# 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; Request for New Information Collection for	)	
a Program Instruction on Guidance for the Development and	)	FR Doc. 2016–14612
Submission of State Plans on Aging, State Plan Amendments and	)	
the Intrastate Funding Formula	)	

#### COMMENTS OF WHITMAN-WALKER HEALTH

Pursuant to the request for comments issued by the Department of Health and Human Services, Administration for Community Living, Administration on Aging on June 21, 2016, 81 Fed. Reg. 40,311, Whitman-Walker Clinic, Inc., d/b/a Whitman-Walker Health (WWH or Whitman-Walker), hereby submits the following comments.

Whitman-Walker Health commends the Administration for its express recognition that sexual orientation and gender identity "can limit the degree to which older adults experience full inclusion in society and are able to access available services and supports." We are concerned, however, that the revised guidance does not unambiguously require the States to assess the needs of LGBT older adults. We therefore recommend that the Administration modify the proposed guidance to expressly require States to describe the actions to be taken to assess the needs of lesbian, gay, bisexual and transgender (LGBT) older individuals.

## 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

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 6, <a href="http://www.aoa.acl.gov/AoA">http://www.aoa.acl.gov/AoA</a> Programs/OAA/Aging Network/pi/PI-Template.aspx.

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 2015, WWH provided health services to more than 15,393 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 27 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 2015, our legal staff and volunteers assisted 2,637 new clients on 4,944 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 2015, 57% those who reported their sexual orientation identified as gay, lesbian or bisexual; and 7% of our total healthcare patients identified as

transgender. In Legal Services, 51% of those who disclosed their sexual orientation identified as gay, lesbian or bisexual, and 18% 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 2015, approximately 22% of our total healthcare patients were age 50 or older – and approximately 19% of patients who identified as LGBT were age 50 or older. Moreover, 44% of all patients who were living with HIV or AIDS were 50 or older. Also in 2015, 39% of our total new legal clients, 25% 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 NEW INFORMATION COLLECTION

I. The collection of information on LGBT older adults, in order to explicitly assess their needs, is necessary because they have a heightened risk of "greatest social need."

Under the Older Americans Act ("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," for the following reasons.

Because of their sexual orientation or transgender identity, LGBT elders face unique challenges in aging, in part because of the invisibility resulting from their LGBT status. "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."<sup>2</sup> In particular, many older gay men lost much of their friendship network to the AIDS epidemic of the 1980's and 90's. As a result, older LGBT individuals face a much higher risk of isolation than their heterosexual counterparts. Furthermore, "[f]orty-one percent of lesbian, gay and bisexual adults age 50 and older have a disability," much higher than the national average.<sup>3</sup> 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."<sup>4</sup> 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." Isolation, disability, and poverty result in poorer health outcomes for this population.

<sup>&</sup>lt;sup>2</sup> Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE), "Social Isolation," <a href="http://www.sageusa.org/issues/isolation.cfm">http://www.sageusa.org/issues/isolation.cfm</a> (last visited Aug. 17, 2016).

<sup>&</sup>lt;sup>3</sup> SAGE, "Disability," http://www.sageusa.org/issues/disability.cfm (last visited Aug. 17, 2016).

<sup>&</sup>lt;sup>4</sup> SAGE, "Economic Security," <a href="http://www.sageusa.org/issues/economic.cfm">http://www.sageusa.org/issues/economic.cfm</a> (last visited Aug. 17, 2016).

<sup>&</sup>lt;sup>5</sup> 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), <a href="http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2011.300384">http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2011.300384</a>, *also available at* <a href="http://williamsinstitute.law.ucla.edu/research/health-and-hiv-aids/stress-and-mental-health-among-midlife-and-older-gay-identified-men/#sthash.7Z2oEjkW.dpuf.">http://williamsinstitute.law.ucla.edu/research/health-and-hiv-aids/stress-and-mental-health-among-midlife-and-older-gay-identified-men/#sthash.7Z2oEjkW.dpuf.</a>

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 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 their ability "to perform normal daily tasks" and to "live independently." 42 U.S.C. § 3002(24)(C) (definition of individuals of "greatest social need"). It is imperative, therefore, that State agencies responsible for meeting the needs of elderly and older individuals and families be required to assess whether LGBT older adults are a population of "greatest social need."

- II. The revised Program Instruction should expressly require that LGBT older adults be included as one of those groups whose needs must be assessed by the State Units on Aging.
  - A. The targeting guidance should be clarified to remove any ambiguity regarding the need to assess the specific needs of sexual and gender minority elders.

