October 2, 2023

Administration for Community Living
Department of Health and Human Services
Attention: Kristen Robinson
Washington, DC 20201
Submitted via email to Kristen.Robinson@acl.hhs.gov

To Whom It May Concern:

We are grateful for the opportunity to provide comments to the Administration for Community Living (“the Administration”) regarding proposed changes to the National Survey of Older Americans Act Participants (NSOAAP). See 88 Fed. Reg. 50,869 (August 2, 2023).

The undersigned are scholars affiliated with the Williams Institute at the UCLA School of Law. The Williams Institute is dedicated to conducting rigorous and independent research on sexual orientation and gender identity (SOGI), including on disparities and discrimination experienced by lesbian, gay, bisexual, and transgender (LGBT) people. The Williams Institute collects and analyzes original data and analyzes governmental and privately collected data. It has also worked with federal agencies to improve data collection on the U.S. population, including producing widely cited best practices for the collection of SOGI information in population surveys.1 The Williams Institute has published research on the experiences of older LGBT people specifically,2 and scholars with the Williams Institute have previously provided comment to the Administration on the NSOAAP3 and regulations implementing the Older Americans Act (OAA).4

The Administration seeks comment related to “whether the proposed collection of information is necessary for the proper performance of the Administration’s functions, including

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whether the information will have practical utility.” Previous versions of the NSOAAP have included a question asking about sexual orientation, and scholars from the Williams Institute have provided comment regarding the need for such data on older sexual minority adults. The Administration now proposes to include a two-step question asking about gender identity. Therefore, we direct this comment specifically to that proposal and the need for data on transgender older adults.

The proposed data collection will further the proper performance of the Administration’s functions insofar as the Administration is obligated under relevant law to collect such data. The 2020 Reauthorization of the OAA contained several provisions calling for the collection and evaluation of data on populations with greatest social need. The proposed regulations currently under consideration by the Administration reaffirm data collection requirements and define gender and sexual minority groups as populations of “greatest social need.” Therefore, adding questions to the NSOAAP concerning gender identity would further the performance of the Administration’s functions by collecting data on a population of greatest social need. Furthermore, President Biden’s Executive Order 14,075 explicitly included a provision on improving and increasing data collection on sexual orientation and gender identity of LGBTQI+ older adults. Thus, the proposed collection of respondent’s gender identity serves to further the Administration’s responsibilities under federal law to collect data on sexual and gender minorities.

The undersigned write to express our support for the proposed changes to the NSOAAP that promote the collection and reporting of data concerning gender minority people. While existing research provides valuable insight into the lives and experiences of LGBT older adults, there is a continued need for high-quality representative data on this population across a range of contexts.

I. Demographics of LGBTQI+ Populations

LGBT-identified people comprise approximately 4.5% of the U.S. adult population. Williams Institute researchers estimated that approximately 11.3 million adults in the U.S.

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6 See VASQUEZ, NATIONAL SURVEY OF OLDER AMERICANS ACT PARTICIPANTS: PUBLIC COMMENT, supra note 3.
8 See, e.g., 42 U.S.C. § 3026(a)(1).
11 See ANDREW BURWICK ET AL., MATHEMATICA POLICY RESEARCH, HUMAN SERVICES FOR LOW-INCOME AND AT-RISK LGBT POPULATIONS: AN ASSESSMENT OF THE KNOWLEDGE BASE AND RESEARCH NEEDS 19 (2014) (advising that “data from federal and state surveys with large population-based samples are needed to develop findings that are representative of the LGBT population at the state or national level and to generate sample sizes large enough to explore the characteristics and experiences of LGBT subpopulations…”).
identify as LGBT, including approximately 1.3 million adults who are transgender. The best estimate to date is that intersex people comprise approximately 1.7% of the population. However, a more precise estimate of the number of intersex individuals in the United States, including intersex older adults, remains impossible due to a lack of population-wide measures on federal surveys. Estimates of the LGBT older adult population in the U.S. indicate that they are a sizeable minority. Approximately 7% of LGBT adults in the U.S. are age 65 or older, which means there are about 794,000 LGBT adults over 65, including approximately 172,000 transgender older adults. Estimates for the LGBT older adult population, including transgender adults, are expected to continue to grow due to the exponential growth of the older adult population in the U.S., increased rates of younger cohorts identifying as LGBT, and greater LGBT visibility.

