

August 15, 2023

Submitted online at: <https://www.federalregister.gov/documents/2023/06/16/2023-12829/older-americans-act-grants-to-state-and-community-programs-on-aging-grants-to-indian-tribes-for>

**RE: Older Americans Act: Grants to State and Community Programs on Aging; Grants to Indian Tribes for Support and Nutrition Services; Grants for Supportive and Nutritional Services to Older Hawaiian Natives; and Allotments for Vulnerable Elder Rights Protection Activities**

Howard Brown Health is the largest LGBTQ+ health center in the Midwest, serving more than 35,000 patients across eleven clinic locations in Chicago. We provide primary care, behavioral health care, HIV/STI treatment and prevention, and elder services. Around 9% of Howard Brown's clients are 55 and older. Howard Brown is invested in the updated implementation of Older Americans Act (OAA) because of the unique, and often unmet, needs of older LGBTQ+ adults and older adults living with HIV. Accordingly, we support the ACL's proposed changes to improve equity in elder services delivery for marginalized populations, and we especially support categorizing older LGBTQ+ adults and older people living with HIV (PLWH) as populations of greatest social need under the OAA.

Advances in HIV treatment and drug adherence have led to longer life spans for PLWH. In 2018, 51% of people in the United States and dependent areas living with HIV were aged 50 and older.<sup>1</sup> As the population living with HIV continues to age, there has not been an appropriate response to address specific needs and ensure older PLWH are able to thrive. Older PLWH experience an increased prevalence of other chronic illnesses and comorbidities, like cardiovascular disease, malignancies, osteoporosis, cognitive impairment, frailty, and disability.<sup>2</sup> Because of this, older PLWH generally have a higher risk of hospitalization linked to adverse events from polypharmacy.<sup>3</sup> Another cause for concern in older PLWH is mental well-being as there have been findings that relate HIV-associated stigma and increased loneliness in this population to increased depression.<sup>4</sup>

Along with these health disparities, aging PLWH experience unique social and economic disparities. A study of older PLWH found that 96% reported experiencing HIV stigma itself, and 71% reported experiencing both ageism and HIV stigma. In addition, 56% reported experiencing rejection from

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<sup>1</sup> "HIV Life Expectancy: Aging with HIV." *HIV.gov*, 17 May 2021, [www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv/](http://www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv/).

<sup>2</sup> Roomaney, R. A., van Wyk, B., & Pillay-van Wyk, V. (2022). Aging with HIV: Increased Risk of HIV Comorbidities in Older Adults. *International journal of environmental research and public health*, 19(4), 2359. <https://doi.org/10.3390/ijerph19042359>

<sup>3</sup> Roomaney, R. A., van Wyk, B., & Pillay-van Wyk, V. (2022). Aging with HIV: Increased Risk of HIV Comorbidities in Older Adults. *International journal of environmental research and public health*, 19(4), 2359. <https://doi.org/10.3390/ijerph19042359>

<sup>4</sup> Grov, C., Golub, S. A., Parsons, J. T., Brennan, M., & Karpiak, S. E. (2010). Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS care*, 22(5), 630–639. <https://doi.org/10.1080/09540120903280901>

service providers, family, friends, church members. This many leave many older PLWH disconnected from traditional social support networks. HIV stigma also made it challenging for many older PLWH to establish strong economic safety nets. Job loss because of discrimination or due to fatigue and periodic hospitalization caused by HIV-related illnesses created barriers to establishing financial sustainability. Additionally, the high costs of healthcare and lack of insurance coverage for older PLWH contributed further to economic instability. Until the Affordable Care Act (ACA), many HIV-positive individuals had to have an AIDS diagnosis to qualify for Medicaid, and private insurance routinely discriminated against people with pre-existing conditions. This lack of access to insurance only furthered economic strain on older PLWH.<sup>5</sup>

