

November 27, 2017

Submitted via e-mail: heather.menne@acl.hhs.gov

Administration for Community Living
U.S. Department of Health and Human Services
330 C Street SW
Washington, DC 20201

Re: Agency Information Collection Activities; Public Comment Request; Redesign of Existing Data Collection; National Survey of Older Americans Act Participants

To Whom It May Concern:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”) appreciates the opportunity to provide these comments to the Department of Health and Human Service’s (“HHS” or “the Department”) in response to the September 26, 2017, Notice of Opportunity for Comment on a proposed revision to existing data collection related to the National Survey of Older Americans Act Participants (“NSOAAP”). 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 protect the health care needs of LGBT people and people living with HIV, including through numerous cases in which Lambda Legal has represented elderly and disabled members of the LGBT population.

Lambda Legal additionally appreciates that HHS’s information collection requirements relating to the Administration for Community Living’s (“ACL”) consumer assessment surveys that measure program performance for programs funded under Title III of the Older Americans Act (“OOA”) includes a demographic question related to sexual orientation. However, in the strongest possible terms, Lambda Legal now urges ACL to correct the continued omission of any survey question that would also allow transgender respondents to identify themselves.

While we appreciate that the question regarding sexual orientation was reinstated in the June 2017 revisions, we are deeply troubled by the agency’s failure to similarly reinstate the question regarding gender identity. As you know, the data in the NSOAAP is critical for evaluating the demographics of who is being served by federally funded aging programs and whether those programs are adequately meeting the needs of our nation’s elders. Transgender older adults rely heavily upon aging services. As they are important members of our diverse communities of

seniors, it is vital that their voices help to shape future program development and program budget requests.

As transgender people age, they become especially reliant upon federally-funded programs to assist aging populations. Transgender adults experience higher rates of social isolation and have weaker support networks and more limited extended family than their non-transgender peers. 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, transgender 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 pass away.²

Older transgender adults also need to rely heavily on aging services because they have experienced a lifetime of discrimination and stigmatization resulting in both diminished health outcomes and diminished economic resources to support them as they age.³ More specifically, transgender seniors have faced greater instability and fewer opportunities to build savings as a result of employment discrimination and exclusion from legal and social programs designed to provide financial assistance to older adults, resulting in higher poverty rates.⁴

In addition, LGBT older adults, including transgender elders, experience dramatic health care 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 that 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.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.

¹ See Kyu Choi & Ilan H. Meyer, *LGBT Aging: A Review of Research Findings, Needs, and Policy Implications*, The Williams Institute, at 8 (Aug. 2016), <https://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), available at <http://www.lgbtmap.org/policy-and-issue-analysis/improving-the-lives-of-lgbt-older-adults>.

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.

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/wp-content/uploads/LGB-Poverty-Update-Jun-2013.pdf>.

⁵ See Karen I. Fredriksen-Goldsen *et al.*, *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* at 2,4-5, 51 (Nov. 2011), <http://age-pride.org/wordpress/wp-content/uploads/2012/10/Full-report10-25-12.pdf>.

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, transgender older adults often lack access to culturally competent aging programs and services. Having confronted discrimination from entities traditionally relied upon for support, transgender adults frequently are reticent to access the aging network. As the Administration on Aging found in 2001, LGBT older adults are 20% less likely than their non-LGBT peers to access governmental aging services such as housing assistance, meal programs, food stamps, and senior centers.⁷ If transgender seniors aren't counted and their voices accordingly can't be taken into account in the design and delivery of these essential services, they will continue to avoid those services that they desperately need.

Congress passed the OAA to address exactly these types of barriers to successful aging, and the NSOAAP is intended to identify when programs fail to address the needs of the diverse communities of seniors for whom these programs are designed. ACL has previously recognized the importance of assessing how these programs serve transgender seniors. It is consequently of great concern that ACL is now threatening to turn its back on the needs of transgender older adults, even to the point of ensuring that they remain invisible in critical data collection. This is particularly troubling in light of the history, over too many generations, of the transgender community having been misunderstood, mischaracterized, maligned, and systematically mistreated by government and researchers.

Indeed, the need to collect accurate data on gender identity, as well as the feasibility of doing so, is already reflected in other federal surveys that collect these data.⁸ HHS itself acknowledged in its 2017 LGBT Policy Coordinating 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 these data “will prove invaluable in informing the process.”¹⁰

Finally, in the federal government's statutorily mandated assessment of programs that help older adults age successfully in their homes and communities, a thorough and meaningful analysis of the needs of affected demographic groups is necessary for the proper performance of ACL's functions. Ensuring that transgender seniors and their caregivers are being supported by OAA programs in a comprehensive, non-discriminatory fashion is core to ACL's mission of “maximiz[ing] the

⁶ Lambda Legal, *When Health Care Isn't Caring: LGBT Older Adults and Older Adults Living with HIV*, https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring_1.pdf.

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. at 11 (2016), <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

¹⁰ *Supra* n. 9 at 11.



independence, well-being, and health of older adults, people with disabilities across the lifespan, and the 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 strongly urge the Administration of Community Living to reinstate the question pertaining to gender identity that was removed in the March 2017 revisions to the NOSAAP and that was not reinstated in the June 2017 or September 2017 revisions.

We appreciate this opportunity to comment on this important matter.

Most respectfully,

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¹¹ ACL, *About ACL*, <https://www.acl.gov/about-acl>.