Similar to the country as a whole, the population of transgender adults in the U.S. is demographically diverse. For example, researchers at the Williams Institute estimated that 39% of transgender adults are transgender women, 36% are transgender men, and 26% are transgender nonbinary. Similarly, Williams Institute researchers estimated that 45% of transgender adults in the U.S. are people of color, including 22% who are Latinx, 13% who are Black, and 6% who are Asian.

II. The Proposed Changes Offer Practical Utility in Furthering Research Documenting Discrimination & Health Disparities Among Older Transgender People

The metrics assessed in the NSOAAP, such as economic and food insecurity, mental and physical health outcomes, and barriers to receiving health care and social support, are all metrics in which Williams Institute research has shown that sexual and gender minority older adults face unique challenges compared to their straight and cisgender peers. Below, we offer a brief

16 7% of LGBT people are age 65 or older. Id. To estimate the number of LGBT people over 65, we applied this percentage to the Williams Institute’s overall estimate that there are approximately 11,343,000 LGBT people in the United States. CONRON & GOLDBERG, supra note 12.
17 HERMAN, FLORES & O’NEILL, supra note 14 at 5.
19 Id. at 7.
20 HERMAN, FLORES & O’NEILL, supra note 14 at 4.
21 See generally, CHOI & MEYER, supra note 2; ADMIN. FOR CMTY. LIVING, supra note 7.
review of existing research on older LGBT people, noting specific findings on older transgender people where possible. Research has shown that anti-transgender stigma and discrimination is widespread while certain economic and health disparities continue to widen, in particular when factoring in the compounding effects of discrimination faced along intersectional dimensions of race, ethnicity, age, and sex.

A. Transgender Older Adults Experience Worse Health Outcomes When Compared to Cisgender People

A 2016 Williams Institute literature review on LGBT aging gathered a number of studies on the experiences of older LGB and transgender people and outlined a number of examples of the disparate health outcomes that this population faces when compared to other groups. Concerning health, sexual and gender minority older adults had worse health outcomes compared to cisgender heterosexual older adults even when these groups had similar demographic characteristics (e.g., race/ethnicity). Many studies show similar findings comparing transgender and cisgender populations, especially for mental health outcomes; however, research is less conclusive regarding their physical health outcomes—and therefore in need of further inquiry. The proposed changes to the NSOAAP would help to further this area of important research by including questions inclusive of this group.

Research has shown that the transgender population, including older cohorts, has significantly worse mental health outcomes compared to the general population, specifically in terms of stress, depression, anxiety, and suicidality. One National Institutes of Health (NIH) funded study used both state population data from the CDC’s Behavioral Risk Factor Surveillance System (BRFSS) and a cross-sectional survey of 11 community-based agencies across the nation. It concluded that, among LGBT adults over age 50, 31% reported depressive symptoms and transgender people over age 50 reporting the highest proportion of depressive symptoms, at 48%. Similarly, a Williams Institute report analyzing data from the 2015 U.S. Transgender Survey (USTS), the largest nonprobability study of transgender adults, found that 25% of transgender people over the age of 50 had thought about suicide in the past year compared with 3% of the general population. Among transgender people over the age of 65, 57% had thoughts about suicide in their lifetime and 15% had thought about suicide in the past year. Suicidal behavior was found to be more common among transgender people of color than among transgender people who are White. A state-based representative survey in California among

23 CHOI & MEYER, supra note 2 at 24.
27 Id. at 9.
adults of all ages found similarly high rates of suicidality among transgender adults compared to cisgender adults in addition to high rates of psychological distress. 28