Likewise, discrimination and stigma also negatively affect health outcomes and financial sustainability for older LGBTQ+ adults. The historical criminalization of LGBTQ+ identities has resulted in many older LGBTQ+ adults experiencing a lifetime of social exclusion, discrimination, victimization, stigma, and identity concealment.<sup>6</sup> Additionally, older LGBTQ+ adults had no legal protections against discrimination in the workplace, in housing, and in healthcare. These experiences greatly affect health outcomes, as research has shown that LGBTQ+ older adults report poorer general health, mental distress, disability, sleep problems, and chronic pain compared to their heterosexual, cisgender counterparts.<sup>7</sup> Lifetime disparities in earnings, employment, and retirement saving opportunities also put older LGBTQ+ adults at risk of financial instability and poverty.<sup>8</sup>

Because of the unique lived experiences and needs of older LGBTQ+ adults and older PLWH, it is vital that these populations receive tailored interventions, support services, and resources that are comprehensive and affirming of all identities. At Howard Brown, we have seen firsthand how critical and life-changing this can be. Howard Brown offers a comprehensive suite of health and social services specifically for older LGBTQ+ people and older PLWH through our Aging Services Department. Below are some stories of patients who utilize our aging services and programming:

- A 60 year old woman who is a long-term survivor of HIV reported feeling very isolated and discriminated against because of her HIV status while trying to get services from other organizations. She was told about Rising Phoenix, our support group for older adults living long-term with HIV, and has since found a community where she feels safe and accepted.
- A 78 year old trans woman felt out of place in other transfemme support groups, where she couldn't relate to the issues that the younger participants were dealing with and they

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<sup>5</sup> Cahill, S., & Valadéz, R. (2013). Growing older with HIV/AIDS: new public health challenges. *American journal of public health, 103*(3), e7–e15. <https://doi.org/10.2105/AJPH.2012.301161>

<sup>6</sup> Fredriksen-Goldsen K. I. (2016). The Future of LGBT+ Aging: A Blueprint for Action in Services, Policies, and Research. *Generations (San Francisco, Calif.)*, 40(2), 6–15.

<sup>7</sup> Emler C. A. (2016). Social, Economic, and Health Disparities Among LGBT Older Adults. *Generations (San Francisco, Calif.)*, 40(2), 16–22.

<sup>8</sup> Soon Kyu Choi & Ilan H. Meyer, Williams Inst., LGBT Aging: A Review of Research Findings, Needs, and Policy Implications 8-10 (2016), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf>

likewise couldn't relate to her experience. She expressed finally feeling heard and seen upon joining Transcendence, our support group for older trans adults. She reported feeling relief at finally being in a group of people who really understood her unique concerns as an elder.

As these clients pointed out, experiences of discrimination and exclusion are still all too common for older LGBTQ+ people and older PLWH in accessing mainstream healthcare and elder support services. **That is why we fully support the ACL's proposed changes, especially the categorization of both older LGBTQ+ people and older PLWH as populations of greatest social need.**

In order to further improve implementation of the OAA, we agree with our colleagues at SAGE on the following recommendations:

*State Long-Term Care Ombudsman should track sexual orientation and gender identity (SOGI) data as part of their official duties to identify systemic discrimination issues.*

Gathering SOGI data should be included in ACL data collection efforts as it highlights the specific needs of older LGBTQ+ adults, provides a means to evaluate interventions, and also helps to identify potential instances of discrimination in elder services. For these reasons, there have been calls to prioritize SOGI data collection for years.<sup>9</sup> In 2011, the National Academy of Medicine recommended increased SOGI data collection, stating the "existing body of evidence is sparse, and that substantial research is needed." In 2012, Healthy People 2020 identified the health of older LGBT adults as a national priority.

