



May 12, 2017

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

***Public Comment on Document No. 2017-04843, Collection of Information,
National Survey of Older Americans Act Participants***

Submitted via e-mail: Heather.Menne@acl.hhs.gov

Dear Ms. Menne:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”) appreciates the opportunity to provide comments in response to the Notice of Proposed Collection of Information published in the Federal Register on March 13, 2017, at 82 FR 13457-58. Lambda Legal is the oldest and largest national legal organization dedicated to achieving full recognition of the civil rights of lesbian, gay, bisexual, and transgender (“LGBT”) people and everyone living with HIV, through impact litigation, policy advocacy, and public education. Lambda Legal has been a leader in the fight to ensure that LGBT older adults and people aging with HIV have equal access to the programs, facilities, benefits, and services designed to support healthy and successful aging, including through a number of cases in which Lambda Legal has represented elderly and disabled members of the LGBT population.

On behalf of Lambda Legal, please accept the following comments regarding the Department of Health and Human Service’s (“HHS”) information collection requirements relating to the Administration for Community Living’s (“ACL”) consumer assessment surveys to measure program performance for programs funded under Title III of the Older Americans Act (“OAA”), the National Survey of Older Americans Act Participants (“NSOAAP”). We are particularly concerned about the removal of LGBT people from the 2017 Draft Survey Instrument. We appreciate the opportunity to provide our views.

Lambda Legal strongly supports evidence-based policy making. We believe that the federal data in the NSOAAP is critical for evaluating whether federally-funded aging programs, including nutrition, transportation, case management, homemaker, and

caregiver support services for seniors, accurately reflect the demographics of the United States. Ensuring such accuracy will better serve ACL in its research and provision of critical services, and will result in better-informed decisions about how to utilize limited public resources to meet the needs of older adults across the country who seek to lead productive, active and self-determined lives.

In that vein, it is imperative that the NSOAAP paint an accurate picture of diverse communities, including through accurate data about the existence of LGBT people within the population being served by the aging network. High quality, accurate data that capture the diversity of our community are essential to ensuring that LGBT older adults “count,” both in a literal sense and in terms of fundamental protections for a vulnerable population. Data sets that do not include sexual orientation and gender identity information are inadequate and incomplete.

It is well-established that LGBT people face substantial barriers to successful aging. First, LGBT older adults experience higher rates of social isolation and have more precarious support networks than their non-LGBT contemporaries. They are more likely to live alone, less likely to have children, and more likely to be alienated from their families of origin – the predominant source of informal caregiving in this country.¹ As a result, LGBT seniors often look to peer-based support networks, which can leave them without needed care as those peers face their own health and aging challenges or die.²

Second, LGBT older adults have experienced a lifetime of discrimination, social exclusion, stigmatization, and the need to conceal their identities, resulting in both diminished health outcomes and diminished resources to support them as they age.³ More specifically, LGBT seniors have faced greater financial instability and fewer opportunities to build savings as a result of employment discrimination and exclusion

¹ See Soon Kyu Choi & Ilan H. Meyer, *LGBT Aging: A Review of Research Findings, Needs, and Policy Implications*, The Williams Institute, at 8 (Aug. 2016), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-A-Review.pdf>; LGBT Movement Advancement Project & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (MAP & SAGE), *Improving the Lives of LGBT Older Adults*, at 6-7 (2010), <http://www.lgbtmap.org/file/improving-the-lives-of-lgbt-older-adults.pdf>.

² See Karen I. Fredriksen-Goldsen, *The Future of LGBT+ Aging: A Blueprint for Action in Services, Policies, and Research*, *Generations: Journal of the American Society on Aging*, vol. 40, No. 2, at 9-10 (2016).

³ See, Fredriksen-Goldsen, *supra* n.2, at 9.

from legal and social programs designed to provide financial assistance to older adults, resulting in higher poverty rates than their non-LGBT peers.⁴

Third and relatedly, LGBT older adults face dramatic health disparities, along with high levels of discrimination in the provision of health care, substandard health care, and obstacles to accessing health care. Studies have shown the LGBT older adults have higher rates of disability, mental health challenges, chronic health problems like asthma, diabetes, HIV/AIDS, obesity, and rheumatoid arthritis, and certain illnesses such as cancer. These conditions are exacerbated by the tendency of LGBT older adults to withhold information about their identities from providers and to delay testing and screening for fear of discrimination.⁵ This fear is warranted. In 2009, Lambda Legal conducted a survey, with the help of over 100 partner organizations, as part of a national Health Care Fairness Campaign. The results of this survey revealed that LGBT people and people living with HIV, and particularly people of color, experience widespread discrimination in health care, ranging from outright refusals to provide care to harsh verbal and physical treatment by health care providers. The results were particularly pronounced for LGBT seniors, who are significantly more likely to have faced discrimination in health care than their younger counterparts.⁶

