

**BEFORE THE UNITED STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES
ADMINISTRATION FOR COMMUNITY LIVING
ADMINISTRATION ON AGING**

Agency Information Collection Activities; Proposed Collection; Comment Request;
Proposed Extension with Modifications of a Currently Approved Collection;
National Survey of Older Americans Act Participants;
Correction

COMMENTS OF WHITMAN-WALKER HEALTH

Pursuant to the request for comments issued by the Department of Health and Human Services, Administration for Community Living (ACL or the Administration), on March 13, 2017, 82 Fed. Reg. 13,457, *corrected*, March 24, 2017, 82 Fed. Reg. 15,062, Whitman-Walker Clinic, Inc., d/b/a Whitman-Walker Health (WWH or Whitman-Walker), hereby submits the following comments.

Whitman-Walker Health opposes the proposed modification of the National Survey of Older Americans Act Participants (NSOAAP or National Survey) contained in its Draft 2017 Survey Instrument of March 3, 2017.¹ That proposed draft Survey Instrument for 2017 eliminates questions about sexual orientation and identity in section DE(1) that were included in the survey during the previous three years. Without collecting information on the sexual orientation and gender identity of survey participants, the Administration will not have any way to assess the impacts of Older Americans Act (OAA) - funded programs on elder lesbian, gay, bisexual, or transgender (LGBT) Americans. Eliminating such information collection would, moreover, impede the efforts of many other federal, state, and local agencies, private nonprofit agencies, and researchers that depend on data collected by the NSOAAP. Eliminating any data

¹ Administration on Aging (AoA), OAA Performance Information, Description of National Surveys of OAA Participants, National Survey of Older Americans Act Participants (2017 Draft), https://aoa.acl.gov/Program_Results/docs/National_Survey_of_OAA_Participants.docx (last visited May 8, 2017) (noting that the “2017 Survey Instrument does contain modifications from the currently approved collection”); also at <https://acl.gov/NewsRoom/Index.aspx> as of May 4, 2017.

on LGBT older Americans in this critical survey would, in essence, render them invisible. Abandoning older LGBT persons in this way would be a betrayal of the Administration's mandate to protect elder populations that are particularly vulnerable. Older LGBT Americans are at particular risk of isolation and greater need for support, precisely because of their LGBT identity. We therefore urge the Administration to continue, in the 2017 Survey Instrument, to include the questions on sexual orientation and gender identity in section DE(1)(a) of the 2016 Survey Instrument.

EXPERTISE AND INTEREST OF WHITMAN-WALKER HEALTH

Whitman-Walker Health is a community-based, nonprofit, Federally Qualified Health Center offering primary medical care and HIV specialty care, mental health and addiction treatment services, dental care, medical adherence case management, and legal services to residents of the greater Washington metropolitan area. WWH has a special mission to the LGBT members of our community, as well as to all Washington-area residents with HIV regardless of race, gender or sexual orientation. In 2016, WWH provided health services to 16,253 unique persons.

Whitman-Walker's Legal Services Program was established in 1986 to provide *pro bono* legal assistance to people living with HIV on matters related to their diagnosis. In more recent years our work has expanded to include legal counsel and representation to LGBT individuals and families in the Washington, D.C. metropolitan area. Over the past 30 years, Whitman-Walker Legal Services has provided *pro bono* assistance to tens of thousands of individuals and families on a wide range of issues including access to health care; private insurance; public benefits (Social Security disability benefits, Medicaid, Medicare, and DC, Maryland and Virginia programs); discrimination based on HIV status, sexual orientation, or gender identity in

health care, employment and public accommodations; immigration matters; wills, advance healthcare directives and powers of attorney; and medical privacy. Since 2012, we have run a legal clinic to assist transgender individuals with name and gender marker changes in their identity documents that has helped hundreds of transgender and gender nonconforming individuals. In 2016, our legal staff and volunteers assisted 3,120 new clients on 6,069 new legal matters. In 2013, we launched a new initiative to meet the specific legal needs of older adults who are LGBT or living with HIV.

