



*James Firman, Chair*

November 27, 2017

U.S. Department of Health and Human Services  
Administration for Community Living  
Washington, DC 20201  
Attention: Heather Menne.  
VIA E-MAIL: [heather.menne@acl.hhs.gov](mailto:heather.menne@acl.hhs.gov)

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

The Leadership Council of Aging Organizations (LCAO) is writing to applaud the Administration for Community Living (ACL) for keeping a sexual orientation demographic question in the latest iteration of the National Survey of Older Americans Act Participants (NSOAAP), announced September 26, 2017. LCAO is disappointed, however, that ACL is continuing to deny the opportunity for transgender older adults to identify themselves in the survey.

Earlier this year, LCAO joined overwhelming public opposition to ACL's March 13, 2017, proposal to entirely erase lesbian, gay, bisexual, and transgender (LGBT) older adults from the NSOAAP. When the survey went up to the Office of Management and Budget (OMB) for review, LCAO commended ACL's decision to keep a sexual orientation question in the survey, but condemned ACL's decision to omit a question from the survey designed to identify transgender respondents.

ACL has now announced a new, longitudinal NSOAAP, which is a powerful tool to help address changing needs of populations over time. While we once again commend ACL on its decision to collect data on sexual orientation, we once again condemn ACL's decision to not collect data that will allow ACL and researchers to identify and study the transgender population in this survey. All of our elders, including transgender elders, must be counted. We refuse to let transgender older adults, or any of the elders who are part of our community, be invisible. The more we know, the more we can do to make sure that transgender older adults receive the services they deserve.

The NSOAAP 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, including transgender older adults. While ACL's notice in the Federal Register provides no articulation of, information about, or explanation of ACL's decision to omit a transgender-inclusive gender identity question(s) from the NSOAAP, what we do know is that if this decision stands, ACL will not have important data on how the aging network is meeting the needs of transgender elders.

Since 1980, LCAO has been the country's preeminent coalition representing older Americans. Comprised of 70 national nonprofit organization members, LCAO focuses on the well-being of America's older population and is committed to representing their interests in the policy-making arena. LCAO serves as a source of information about issues affecting older persons and provides leadership and vision as America meets the challenges and opportunities presented by its aging society. ACL's latest proposal is fundamentally at odds with LCAO's vision of recognizing the diversity of America's older population and working to ensure that no older person is a victim of discrimination. In recent years, ACL has made significant progress in addressing the needs of transgender older adults. ACL's decision to not measure gender identity on the NSOAAP, however, represents a lost opportunity to support the progress we have made in recent years and counters the call for more, not less, data from the aging network on the population it serves.

Data, research, and the experience of SAGE, its affiliates, and its partners across the country confirm that transgender older adults face a number of barriers to successful aging. While data on transgender older adults is limited, which further makes the case for ACL collecting this information, the data that do exist prove that transgender older adults face higher rates of social isolation and have thinner support networks than their cis-gender peers.

The existing research also shows that transgender elders age without a network of welcoming or Culturally competent aging, health, and social service providers. According to *Understanding Issues Facing LGBT Older Adults*, 25% of transgender older adults report having faced discrimination based on their gender identity, transgender older adults face much higher rates of psychological distress than their cis-gender peers, and nearly 50% live at 200% of the federal poverty line or lower.<sup>1</sup> These challenges are compounded by concerns related to caregiving and by limited access to healthcare. Almost one third of transgender people don't know who will care for them and approximately two thirds fear their access to healthcare will be limited as they get older.<sup>2</sup> As a result, more than half fear they might be denied medical care as they age.<sup>3</sup> These concerns are often reflected in long-term care settings. In a survey on LGBT older adults living in long-term care facilities, more than 10% of respondents said that they, a client, or loved-one had witnessed staff refusing to call transgender residents by their preferred name or pronoun.<sup>4</sup>

A 2001 U.S. Administration on Aging study found that LGBT older adults are 20% less likely than other older adults to have access to government services such as housing assistance, meal programs, food stamps, and senior centers.<sup>5</sup> In other words, despite their greater need for service providers due to their truncated support networks, transgender older adults lack access to culturally competent care and services. Nonetheless, most State Units on Aging are making no systematic efforts to assess and address the needs of this population.<sup>6</sup> The very age of the 16 year-old ACL study we cite further demonstrates the necessity for ACL to collect updated data on whether the aging network is meeting the needs of this population.