We commend the Administration for its express recognition that sexual orientation and gender identity "can limit the degree to which older adults experience full inclusion in society and are able to access available services and supports." <sup>6</sup> We suggest a modest revision to this language in the guidance as follows:

Numerous factors can contribute to "greatest economic and social need," including (but not limited to) being an American Indian (regardless of membership in a Federal or state-recognized tribe); one's sexual orientation/gender identity (LGBT) being a member of a sexual or gender minority, e.g., being lesbian, gay, bisexual or transgender ("LGBT"); being a Holocaust survivor; status as a refugee; . . . . <sup>7</sup>

By focusing specifically on members of sexual orientation and/or gender identity *minorities*, this language clarifies that it is membership in such a minority that is at issue, and which may result in greater social and cultural isolation. Moreover, "sexual or gender minority" is somewhat broader than "LGBT", and, therefore, would signal that State agencies should take in to account individuals who may not fit neatly into the categories of "gay," "lesbian," "bisexual," or "transgender."

More importantly, Section III(B)(6) of the revised Program Instruction should be amended to remove any ambiguity as to whether assessment of the needs of sexual and gender minority elders is required, as distinct from merely recommended. The current language states

<sup>&</sup>lt;sup>6</sup> 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 6, <a href="http://www.aoa.acl.gov/AoA">http://www.aoa.acl.gov/AoA</a> Programs/OAA/Aging Network/pi/PI-Template.aspx.

<sup>&</sup>lt;sup>7</sup> Cf. id.

that being LGBT is one of "[n]umerous factors" that "can contribute to 'greatest economic and social need," and that "states should describe their approaches for assessing and addressing the needs of such populations of older adults, including (but not limited to) conducting statewide environmental scans and needs assessments . . . . "8 While this language can be read to imply that States *must* address the needs of the specific populations enumerated, including LGBT elders, it might be interpreted to mean that States have the *option* of assessing the needs of LGBT elders and the other populations specifically mentioned. We therefore urge the Administration to clarify the direction in Section III(B)(6) as follows:

To ensure effective targeting of resources to all older adults with greatest economic and social need, states should must describe their approaches for assessing and addressing the needs of such populations of older adults, including (but not limited to) the populations identified above. These approaches should include (but are not limited to) conducting statewide environmental scans and needs assessments, ensuring broad representation on advisory committees, holding public hearings and conducting targeted outreach to ensure all populations are aware of and able to access services.

Such an amendment to the guidance in Section III(B)(6) would thus more likely accomplish the Administration's goal of ensuring that the special needs of all older adults are adequately understood and met.

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

The June 21 Notice invites comments on "whether the targeting guidance as articulated on pages 5–6 of the template is feasible and likely to ensure maximum inclusion of all populations of seniors, including . . . LGBT seniors . . . ." 81 Fed. Reg. at 40,312. We submit that investigating the needs of sexual and gender minority elders is feasible and indeed, readily

<sup>&</sup>lt;sup>8</sup> *Id*.

<sup>&</sup>lt;sup>9</sup> Cf. id.

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. There are a number of reputable, well-known research institutes, as well as LGBT direct service and advocacy organizations, that can assist State agencies to gather data on LGBT elders and assess 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 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. <sup>10</sup>

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 . . ." <sup>11</sup> The Center is currently conducting a "Community-based Participatory Research (CBPR) in LGBT Older

<sup>10</sup> Williams Institute, Census & LGBT Demographic Studies, http://williamsinstitute.law.ucla.edu/category/research/census-lgbt-demographics-studies/ (last visited Aug. 17, 2016) (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/); 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/.

<sup>&</sup>lt;sup>11</sup> Center for Population Research in LGBT Health, The Fenway Institute, <a href="http://lgbtpopulationcenter.org/">http://lgbtpopulationcenter.org/</a> (last visited Aug. 17, 2016).

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." 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 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." <sup>13</sup>

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.

<sup>&</sup>lt;sup>12</sup> http://lgbtpopulationcenter.org/research-projects/ (last visited Aug. 17, 2016).

<sup>&</sup>lt;sup>13</sup> 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," <a href="https://www.lgbthlres.pitt.edu/">https://www.lgbthlres.pitt.edu/</a> (last visited Aug. 17, 2016.)

## **CONCLUSION**

Whitman-Walker Health appreciates 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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