Whitman-Walker's patient populations, and our legal clients, reflect the diversity of the Washington, D.C. metropolitan area, and our special commitment to the LGBT community. Of the persons receiving health services in 2016, 51% reported their sexual orientation identified as gay, lesbian or bisexual; and 8% of our total healthcare patients identified as transgender. In Legal Services, 40% of those who disclosed their sexual orientation identified as gay, lesbian or bisexual, and 20% of our total legal clients identified as transgender.

Whitman-Walker has extensive experience caring for the health and legal needs of older individuals, including those who identify as LGBT. In 2016, approximately 24% of our total healthcare patients were age 50 or older – and approximately 40% of patients who identified as LGBT were age 50 or older. Moreover, 43% of all patients who were living with HIV or AIDS were 50 or older. Also in 2016, 38% of our total new Legal Services clients, 37% of our legal clients who identified as gay, lesbian or bisexual, and 4% of our transgender and gender nonconforming clients, were age 50 or older.

COMMENTS ON THE PROPOSED MODIFICATION OF THE ACL/AOA NATIONAL SURVEY OF OLDER AMERICANS ACT PARTICIPANTS FOR 2017

On March 13, 2017, the ACL published a Notice in the Federal Register, entitled in part, soliciting “comments on” the “National Survey of Older Americans Act (OAA) Participants” for

2017, “with *no changes* of a currently approved collection.” 82 Fed. Reg. 13,457 (*emphasis added*). On March 24, 2017, however, the ACL published a “Correction” to its March 13 Notice, stating that the proposed survey in fact did have “modifications.” 82 Fed. Reg. 15,062. Nowhere in the Correction of March 24, however, did the ACL identify its proposed “modifications” or explain the reasons for them. A comparison of the 2017 proposed Survey Instrument with the 2016 Instrument shows that one of the only substantive differences between the two Instruments is the *absence* of section DE(1)(a) in the proposed Instrument for 2017: all questions regarding sexual orientation and gender identity have been removed from the proposed 2017 Survey.² Elimination of these questions is arbitrary and unwarranted, and would undermine one of the fundamental purposes of the Older Americans Act: to protect older populations with distinctive, important needs.

I. The Administration has already recognized that data needs to be collected in the National Survey on older Americans who are LGBT.

The ACL “collects and reports on the performance of Older Americans Act programs through . . . several data collection systems,” including “its national surveys of OAA [Older Americans Act] participants.”³ The ACL then “reports in detail on this performance . . . in the Program Performance Analysis section of [its] ‘Congressional Justification’ which accompanies the President’s budget each year”⁴ One of the ways the ACL collects information on the effectiveness of OAA programs is by means of an annual telephone survey of a random sample

² Compare, 11th ACL/AoA National Survey of Older Americans Act Participants: 2016 Survey Instrument at 100-101, with ACL/AoA National Survey of Older Americans Act Participants: 2017 Draft Survey Instrument at 100.

³ Admin. on Community Living, U.S. Dept. of Health and Human Services, “OAA Performance Information,” https://aoa.acl.gov/program_results/OAA_Performance.aspx (last viewed April 24, 2017).

⁴ *Id.*

of the clients of over 600 state Area Agencies on Aging throughout the United States.⁵ The sampled clients are asked a series of questions propounded by the ACL in its NSOAAP Survey Instrument.⁶ “[ACL] uses the results of the National Survey to evaluate the effectiveness of the Older Americans Act programs it funds.”⁷ “The instrument[] also measure[s] special needs characteristics such as physical and social functioning of the people who receive services.”⁸ This 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 LGBT older adults. The more we know, the more we can do to make sure LGBT older adults receive the services they need.

From 2014 to 2016, the ACL included questions in its Survey Instrument which asked participants about their sexual orientation and gender identity.⁹ The 2016 Survey Instrument, in section DE(1)(a), asked the following question:

Which of the following best represents how you think of yourself?

