and the federal government must take proactive steps to incorporate transgender older adults within this critical survey.

Sincerely,



Sarah Warbelow
Legal Director

¹⁰ The 2013 Massachusetts SOGI module for the BRFSS includes 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; or No. See Williams Inst., Best Practices for Asking Questions to Identify Transgender and Other Gender Minorities on Population-based Surveys. Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.

¹¹ Survey administrators ask people their sex assigned at birth followed by their current gender identity. See Williams Inst., Best Practices for Asking Questions to Identify Transgender and Other Gender Minorities on Population-based Surveys. Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>.