November 27, 2017

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

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

Dear Dr. Menne,

The Fenway Institute submits this public comment in response to the notice posted by the Administration for Community Living (ACL) on September 26, 2017 titled, Agency Information Collection Activities; Public Comment Request; Redesign of Existing Data Collection; National Survey of Older American Act Participants. Switching the National Survey of Older American Act Participants (NSOAAP) to a longitudinal format rather than a cross-sectional format could provide valuable data on tracking disparities in health outcomes and service utilization among elders over time. This could be a very useful tool for addressing the disparities that exist within specific elder populations, including lesbian, gay, bisexual, and transgender (LGBT) elders. As such, it is important that the redesigned NSOAAP ask about sexual orientation and gender identity (SOGI) in order to ensure that the specific needs of LGBT elders across the country are being met and that LGBT older adults are accessing elder services.

Collecting data on LGBT older adults and the extent to which they access elder services is critically important for reducing the health disparities that this population experiences. Studies have shown that LGBT older adults are more likely to report being physically disabled or have poor mental health outcomes compared to the general population. LGBT elders are also more likely to be isolated than their peers. As such, many LGBT older adults may be in need of elder services. However, research indicates that they may be less likely to access formal caregiving support and other elder services. In general, older Americans are more likely to hold anti-gay views than younger age cohorts, and they are


also more likely to hold inaccurate beliefs about the casual transmission of HIV. These both can contribute to creating a more hostile environment toward LGBT older adults in mainstream elder service facilities.

We are pleased to see that the demographic question regarding sexual orientation is retained in the proposed redesign of the NSOAAP. We also support the addition of the unique topical modules to collect additional information about experiences with discrimination related to sexual orientation. Experiences of discrimination or anticipation of discrimination based on negative experiences of friends in mainstream elder service settings causes many sexual minority elders to choose not to seek the support services they need to age in place and thrive in older adulthood. Asking questions about discrimination based on sexual orientation is important for addressing these barriers to elder services for sexual minority elders.

We are disappointed that the gender identity question was not added back in for the proposed redesign of the NSOAAP. We recommend that the ACL add a gender identity demographic question to the proposed NSOAAP, and we also propose that the ACL add a question regarding discrimination based on gender identity to the topical modules. In general, research has shown that transgender people experience high rates of economic instability, disability, and mental health burden. The 2015 United States Transgender survey of nearly 28,000 transgender respondents found that nearly one third of participants (29%) were living in poverty, which is twice the rate of the general population. The survey also found that 39% of respondents had one or more disabilities as described by the American Community Survey, compared to 15% of the general population. Furthermore, 39% of respondents reported experiencing serious psychological distress in the month prior to completing the survey, compared to 5% of the general population. Some 40% of respondents had attempted suicide in their lifetime. Respondents also indicated that they commonly experienced discrimination in accessing healthcare services, with 33% of respondents reporting at least one negative experience, such as being verbally harassed or refused treatment. Due to the high rates of disability and mental health burden, transgender older adults may be in greater need of elder services, but they may forego accessing these services due to past experiences of discrimination.

In order to better understand the needs and experiences of older LGBT adults, and especially the needs of older transgender adults, it is critical to collect population-level SOGI data. SOGI questions are now included in many public health surveys, such as the Behavioral Risk Factor Surveillance System. While we are pleased that the sexual orientation question is included in the proposed 2017 NSOAAP, in order to better understand the needs and improve the health

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and well-being of older transgender adults, it is critical that a transgender status or other gender identity question be added to the proposed redesign of the NSOAAP. We encourage the ACL to consider adding a two-step question, first asking current gender identity, and then asking for sex assigned at birth. It could also use the transgender question asked on many state BRFSS surveys.

Some may say that the gender identity question should be removed due to the small number of older adults who identify as transgender. We do not believe this is a legitimate reason to remove this question, as other surveys of older Americans have also found lower percentages of participants who identified as transgender. The small number of older adults who identified as transgender on the NSOAAP is in line with the small number of people who identify as transgender in the general population. A Williams Institute analysis of state Behavioral Risk Factor Surveillance System surveys found that 0.58% of Americans aged 18 and older, or 1.4 million people, identify as transgender. In addition, often response rates to sexual orientation and gender identity (SOGI) questions are low when new questions are first added to a survey. Furthermore, transgender elders can be purposefully oversampled in anticipation of a small sample size, or multiple years of data can be aggregated. It is essential that ACL follow the growing consensus among federal agencies and professional health organizations that SOGI data should be collected to better understand LGBT people’s experiences in elder services and other settings. We commend the ACL for keeping the sexual orientation questions for the proposed NSOAPP, and we urge the ACL to add in a gender identity question.

Sincerely,

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