Lesbian or Gay
Straight, that is, not lesbian or gay
Bisexual
Something else

⁵ National Survey of Older Americans Act Participants: Frequently Asked Questions, FAQ No. 3, <https://aoasurvey.org/source/faq.asp> (last visited April 24, 2017).

⁶ See 82 Fed. Reg. 13,457 (March 13, 2017) (citing National Survey of Older Americans Act Participants 2017 Draft, which “may be found on the ACL Web site at: https://aoa.acl.gov/Program_Results/OAA_Performance.aspx.”)

⁷ National Survey of Older Americans Act Participants: Frequently Asked Questions, FAQ No. 1, <https://aoasurvey.org/source/faq.asp> (last visited April 24, 2017).

⁸ AoA, ACL, HHS, “Description of National Surveys of OAA Participants,” https://aoa.acl.gov/Program_Results/OAA_Performance.aspx (last visited April 24, 2017).

⁹ See, e.g., Administration for Community Living; Aging Integrated Database (AGID); Data Files; Survey Databases; National Survey of OAA Participants; 2015—Case Management; Documentation; Survey Instrument, <https://agid.acl.gov/DataFiles/NPS/Files.aspx?year=2015&serviceid=9> (last visited May 8, 2017).

Refused
Don't know

§ DE(1)(a). If the respondent answered, “Something else,” the questioner was then directed to ask,

What do you mean by something else?

§ DE(1)(a)(1). Anticipated responses included options for transgender identity:

You are not straight, but identify with another label such as queer, trisexual, omnisexual, or pansexual

You are transgender, transexual or gender variant

You have not figured out or are in the process of figuring out your sexuality

You do not think of yourself as having sexuality

You do not use labels to identify yourself

....

§ DE(1)(a)(1)-(1)(a)(3). This script, which includes questions intended to elicit information on sexual orientation and gender identity from respondents who may initially be confused or reticent, clearly recognizes the importance of gathering data about the effectiveness of OAA programs for LGBT older adults.

ACL should restore those questions by simply using the currently approved Survey Instrument from 2016 in order to continue to collect information on LGBT older adults, because they are a population with unique, critical needs.

II. The collection of information on LGBT older adults is necessary because they are a population of “greatest social need.”

The ACL deleted questions about sexual orientation and gender identity from its proposed 2017 NSOAAP survey with no explanation and no stated basis. Its action therefore

appears arbitrary, and certainly contravenes the ACL’s goal of optimizing OAA services for this vulnerable population. Under the OAA, “[e]ach [state] area agency on aging . . . shall . . . prepare and develop an area plan,” which, among other things, shall “provide assurances that the area agency on aging will . . . set specific objectives, consistent with State policy, for providing services to older individuals with greatest economic need, [and] older individuals with greatest social need.” 42 U.S.C. § 3026(a)(4)(A)(i)(I)(aa). “The term ‘greatest social need’ means the need caused by [economic as well as] noneconomic factors, which include . . . cultural, social, or geographical isolation, . . . [that] restricts the ability of an individual to perform normal daily tasks; or threatens the capacity of the individual to live independently.” 42 U.S.C. § 3002(24)(C) (Definitions). By this definition, LGBT older adults constitute a population of “greatest social need.” Indeed, in its *Guidance for the Development and Submission of State Plans on Aging*, the ACL has advised States that one of the “[n]umerous factors [that] can contribute to ‘greatest economic and social need’ ” includes “one’s sexual orientation/gender identity (LGBT).”¹⁰

Because of their sexual orientation or transgender identity, LGBT elders face unique challenges in aging, in part because of the invisibility that results from pervasive stigma and discrimination. “LGBT older people are twice as likely to live alone, twice as likely to be single, and 3 to 4 times less likely to have children—and many are estranged from their biological families.”¹¹ As a result, older LGBT individuals face a much higher risk of isolation than their heterosexual counterparts. Many older gay men lost much of their friendship network to the

¹⁰ *Standard Template, Administration on Aging Program Instruction: Guidance for the Development and Submission of State Plans on Aging, State Plan Amendments and the Intrastate Funding Formula*, § III(B)(6), page 5-6, http://www.aoa.acl.gov/AoA_Programs/OAA/Aging_Network/pi/PI-Template.aspx (last viewed April 27, 2017).