ACL can increase the quality and utility of the data it collects about transgender older adults 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. To that end, we believe a concise gender identity question or questions can be included in this newest version of the NSOAAP. The widely-cited best practices guidelines, edited by the Williams Institute, for measuring gender identity on population surveys, identifies an effective and well-vetted two-step approach to collecting information about gender identity.<sup>7</sup> In short, we encourage ACL to adopt a measure of gender identity on the NSOAAP.

ACL must continue collecting data on whether the aging network is reaching transgender older adults in order to ensure maximum inclusion of transgender older adults in programs funded under the Older Americans Act (OAA). From State Units on Aging to Area Agencies on Aging, the aging network has asked ACL for more and better data on transgender older adults in the communities it serves.<sup>8</sup> We need more of this data on the experiences and needs of transgender elders in our country – not less of it. We therefore urge ACL to include both sexual orientation and gender identity questions in the NSOAAP.

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<sup>1</sup> Understanding Issues Facing LGBT Older Adults. 2017. The Movement Advancement Project and SAGE. <http://www.lgbtmap.org/file/understanding-issues-facing-lgbt-older-adults.pdf>

<sup>2</sup> Understanding Issues Facing LGBT Older Adults. 2017. The Movement Advancement Project and SAGE. <http://www.lgbtmap.org/file/understanding-issues-facing-lgbt-older-adults.pdf>

<sup>3</sup> Understanding Issues Facing LGBT Older Adults. 2017. The Movement Advancement Project and SAGE. <http://www.lgbtmap.org/file/understanding-issues-facing-lgbt-older-adults.pdf>

<sup>4</sup> Improving the Lives of Transgender Older Adults, Recommendations for Policy and Practice. 2012. SAGE and NCTE. Available at <http://www.sageusa.org/resources/publications.cfm?ID=13>

<sup>5</sup> Improving the Lives of LGBT Older Adults. 2010. LGBT Movement Advancement Project & Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (MAP & SAGE). Available at <http://www.lgbtmap.org/file/improving-the-lives-of-lgbt-older-adults.pdf>

<sup>6</sup> A SAGE report found that: State Plans filed by 29 States make no reference whatsoever to LGBT older adults; an additional 12 State Plans have isolated references to LGBT older adults, but do not address specific actions being taken to reach and target this population; and only nine States, and the District of Columbia, specifically address efforts to reach out and target LGBT older adults.

<sup>7</sup> 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>

Asking a demographic question about gender identity will increase the quality, utility, and clarity of the information collected. We further believe that by continuing to collect this data, and learning more about this population, ACL and the aging network will help more members of our older transgender community to live independently, minimize the burden on the aging network, and ultimately save taxpayer resources by reaching those who are most vulnerable.

Sincerely,

AFL-CIO  
Aging Life Care Association  
Alliance for Retired Americans  
Altarum Center for Elder Care and Advanced Illness  
Alzheimer's Association  
AMDA: The Society for Post-Acute and Long-Term Care Medicine  
American Federation of Labor-Congress of Industrial Organizations (AFL-CIO)  
American Federation of State, County and Municipal Employees (AFSCME)  
American Foundation for the Blind  
American Society on Aging  
Center for Medicare Advocacy  
Community Catalyst  
Gerontological Society of America  
Jewish Federations of North America  
Justice in Aging  
Lutheran Services in America  
Medicare Rights Center  
National Academy of Elder Law Attorneys  
National Adult Day Services Association (NADSA)  
National Alliance for Caregiving  
National Asian Pacific Center on Aging  
National Association of Nutrition and Aging Services Programs (NANASP)  
National Association of Social Workers (NASW)  
National Committee to Preserve Social Security and Medicare  
National Consumer Voice for Quality Long-Term Care  
National Council on Aging  
National Hispanic Council on Aging (NHCOA)  
National Senior Corps Association  
PHI  
SAGE  
Service Employees International Union (SEIU)

cc:

Mr. Lance Robertson  
Assistant Secretary for Aging  
Administrator, Administration for Community Living