Research on physical health outcomes among transgender older adults is an evolving area in need of further inquiry. 29 This is, in part, due to a historic lack of population-based surveys measuring gender identity. 30 Thus, the proposed addition to the NSOAAP presents an opportunity to greatly expand our understanding of this subpopulation. The NIH-funded community level study found that transgender older adults were at significantly higher risk for poor physical health and were 55% more likely to report disability symptoms than non-transgender older adults. 31 The state-level representative survey in California found that transgender and cisgender adults reported similar rates of fair or poor general health, however significantly more transgender adults (60%) reported a disability “due to a physical, mental, or emotional condition” compared to cisgender adults (27%). 32 One study utilizing BRFSS data consisting of a probability sample from 19 U.S. states found that, compared to cisgender adults, more transgender adults reported their general health as fair or poor, and simultaneously reported similar rates of poor physical health and disability as cisgender adults. 33 In addition, transgender and cisgender adults were diagnosed with chronic health conditions at similar rates, though more transgender than cisgender adults reported difficulties with walking, their eyesight, and remembering and concentrating. 34 However, a recent study comparing three different types of surveys (USTS, the nationally representative probability survey TransPop, and results from BRFSS) found that, overall, transgender people were more likely to report fair or poor health and chronic health conditions such as HIV, COPD and emphysema, liver disease, and ulcers compared to cisgender people. 35

31 Fredriksen-Goldsen et al., supra note 29 at 494; FREDRIKSEN-GOLDSEN ET AL., supra note 25 at 23.
34 Id.
B. Transgender People Experience Victimization and Discrimination Throughout Their Lifetimes

Minority stress theory and other research have demonstrated that health disparities among LGBT populations are linked with experiences of discrimination and victimization due to stress associated with anti-LGBT stigma. Moreover, disparate rates of discrimination and victimization among LGBT people, specifically transgender people, across all aspects of public life, is well documented. Research on transgender older adults in particular has also demonstrated high rates of victimization and discrimination in employment, housing, and healthcare. Williams Institute reports on data collected from the NIH-funded Generations Study (HD078526, concerning three age cohorts of LGB adults 18-60) and TransPop Study (HD090468, survey of transgender adults of all ages) showed that many transgender people report lifetime experiences of discrimination and victimization, and adverse employment and housing experiences. For example, 20% of transgender people were subjected to conversion therapy in an effort to change their sexual orientation or gender identity compared with 6% of sexual minority women and 9% of sexual minority men.

The Williams Institute literature review on LGBT aging found that transgender older adults reported an average of 11 lifetime incidents of victimization and discrimination, with high rates of verbal and physical abuse. Another study using a nationally representative sample found that “transgender people experienced violence at a rate of 86.2 victimizations per 1000 persons compared with 21.7 per 1000 persons among cisgender people” and that transgender people experienced twice as many property victimizations as cisgender people. More older transgender respondents to the USTS reported sexual assault in childhood compared with

40 Choi & Meyer, supra note 2 at 14, citing Fredriksen-Goldsen et al., supra note at 488.
41 Choi & Meyer, supra note 2 at 2.
younger transgender respondents. This can in part be explained by the younger average age of transgender populations compared to cisgender populations; however, there is evidence that disparity in housing experiences of gender minority people continue into older ages. For example, among respondents to the 2015 USTS study, 58% of transgender adults age 55-64 owned a home compared to 75% of adults age 55-64 in the U.S. population, and 69% of transgender adults age 65 and older own a home while 78% of adults 65 and older in the U.S. population do. A panel survey from the AARP on LGBT people over the age of 45 found that 14% of gender minority people over the age of 45 recently experienced housing discrimination based on their gender identity compared with 4% of sexual minority people based on their sexual orientation. A Williams Institute review of research on housing provided additional evidence of housing disparities impacting older LGBT people and concluded that, “fear of discrimination in senior housing and long-term care facilities is a major concern for LGBT adults and elders.” For example, the AARP survey found that among gender minority individuals who responded to the survey, 76% were concerned about being neglected or refused services if they or their partner required long-term care in the future. Similarly, 72% of gender-minority respondents were concerned about being abused or feared verbal or physical harassment under the same circumstances. Another community-based survey of LGBT seniors living in care facilities found that staff refused to refer to transgender residents by their preferred name or pronouns for 9% of respondents.