¹¹ Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE), “Social Isolation,” <http://www.sageusa.org/issues/isolation.cfm> (last visited April 27, 2017).

AIDS epidemic of the 1980's and 90's. Furthermore, “[f]orty-one percent of lesbian, gay and bisexual adults age 50 and older have a disability,” much higher than the national average.¹² Older LGBT individuals therefore tend to need more help, yet have fewer—or no—helpmates, compared to heterosexual individuals the same age. Also, a recent study “found that same-sex elder couples face higher poverty rates than their heterosexual peers.”¹³ Current studies further demonstrate that older LGBT individuals tend to “re-closet” when age, disability, or poverty forces them to leave the homes and communities of choice that allowed them to express themselves openly. For example, older gay men tend to perceive themselves as needing “to conceal their sexual orientation or that others [are] uncomfortable with or avoid[] them because of their sexual orientation.”¹⁴ Isolation, disability, and poverty result in poorer health outcomes for this population.

Whitman-Walker healthcare providers, lawyers, and paralegals repeatedly see evidence of these trends in our regular interactions with our older LGBT patients and legal clients. For example:

- David is a 68-year-old HIV positive gay man who lost his life partner several years ago, and lives alone now, on less than \$2000 a month from Social Security. Most if not all of his friends have either died or moved away. He has had no contact with his family of origin since his early adulthood, when he came out and fled an abusive adoptive father. He came to Whitman-Walker Legal Services for help because, aside from one friend (who might move out of the area), he has no one to whom to give power of attorney to act on his behalf should he lose mental competency.
- Richard is a sixty-year-old African American gay man on Social Security Disability who has multiple disabling conditions, including mild dementia. He lives alone, and struggles

¹² SAGE, “Disability,” <http://www.sageusa.org/issues/disability.cfm> (last visited April 27, 2017).

¹³ SAGE, “Economic Security,” <http://www.sageusa.org/issues/economic.cfm> (last visited April 27, 2017).

¹⁴ Richard G. Wight, Allen J. LeBlanc, Brian de Vries, & Roger Detels, *Stress and Mental Health Among Midlife and Older Gay-Identified Men*, Am. J. Pub. Health, vol. 102, no. 3, pp. 503-510 (March 2012), <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2011.300384> (last viewed April 27, 2017).

to keep his apartment orderly and maintain his activities of daily living. He is a cancer survivor, and also has marked impairment in his lower extremities from injuries he sustained when he was hit by a car 20 years ago. He often uses a walker or cane. His partner of many years, who helped to keep him organized, died some time ago. He now has little opportunity to socialize with other gay men, because of the physical difficulty of getting out. He has no one to help him at home.

- Joan is a 65-year-old lesbian who lived with her partner for many years until domestic violence grew intolerable. She moved into a women’s shelter as a result. In the shelter, however, she faced pressure to “re-closet” with some of the other residents and staff, in order to avoid conflict.
- Susan is a disabled male-to-female transgender individual who is physically disabled and qualified for assisted living placement in Virginia. One assisted living facility she sought to enter, however, rejected her application on grounds of her transgender identity. She struggled to find a facility that would accept her. Many transgender individuals have expressed fear of ever having to live in an assisted living or long-term care facility, because of the high potential for abuse or humiliation, either from staff or other residents.

These and our other similar patients face unique “cultural [and] social ... isolation” as a result of their LGBT identity, and that isolation “restricts the ability of [these] individual[s] to perform normal daily tasks ... [and] live independently.” 42 U.S.C. § 3002(24)(C) (definition of individuals of “greatest social need”). As a result, they are in greater need of OAA programs. Yet, because of discrimination and stigma, we know they are already less likely to access them. “We need SOGI data collection so that we can better understand LGBT disparities and how they intersect with racial/ethnic and other disparities, and to develop effective interventions to reduce and eliminate these disparities.”¹⁵ It is imperative, therefore, that the ACL continue to gather data on how State agencies are succeeding—or not—in addressing the needs of LGBT older adults.

