



March 22, 2018

Submitted via e-mail: [OIRA\\_submission@omb.eop.gov](mailto:OIRA_submission@omb.eop.gov)

The Office of Management and Budget  
Attn: OMB Desk Officer for the Administration for Community Living  
725 17th Street, NW  
Washington, DC 20503

**Re: Comment Request on a Proposed Revision to an Existing Data Collection Related to the National Longitudinal Survey of Older Americans Act Participants (NLSOAAP)**

To Whom It May Concern:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”) appreciates the opportunity to provide these comments to the Office of Management and Budget (“OMB”) in response to the February 20, 2018 request for comment related to the redesign of existing data collection on the National Longitudinal Survey of Older Americans Act Participants Survey (“NLSOAAP”). 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 is writing to request that the Office of Management and Budget (“OMB”) condition its approval of the Administration for Community Living’s (“ACL”) request to conduct cognitive testing of questions in the revised survey upon a requirement the ACL meaningfully assess whether the revised Survey accurately collects information about a respondent’s gender identity. The best way to ensure there is a meaningful assessment would be for ACL to include representatives from the LGBT—and especially from the transgender—community in its sample, and to engage experts on the collection of sexual orientation and gender identity data. We also request that OMB not grant final approval to the revised Survey until ACL demonstrates that it is accurately collecting data about the participation of transgender older adults.

This national survey provides critical data on whether federally funded aging programs like meals on wheels, family caregiver support, adult daycare, and senior centers reach all older adults. A Survey that does not accurately capture gender identity is fundamentally at odds with Congress’s intent that programs funded under the Older Americans Act (“OAA”) prioritize the neediest and most isolated segments of the population. If ACL does not meaningfully collect data on the participation of transgender elders, ACL will not have the most basic data on whether the aging network is meeting the needs of this vulnerable population.

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.<sup>1</sup> 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.<sup>2</sup>

Older transgender adults also need to rely heavily on aging services because most have experienced a lifetime of discrimination and stigmatization resulting in both diminished health outcomes and diminished economic resources to support them as they age.<sup>3</sup> 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.<sup>4</sup>

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.<sup>5</sup> 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 of 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.<sup>6</sup>

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.<sup>7</sup> If transgender

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<sup>1</sup> 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), <http://www.lgbtmap.org/policy-and-issue-analysis/improving-the-lives-of-lgbt-older-adults>.

<sup>2</sup> 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).

<sup>3</sup> See, Fredriksen-Goldsen, *supra* n.2, at 9.

<sup>4</sup> 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>.

<sup>5</sup> 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>.

<sup>6</sup> 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/whic-report\\_when-health-care-isnt-caring\\_1.pdf](https://www.lambdalegal.org/sites/default/files/publications/downloads/whic-report_when-health-care-isnt-caring_1.pdf).

<sup>7</sup> See Choi and Meyer, *supra*, n.1, at 6.

seniors are not counted and their voices accordingly cannot 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 NLSOAP is intended to identify when programs fail to address the needs of the diverse communities of seniors for whom these programs are designed. 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 independence, well-being, and health of older adults, people with disabilities across the lifespan, and the families and caregivers."<sup>8</sup> 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.

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.<sup>9</sup> 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."<sup>10</sup> As the report further stated, the collection of these data "will prove invaluable in informing the process."<sup>11</sup>

The ACL acknowledged that the vast majority of the comments the agency received in response to an ACL proposal to include sexual orientation of OAA-funded program participants were from organizations and individuals encouraging the ACL to adopt a measure of gender identity or to improve the methodology for collecting information about the participation of transgender older adults. ACL does not dispute the need to collect information about the extent to which OAA-funded programs meet the needs of transgender older adults. Rather, in response to the many comments requesting that ACL adopt or improve the collection of data regarding the extent to which OAA-funded programs are serving the needs of transgender older adults, the agency has told OMB that the agency needs to conduct cognitive testing on the question for the redesigned information collection tool.

As part of the cognitive testing, ACL plans to assess whether the question in the revised survey that seeks information about respondents' gender will provide an adequate means to assess whether OAA programs are serving transgender older adults.<sup>12</sup> We think it unlikely that a question that informs surveyors not to ask the gender question altogether "if it's obvious" and that only provides three response options—male, female, or don't know—will provide an adequate means to collect information about whether respondents are transgender—and consequently, whether OAA-funded programs are

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<sup>8</sup> Administration for Community Living Mission Statement, <https://www.acl.gov/about-acl>.

<sup>9</sup> See Kellan Baker and Laura Durso, *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/>.

<sup>10</sup> *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>.

<sup>11</sup> *Supra* n. 9 at 11.

<sup>12</sup> See Proposed Changes to Survey Instrument: National Survey of Older Americans Act Participants Redesign NLSOAP Years 2/ Year 3 tool, <https://www.acl.gov/about-acl/public-input> (the question informs surveyors not to "ask if obvious" and limits the options to: male, female, refused and don't know).



serving them. This question will fail to identify transgender participants because it fails to explicitly ask an affirmative question regarding gender identity or transgender status. In addition, the question encourages surveyors to engage in form of gender stereotyping that would severely hinder data collection on transgender older adults.

Based on these concerns, we urge that OMB condition its approval of ACL's request to conduct cognitive testing on a requirement that this testing meaningfully assess whether the revised Survey collects information about whether a respondent is transgender. To do so, ACL should ensure that the sample includes representatives from the LGBT community, and engage experts on the collection of sexual orientation and gender identity data.

Because ACL does not anticipate starting to administer the revised survey until June 2019, ACL should have ample time to make any modifications needed to assess the extent to which OAA-funded programs are meeting the needs of transgender older adults. Accordingly, OMB should not grant final approval to the revised Survey until ACL demonstrates that it is collecting data about the participation of transgender older adults. ACL could do so by following the lead of other federal and state surveys that have successfully implemented procedures to identify transgender respondents, such as the National Crime Victimization Survey, the Behavioral Risk Factor Surveillance System ("BRFSS"), and the California Health Interview Survey.<sup>13</sup> By collecting these data, and learning more about this population, ACL can ensure that more transgender older adults live independently, minimize the burden on the aging network, and ultimately save taxpayer resources by reaching those who are most vulnerable.

We appreciate this opportunity to comment on this important matter.

Most respectfully,

**LAMBDA LEGAL DEFENSE AND EDUCATION FUND, INC.**

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<sup>13</sup> The Williams Institute, *Best Practices for Asking Questions to Identify Transgender and other Gender Minority Respondents on Population-Based Surveys* (Sept. 2014), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>; Bureau of Justice Statistics; *Data Collection: National Crime Victimization Survey* (2016), <https://www.bjs.gov/index.cfm?ty=dcdetail&iid=245>; Kellen Baker and Margaret Hughes, *Sexual Orientation and Gender Identity Data Collection in the Behavioral Risk Factor Surveillance System*, CENTER FOR AMERICAN PROGRESS (Mar. 29, 2016), <https://www.americanprogress.org/issues/lgbt/reports/2016/03/29/134182/sexual-orientation-and-gender-identity-data-collection-in-the-behavioral-risk-factor-surveillance-system/>; UCLA Center for Health Policy Research; *California Health Interview Survey* (2016), [http://healthpolicy.ucla.edu/chis/design/Documents/2015-2016%20Questionnaires/CHIS%202016%20Adult%20Questionnaire%20\(FINAL\).pdf](http://healthpolicy.ucla.edu/chis/design/Documents/2015-2016%20Questionnaires/CHIS%202016%20Adult%20Questionnaire%20(FINAL).pdf).