Healthcare discrimination experienced by transgender older adults may include incidents of overt transphobia by health care providers, leading some to delay or avoid obtaining care, or

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44 Id. at 197-209.
46 HERMAN & O’NEILL, Id. at 5.
47 JAMES ET AL., supra note 43 at 177.
50 AARP supra note 48 at 46.
otherwise conceal their gender identity from providers.\footnote{52} This is consistent with findings about the experiences of transgender people generally. For example, almost two-thirds of respondents to the TransPop study reported worrying about being negatively judged when interacting with a healthcare provider.\footnote{53} Among respondents to the 2015 USTS, 33% reported one or more negative experiences with a healthcare provider in the past year and 24% said they had to educate their healthcare provider about gender identity to get care in the past year.\footnote{54} The NIH-funded study among adults aged 50 and older from 11 community-based agencies nationwide found that transgender adults “were significantly more likely to report fear as a barrier to accessing health services” compared to cisgender sexual minority adults.\footnote{55} 40% of respondents reported that they were denied or given inferior health care as a result of disclosing their gender identity.\footnote{56} Additional studies have also found that transgender older adults faced discriminatory experiences with medical providers and a significant lack of access to gender-affirming care throughout their lifetimes.\footnote{57}

Poorer health outcomes among transgender populations are also likely influenced in part by experiences with economic insecurity. Research shows that one third of LGBT older adults – and approximately half of transgender older people – live on incomes that are below 200% of the Federal Poverty Level.\footnote{58} Transgender people, especially transgender people of color, experience poverty at higher rates across the life course than many cisgender people.\footnote{59} A 2022 Williams Institute study using the Census Bureau’s Household Pulse Survey data found that transgender people are significantly more likely to experience poverty and other economic inequality compared to cisgender people even when controlling for age.\footnote{60} The Pathways to Justice Project, a Williams Institute qualitative study focusing on poverty among LGBTQ adults in California, noted high rates of food insecurity among transgender adults, including transgender older

\footnote{52} White-Hughto et al., supra note 36 at 226. \footnote{53} M\textsc{eyer}, W\textsc{ilson}, & O’N\textsc{eill}, supra note 39 at 27. \footnote{54} J\textsc{ames et al.}, supra note 43 at 97. \footnote{55} Kristen E. Porter, Mark Brennan-Ing, Sand C. Chang, lore m. dickey, Anneliese A. Singh, Kyle L. Bower, & Tarynn M. Witten, Providing Competent and Affirming Services for Transgender and Gender Nonconforming Older Adults, 39 CL\textsc{i}N\textsc{ICAL} G\textsc{E\textsc{R}ON\textsc{O}N\textsc{T}OL\textsc{O}G\textsc{IST}\textsc{E}\textsc{R} 734 (2016) https://doi.10.1080/07317115.2016.1203383, citing Fredriksen-Goldsen et al., supra note 29. \footnote{56} Id. \footnote{57} See, e.g., Xiang Cai, Jaclyn M.W. Hughto, Sari L. Reisner, John E. Pachankis & Becca R. Levy, Benefit of Gender-Affirming Medical Treatment for Transgender Elders: Later-Life Alignment of Mind and Body 6 LGBT Health 34, 34-9 (2019), https://doi.10.1089/lgbt.2017.0262; Charles P. Hoy-Ellis, Karen I. Fredriksen-Goldsen & Hyun-Jun Kim, Utilization of Recommended Preventive Health Screenings Between Transgender and Cisgender Older Adults in Sexual and Gender Minority Communities, 34 J. of Aging & Health 1, 1-14 (2022). \footnote{58} M\textsc{ovement a}dv\textsc{ancement} P\textsc{roj.} & S\textsc{age}, supra note 38 at 2. \footnote{59} B\textsc{iana}ca D.M. Wilson, Lauren J.A. B\textsc{outon}, M.V. Lee B\textsc{adgett} & Moriah L. M\textsc{acklin}, W\textsc{illiams I}nst., L\textsc{GBT} P\textsc{overty} in the U\textsc{nited States}: T\textsc{rends} at the O\textsc{nset} of COVID-19, 4 (2023), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Poverty-COVID-Feb-2023.pdf. A previous study found that poverty rates were higher for LGBT people when compared to non-LGBT people across every age group including those over age 65, the observed differences were only statistically significant among people aged 18 to 44 years old. M.V. Lee B\textsc{adgett} et al., Williams Inst., LGBT Poverty in the United States: A Study of Differences Between Sexual Orientation and Gender Identity Groups, 14-15 (2019), https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf. \footnote{60} H\textsc{erman} & O’N\textsc{eill}, supra note 45 at 11.
Another Williams Institute study using the population-based California Health Interview Survey (CHIS) found that 18% of transgender adults 65 years of age and older were food insecure. Likewise, a study using U.S. Census Bureau’s Household Pulse Survey administered during the COVID-19 pandemic found similar results, with 20% of transgender people reporting sometimes or often not having enough food to eat compared with 8% of cisgender people.