¹⁵ Sean R. Cahill, and Harvey J. Makadon, M.D., “If They Don’t Count Us, We Don’t Count: Trump Administration Rolls Back Sexual Orientation and Gender Identity Data Collection,” 4(3) LGBT Health 2 (2017).

III. Challenges in collecting data about LGBT participants are not a reason to stop collecting such data—they constitute all the more reason *to* collect such data.

A. Low response rates to questions about sexual orientation or gender identity in the current NSOAAP Survey Instrument should not be construed as a reason to stop asking those questions.

While the Administration did not state in its Notice any reason for deleting the questions about sexual orientation and gender identity from its proposed 2017 Survey Instrument, one reason sometimes proffered for not collecting such data is low response rate and high error rate.¹⁶ Yet low response and high testing error can themselves be revealing. Low response rate may mean that OAA programs are not targeting and serving LGBT elders, or that LGBT elders do not feel welcome in such programs. Low response rate would therefore reflect on the effectiveness of OAA programs for this population. Moreover, “[o]ther surveys that ask older people about their [sexual orientation and gender identity],” such as the Gallup Poll, “have also found that a relatively small percentage of older adults identify as LGBT compared with middle age and young respondents.” In many cases response rates are low when questions are initially added to a surveys, but then “increase over time.”¹⁷

A high error rate may mean that there is a need to fine-tune the questions or manner of questioning, or that LGBT elders are not comfortable disclosing their orientation or identity over the phone to a stranger. Either way, an unusually low response rate would be reason for further investigation, not less. “Ironically, . . . historically sanctioned discrimination against LGBT

¹⁶ In an “information” icon attached to the hyperlink for the 2014 and 2015 surveys, the ACL noted problems in gathering information on sexual orientation and gender identity “because of small sample size and a large statistical measure of standard error (>30%).” Administration for Community Living; AGing Integrated Database (AGID); Data Files; Survey Databases; National Survey of OAA Participants; 2015; Information (“I”), <https://agid.acl.gov/DataFiles/NPS/> (last visited May 8, 2017). The ACL said in this comment that it was “working to refine these questions”—not eliminate them. *Id.*

¹⁷ Sean R. Cahill, *et al.*, “If They Don’t Count Us, We Don’t Count,” at 2.

people creates a catch-22 where government agencies do not research or collect data on LGBT elders, but in turn use this very lack of data to argue against a documented need to better serve this population.”¹⁸

The ACL’s March 13th Notice invites comments on “ways to enhance the quality, utility, and clarity of the information to be collected.” 82 Fed. Reg. at 13457. *Deleting* questions about sexual orientation and gender identity of OAA participants could not possibly “enhance the quality, utility, and clarity of the information to be collected,” for all the reasons stated above. *Id.* The ACL should therefore retain those questions as already provided in section DE(1)(a). If the ACL is experiencing difficulty collecting such data, there are better ways to solve that problem than by ceasing to attempt to do so.

B. Targeting sexual and gender minority older adults for assessment is feasible.

We submit that broader investigation of the needs of sexual and gender minority elders is readily achievable. The lack of information on LGBT elders is largely the result of a traditional reluctance to inquire about their needs—or even to acknowledge the existence of sexual and gender minority older adults. The ACL has stated that it is working “with other experts in the field”¹⁹ to refine and improve its survey questions for sexual orientation and gender identity. To that end, we draw to the ACL’s attention several reputable, well-known research institutes, as well as LGBT direct service and advocacy organizations, that can assist the ACL and State agencies in gathering data on LGBT elders and assessing their needs. The Williams Institute of the U.C.L.A. School of Law has published numerous studies on the U.S. LGBT population that measure and collect data on sexual orientation and gender identity. For example, in *Human*

¹⁸ SAGE, *Improving the Lives of LGBT Older Adults*, at 9 (March 2010), <http://www.lgbtmap.org/file/improving-the-lives-of-lgbt-older-adults.pdf> (last viewed April 27, 2017).