Finally, and most critically with regard to the NSOAAP, LGBT older adults lack access to culturally competent aging programs and services. This is particularly problematic in light of their increased need for these services given their limited support networks. Having confronted discrimination from entities traditionally relied upon for

⁴ See Choi and Meyer, *supra*, n.1, at 8-10; M.V. Lee Badgett, et al., *New Patterns of Poverty in the Lesbian, Gay and Bisexual Community*, Williams Institute (2013), <https://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/lgbt-poverty-update-june-2013/>.

⁵ See Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, and Susan E. Barkan, *Disability Among Lesbian, Gay, and Bisexual Adults: Disparities in Prevalence and Risk*, *American Journal of Public Health* 102 (1) (January 2012): e16–e21, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3490559/>; Karen I. Fredriksen-Goldsen et al., *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (Nov. 2011), <http://age-pride.org/wordpress/wp-content/uploads/2012/10/Full-report10-25-12.pdf>; Movement Advancement Project, Services and Advocacy for GLBT Elders, and Center for American Progress, *LGBT Older Adults and Health Disparities* (Sept. 2010), <http://sageusa.org/files/lgbt%20older%20adults%20and%20health%20disparities.pdf>.

⁶ Lambda Legal, *When Health Care Isn't Caring: LGBT Older Adults and Older Adults Living with HIV*, http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-older-adults-and-older-adults-living-with-hiv.pdf (last accessed May 11, 2017).

support, LGBT adults are reticent to access the aging network. As the Administration on Aging, now part of ACL, found in 2001, LGBT older adults are 20 percent less likely than their non-LGBT peers to access governmental aging services like housing assistance, meal programs, food stamps, and senior centers.⁷

Congress passed the OAA to address exactly these types of barriers to successful aging, and the NSOAAP is intended to identify when OAA programs fail to address the needs of the diverse communities of seniors for whom these programs are designed. The ACL has recognized the importance of assessing how these programs are serving LGBT seniors by gathering data about this population for the last three years. It is consequently of great concern that the ACL, through the recent revisions to the NSOAAP, is now threatening to turn its back on the needs of LGBT older adults, even to the point of denying their existence for purposes of accurate data collection. This is particularly troubling in light of the history, over too many generations, of the LGBT community's invisibility to government and researchers, exacerbating misunderstanding and discrimination.

Indeed, the need to collect accurate data on sexual orientation and gender identity, as well as the feasibility of doing so, is already reflected in other federal surveys that collect these data (as was originally the case in the previous version of the NSOAAP).⁸ HHS itself acknowledged in its 2017 LGBT Policy Coordinating Committee Report that “there are many questions still left unanswered about LGBT health and human services, which is why improved data collection and coordination of research efforts will continue to be at the forefront of our efforts in this area.”⁹ As the report further stated, the collection of sexual orientation and gender identity data “will prove invaluable in informing the entire process.”¹⁰

Finally, in the federal government's assessment of programs that help older adults age successfully in their homes and communities, a thorough and meaningful analysis of

⁷ See Choi and Meyer, *supra*, n.1, at 6.

⁸ See Baker, K. and Durso, L. E., *Filling in The Map: The Need for LGBT Data Collection*, Ctr. For Am. Progress (September 16, 2015), <https://www.americanprogress.org/issues/lgbt/news/2015/09/16/121128/filling-in-the-map-the-need-for-lgbt-data-collection/>.

⁹ *Advancing LGBT Health & Well-Being: 2016 Report*, HHS LGBT POLICY COORDINATING COMM., (2016), available at <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

¹⁰ *Lesbian, Gay, Bisexual, and Transgender Health: Objectives*, OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION, available at <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives>.

the needs of affected demographic groups is necessary for the proper performance of ACL's functions. Ensuring that LGBT seniors and their caregivers are being supported by OAA programs in a comprehensive and non-discriminatory fashion is core to ACL's mission of "maximize[ing] the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers."¹¹ The more people are reached through OAA programs, the more they can contribute to society, and the less they will need more costly and burdensome forms of government assistance.

For these reasons, we urge the Administration for Community Living to reinstate the question pertaining to LGBT individuals that has been removed through the March 2017 revisions to the NSOAAP. We appreciate the opportunity to comment on this important matter.

Sincerely,



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Counsel and Seniors Strategist

¹¹ https://acl.gov/About_ACL/Index.aspx.