C. Support Systems Are Vital But Lacking Among Transgender Older People

Transgender older people face high rates of social isolation and loneliness and have limited social support, factors that are particularly relevant to the data collected by the NSOAAP. The USTS study found that 37% of transgender people aged 45 to 64 had family members stop speaking to them or end the relationship while 18% of 18-24 year olds had the same experience. The report additionally showed that for 20% of transgender people over the age of 65, a partner had ended the relationship due to their gender identity and that this was two times the rate found among transgender people overall. The study reported that 45% of transgender people over the age of 65 were married compared with 56% of the general population. One Williams Institute report which analyzed population-based data in California found that 43% of transgender adults aged 65 and older lived alone, whereas the Pew Research Center estimated that 27% of the U.S. population over the age of 60 lived alone.

Lacking the support of spouses and other family members, many transgender elders rely upon alternate sources of community such chosen families. But even then, they face challenges. An analysis of BRFSS data affirmed prior findings that LGBT adults are overrepresented as caregivers. However, institutional regulations can fail to recognize non-biologic caregiving

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65 JAMES ET AL., supra note 43 at 71.
66 Id. at 67.
67 Id. at 59.
68 CHOI, KITTLE & MEYER, supra note 62.
70 CHOI & MEYER, supra note 2 at 8.
relationships—such as “chosen families” that transgender older adults can rely on in place of their families of origin. The lack of official recognition of families of choice can create challenges for both the caregiver and recipient of care.

While facing greater health disparities compared to cisgender people, economic insecurity, and less social support as they age, transgender older people also experience discrimination in networks of care and functional support, including many benefits and services designed for retirement and elder care. Healthcare providers have also recognized that many LGBT older adults lack LGBT-friendly senior services or other social resources, creating a social care deficit. Research from the 2001 Administration on Aging study found that LGBT older adults were 20% less likely than heterosexual and cisgender counterparts to access government services, such as “housing assistance, meal programs, food stamps, and senior centers.” Listening sessions conducted by Fenway Health with LGBTQ older adults across Massachusetts identified many needs expressed by the participants, including access to LGBT-friendly senior services. Participants to the focus groups highlighted the lack of LGBT-friendly housing, targeted support groups and services, and LGBT-friendly legal services and end-of-life planning.

While existing research demonstrates that older transgender people experience social isolation and need LGBTQ-inclusive aging-related support, additional research is needed to further understand the needs of transgender older adults. The proposed addition to the NSOAAP would assist in filling this existing information gap.

III. Best Practices for Collecting Sexual Orientation & Gender Identity Data

A prior Administration removed gender identity questions and nearly removed sexual orientation questions from the NSOAAP. In 2021, the Administration sought to remedy this, stating that it was “taking steps to increase data and research on the unique needs of, and approaches to serving, members of the LGBTQ+ community.” The Administration pointed to a then-forthcoming report from the National Academies of Science, Engineering and Medicine (NASEM) as a critical step toward SOGI data collection for the NSOAAP.

