November 27, 2017

VIA E-MAIL: 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, however, is disappointed that ACL is continuing to deny the ability of 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. Following an initial comment period, LCAO commended ACL on its decision to keep the sexual orientation question on the survey, but condemned ACL’s decision to eliminate the opportunity for transgender older adults to identify themselves, as the survey went to the Office of Management and Budget (OMB) for review.

ACL has now announced a new, longitudinal NSOAAP. While we once again commend ACL on its decision to collect data on sexual orientation, we once again condemn ACL’s decision to not include a transgender demographic question on the survey. All of our elders, including our 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 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,

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 transgender older adults from the

NSOAAP, what we do know is that ACL will not have the important data it needs on how the aging network is meeting the needs of this population.

Since 1980, LCAO has been the country’s preeminent coalition representing older Americans. Comprised

of 72 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, which once again fails to include a transgender demographic question in the survey, 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 include a gender identity question, however, represents a significant step backward from the progress we have made in recent years and counters the call for more data from the aging network on the population it serves, not less.

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 does exist proves that transgender older adults face higher rates of social isolation and have thinner support networks than their non-transgender 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 non-transgender peers, and nearly 50% live at 200% of the federal poverty line or lower.[[1]](#footnote-1) 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.[[2]](#footnote-2) As a result, more than half fear they might be denied medical care as they age.[[3]](#footnote-3) Many of our transgender elders fear health professionals discovering their transgender status - particularly those whose presentation does not conform with their anatomy.[[4]](#footnote-4) 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.[[5]](#footnote-5)

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.[[6]](#footnote-6) 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.[[7]](#footnote-7) 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.

Rather than abandoning the progress that has been made during the last three years, ACL can increase the quality and utility of the data it collects about transgender older adults by learning from the experience of other federal and state agencies that have successfully implemented procedures to collect gender identity information. To that end, we believe a concise gender identity question or questions can be included in this newest version of the NSOAAP. 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.[[8]](#footnote-8) 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.[[9]](#footnote-9) In short, we encourage ACL to update its approach, rather than abandoning transgender older adults, and adopt one of these more effective and efficient means of counting transgender elders.

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.[[10]](#footnote-10) 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.

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,

James P. Firman, Ed.D.

President & CEO, National Council on Aging

Chair, Leadership Council of Aging Organizations

cc:

The Honorable Eric D. Hargan

Acting Secretary and Deputy Secretary

The U.S. Department of Health & Human Services

Mr. Lance Robertson

Assistant Secretary for Aging

Administrator

Administration for Community Living

1. 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 [↑](#footnote-ref-1)
2. 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 [↑](#footnote-ref-2)
3. 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 [↑](#footnote-ref-3)
4. 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 [↑](#footnote-ref-4)
5. 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 [↑](#footnote-ref-5)
6. 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 [↑](#footnote-ref-6)
7. 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. [↑](#footnote-ref-7)
8. 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 [↑](#footnote-ref-8)
9. 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 [↑](#footnote-ref-9)
10. Choi SK, Meyer IH: LGBT Aging: A Review of Research Findings, Needs, and Policy Implications. 2016. Los Angeles, CA: The Williams Institute, UCLA School of Law. Available at http://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-A-Review.pdf [↑](#footnote-ref-10)