There may be specific barriers and concerns when collecting SOGI data from older populations. Lifetime experiences of discrimination, including discrimination from the government, may make many LGBTQ+ older adults wary of disclosing SOGI data. The onset of the AIDS epidemic beginning in the 1980s only heightened fears over SOGI disclosure. Other barriers to SOGI data collection include clinician misperception that patients do not want to answer these questions and structural barriers with data collection systems and EHRs. Below we provide some best practices and resources for SOGI data collection:

- Fundamental to any attempts to increase SOGI data collection and improve equity for LGBTQ+ populations is the need for more robust nondiscrimination and cultural competency requirements and training, which ACL should build into this proposed rule.
- Many issues with the collection of SOGI is the lack of best practices and supportive guidance on collecting SOGI data. There are a number of resources that provide guidance on best practices for collecting SOGI data that keep in mind being sensitive and affirming to the

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<sup>9</sup> Candrian, Carey. "Why Routinely Collecting Sexual Orientation and Gender Identity Information Matters for Elders." *LGBT Aging Center.org*, Jan. 2020, [www.lgbtagingcenter.org/resources/resource.cfm?r=983](http://www.lgbtagingcenter.org/resources/resource.cfm?r=983).

fears and needs of older LGBTQ+ adults. Our colleagues at SAGE have resources including “Inclusive Questions for Older Adults: A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity,” and a series of seminars and credentialing to support SOGI collection.<sup>10,11</sup>

- Healthcare systems need to integrate SOGI data collection, including in HER systems and intake forms. ACL should investigate ways to incentivize elder care facilities to implement SOGI data collection.
- Conversations around SOGI data need to be conducted in safe, affirming, and private settings. Older LGBTQ+ adults Providers should elicit consent from patients for sharing data and discuss how their data is protected and used.

*We also agree with our colleagues at SAGE on the below suggestions for improvements to the ACL’s proposed changes:*

- ACL should require increased specificity for reporting requirements from SUAs and AAAs regarding populations predetermined to have greatest social need and how they are targeting service delivery per population, to avoid blanket statements of intention or generalized approaches that lack cultural and social responsiveness;
- ACL thoughtfully expands the “family caregiver” definition and recognizes the lived realities of LGBTQI+ chosen families;
- ACL should require increased specificity for public engagement by Area agencies on their aging advisory councils, focused on populations of greatest social need;
- ACL helpfully clarifies that legal assistance provision to older adults appropriately prioritizes self-determination, and ACL should encourage legal assistance providers to consistently account for the unique circumstances faced by LGBTQI+ older adults and those living with HIV/AIDS who are subject to guardianship;
- ACL should empower SUAs, AAAs, and service providers to adopt a minimum eligibility age other than 60 years old for older adults living with HIV/AIDS to qualify for benefits and services under the OAA;
- ACL correctly finds that there should be no associated additional costs for affected agencies now required to conduct outreach to and collect data on specific populations, including LGBTQI+ older adults and those living with HIV/AIDS;

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<sup>10</sup> National Resource Center on LGBT Aging. “Inclusive Questions for Older Adults: A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity.” *LGBT Aging Center.org*, Mar. 2023, [lgbtagingcenter.org/resources/resource.cfm?r=601](https://lgbtagingcenter.org/resources/resource.cfm?r=601).

<sup>11</sup> SAGE. “LGBT Aging Center.org - Education.” *LGBT Aging Center.org*, [www.lgbtagingcenter.org/education/index.cfm](https://www.lgbtagingcenter.org/education/index.cfm).

- ACL should consider additional examples of “best available data” that capture the experiences of LGBTQI+ older adults and those living with HIV/AIDS; and
- ACL should require increased specificity in reporting on the intrastate funding formula, reflecting the specific formula proportions per population predetermined to have greatest social need, including LGBTQI+ older adults and those living with HIV/AIDS.

Thank you for the opportunity to provide feedback. If you have any questions feel free to contact Tim Wang, Director of Policy and Advocacy, at [timothyw@howardbrown.org](mailto:timothyw@howardbrown.org).

Sincerely,

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President and CEO