The Administration has now proposed a NSOAAP survey instrument which includes one sexual orientation question and a two-step gender identity question. The Williams Institute,

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72 Barrett & Wholian, supra note 74 at 503, 508-9; BOUTON, BRUSH & MEYER, supra note 2 at 10.
73 Boehmer et al., supra note 71; See also BOUTON, BRUSH & MEYER, supra note 2 at 10 for further discussion of related research.
75 CHOI & MEYER, supra note 2 at 6.
77 Id. at 18-9.
80 Id.
81 ADMIN. FOR CMTY. LIVING, supra note 7.
based on a longstanding body of research on SOGI survey measures and the NASEM report, recommends a two-step gender identity question, which includes a preliminary question asking for respondent’s sex and a secondary question asking for respondent’s gender identity.\textsuperscript{82} Thus, the undersigned support the Administration’s proposed two-step gender identity measure generally as best-practice for collecting data on gender identity in surveys.

The Administration has included, for the first time, “two-spirit” as a potential answer for both the sexual orientation and gender identity questions.\textsuperscript{83} In the publicly available survey instrument, “two-spirit” is accompanied parenthetically with “American Indian or Alaska Native” (AIAN). The Administration should note the NASEM report’s recommendation that “two-spirit” be provided as an option for gender identity and sexual orientation questions only for respondents who are Indigenous.\textsuperscript{84} It is not currently clear if “two-spirit” will be provided as an option for all respondents. The NASEM report suggests that any survey that is not likely to include a sufficient number of AIAN respondents and that cannot be tailored to provide “two-spirit” as an option for AIAN respondents should reconsider the inclusion of “two-spirit” as a response.\textsuperscript{85}

Notably, although intersex people are similarly designated as a population of “greatest social need” under the proposed OAA regulations,\textsuperscript{86} the Administration has not proposed the inclusion of a measure collecting intersex data at this time. The Administration may consider research into the performance of data collection measures concerning intersex older adults. The aforementioned NASEM report includes guidelines, recommendations, and considerations for collecting data on intersex populations.\textsuperscript{87}

We also write to emphasize the importance of protection against discrimination related to data collection. The Administration reorganized its regulations under proposed Section 1321.75 to emphasize confidentiality and protection against harmful disclosure of information.\textsuperscript{88} We note our concern about potential harm to LGBTQI+ program beneficiaries and survey respondents should there be a breach of confidentiality. All entities responsible for data collection must ensure the confidentiality of respondents’ demographic information. We agree with the Administration’s proposed regulatory language requiring states to ensure that the data contemplated here are collected and reported using all appropriate privacy standards.

\textsuperscript{83} ADMIN. FOR CMTY. LIVING, supra note 7.
\textsuperscript{85} Id.
\textsuperscript{86} 88 Fed. Reg. 39,618.
\textsuperscript{88} 88 Fed. Reg. 39,585.
IV. Conclusion

The NSOAAP seeks to assess the economic, housing, health, and social needs of the Americans served through programs funded under Title III of the Older Americans Act. Existing research demonstrates that transgender older people are especially vulnerable to health disparities, economic insecurity, and social isolation and would likely benefit from programs such as meal delivery and transportation services that receive government funding. Finally, including gender identity measures in the NSOAAP would provide additional information about older transgender respondents’ experiences of discrimination; economic and food insecurity; mental and physical health outcomes; and barriers to receiving health care and social support. This information would help the Administration to effectively administer the OAA according to its legal mandate, providing practical utility for the Administration, State and Area Departments on Aging, researchers, and the public.

In conclusion, the undersigned write to provide support for the Administration’s efforts to retain a question assessing sexual orientation and add in a two-step question assessing gender identity amongst respondents to the NSOAAP. Research from the Williams Institute and additional scholars on the discrimination and disparities faced by LGBTQ older adults, and transgender adults in particular, provide the evidentiary support for this change to the survey instrument. Williams Institute research has shown that sexual and gender minority adults, and in particular transgender older adults, face unique challenges within the context of aging compared to their cisgender and heterosexual peers. As such, questions measuring SOGI among respondents to the NSOAAP will serve a practical utility for the Administration as it will increase the Administration’s ability to assess the needs of LGBTQ older Americans.

Thank you for your consideration. Please direct any correspondence, including questions, to tentindo@law.ucla.edu.

Respectfully Submitted,

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