¹⁹ National Survey of OAA Participants; 2015; Information (“I”), <https://agid.acl.gov/DataFiles/NPS/> (last visited May 8, 2017).

Services for Low-Income and At-Risk LGBT Populations: The Knowledge Base and Research Needs, a study conducted for the Administration for Children and Families (ACF) in the U.S. Department of Health and Human Services, the Williams Institute assessed “the scope and estimated size of the LGBT population in the United States as well as factors that may contribute to social and economic disadvantages for LGBT people,” then presented “the framework and methods for the needs assessment” for human services.²⁰

The Fenway Institute Center for Population Research in LGBT Health “supports and stimulates research to fill critical knowledge gaps related to the health of sexual and gender minorities, strengthening the foundation for culturally competent treatment”²¹ The Center is currently conducting a “Community-based Participatory Research (CBPR) in LGBT Older Adults” to “better understand and document the unique needs of LGBT older adults, including their vulnerabilities and sources of strength, and to develop programs and services to better meet these needs.”²² The Fenway Institute and the Center would be another source of guidance on data measurement, collection, and assessment for LGBT elders.

The Center for LGBT Health Research at the University of Pittsburgh Graduate School of

²⁰ Williams Institute, Census & LGBT Demographic Studies, <http://williamsinstitute.law.ucla.edu/category/research/census-lgbt-demographics-studies/> (last visited April 27, 2017) (citing Andrew Burwick, Gary Gates, Scott Baumgartner & Daniel Friend, Williams Institute, *Human Services for Low-Income and At-Risk LGBT Populations: The Knowledge Base and Research Needs*, (December 2014), <http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/human-services-for-low-income-and-at-risk-lgbt-populations-an-assessment-of-the-knowledge-base-and-research-needs/> (last visited April 27, 2017); see also Gary Gates, Williams Institute, *LGBT Demographics: Comparisons among population-based surveys*, <http://williamsinstitute.law.ucla.edu/research/census-lgbt-demographics-studies/lgbt-demogs-sep-2014/> (last visited April 27, 2017).

²¹ Center for Population Research in LGBT Health, The Fenway Institute, <http://lgbtpopulationcenter.org/> (last visited April 27, 2017).

²² <http://lgbtpopulationcenter.org/research-projects/> (last visited April 27, 2017).

Public Health is yet another source for guidance and models for data measurement and collection. For example, it is currently “launching a study to determine ways to promote health among aging gay and bisexual men, who make up about two-thirds of the people aging with HIV.”²³ Services and Advocacy for GLBT Elders – SAGE – is a highly-regarded national organization that provides technical assistance to state and local governments and nonprofit senior service agencies across the U.S. to help them assess the needs of LGBT elders and to improve services to those elders. Local direct service organizations, such as Whitman-Walker, can also assist their local and state government agencies to collect and assess relevant data.

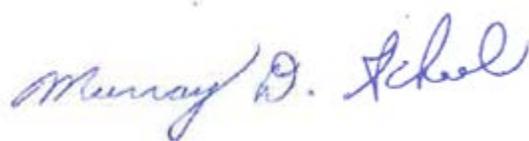
CONCLUSION

For these reasons, Whitman-Walker Health opposes the deletion of questions about sexual orientation and gender identity in the proposed NSOAAP Survey Instrument for 2017, and urges the ACL to continue to use section DE(1)(a) of the already-approved 2016 Survey Instrument. We appreciate the opportunity to submit these comments. We would be happy to provide any additional information that the Administration might request.

Respectfully submitted,



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²³ Center for LGBT Health Research, University of Pittsburgh Graduate School of Public Health, “Pitt launching study to promote health among aging gay and bisexual men with HIV,” <https://www.lgbthlres.pitt.edu/> (last visited April 27, 2017.)