



LGBTQIA+  
AGING PROJECT  
A PROGRAM OF  
THE FENWAY INSTITUTE

 THE FENWAY INSTITUTE

SPECIAL  
LEGISLATIVE  
COMMISSION ON  
LESBIAN, GAY,  
BISexual AND  
TRANSGENDER  
AGING



Alison Barkoff  
Acting Assistant Secretary for Aging and Administrator  
Administration for Community Living  
Department of Health and Human Services  
Attention: ACL-AA17-P  
330 C Street SW  
Washington, DC 20201

Submitted electronically via <http://www.regulations.gov>

RE: [Notice of Proposed Rulemaking: Older Americans Act Regulations, RIN Number 0985-AA17](#)

Dear Ms. Barkoff:

The Fenway Institute at Fenway Health, The LGBTQIA+ Aging Project, and the Massachusetts Commission on LGBT Aging, appreciate the opportunity to submit the following comment regarding The Administration for Community Living's proposed rule on recommended changes, additions, or deletions to regulations for programs authorized under the Older Americans Act (OAA). Please note that LGBT, LGBTQ, LGBTQIA+, LGBTQI+ acronyms are used throughout this document. These acronyms reflect the variety of ways that organizations, research and community groups define themselves and the ever growing populations of sexual and gender minorities.

The Fenway Institute is the research, policy, education, and training arm of Fenway Health, a federally qualified health center and Ryan White Part C HIV clinic in Boston, Massachusetts. We provide care to about 35,000 patients every year. Half of our patients identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, or another identity (LGBTQIA+), and about 5,400 are transgender and nonbinary. About 2,300 of our patients are people living with HIV (PLWH). A main focus of our work is providing healthcare for sexual and gender diverse people, as well as HIV and STI prevention and research.

The LGBTQIA+ Aging Project is the premier resource in New England advocating specifically for LGBTQIA+ older adults, and works towards equity, inclusion, and community for sexual and gender minority older adults ensuring that they can age with the dignity and respect they deserve. The Aging Project has developed and delivered

LGBTQIA+ cultural competency training throughout Massachusetts' elder care network, built community engagement for LGBTQIA+ older adults, and advocated for programs and policies that are inclusive of LGBTQIA+ older adults. The Massachusetts Commission on LGBT Aging is the first statewide commission in the U.S. to focus on the needs of LGBT+ older adults and is tasked with reviewing state policies and regulations related to LGBT+ older adults, as well as state-funded elder services, and making recommendations to ensuring equitable access to treatment, care, services, and benefits.

As a healthcare center, and organizations dedicated to serving the needs of older LGBTQIA+ individuals and older PLWH, we express our overall support for the proposed rule change to the Older Americans Act (OAA). This progressive step towards inclusivity and targeted support for populations facing unique challenges and disparities aligns with the core values of providing equitable and compassionate care for our most vulnerable communities.

In our comment we present content from the proposed rule in italics, and then provide comment on that section of the proposed rule.

- I. In response to significant feedback from stakeholders over the years and numerous responses to the RFI, ACL proposes to specify that the State plan must define greatest economic need and greatest social need, including for the following populations: Native American persons; persons who experience cultural, social, or geographical isolation caused by racial or ethnic status; members of religious minorities; lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; persons living with HIV or AIDS; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality as the State defines it.*

In July of 2012 the US Administration on Community Living issued new guidance on the definition of “populations of greatest social need” under the Older Americans Act that included “individuals socially isolated due to .... sexual orientation or gender identity.” In November of 2012, the Massachusetts Secretary of the Executive Office of Elder Affairs designated LGBT older adults as a population of “greatest social need” under the Older Americans Act through administrative action, making Massachusetts the first state to enact this designation. This designation has meant that all Area Agencies on Aging across the Commonwealth are expected to consider LGBT+ older adults in their assessment of target populations of “greatest social need” when preparing and implementing their area plans. It requires the aging network to engage in outreach to LGBT+ older people, collect data on their needs, and collect data on whether the aging network is meeting their needs. These 4 - year plans dictate service and funding priorities in the AAA's local communities.

Currently, the Massachusetts legislature is considering **(H.636) An Act relative to LGBT and HIV positive seniors in the Commonwealth** which would transform Massachusetts' ten-year-old administrative commitment to LGBTQ+ older adults as a "population of greatest social need" into an established element of the Commonwealth's legislation. The addition of HIV+ older adults reflects a greater awareness of the many challenges such as housing, healthcare and food insecurity, these long term survivors face. Codifying the proposed legislation into law is urgently needed to protect both vulnerable populations from being subjected to malleable administrative policies.

The Massachusetts Commission on LGBT Aging's initial 2015 report recommended that LGBT older adults be maintained, and HIV positive older adults be included, in the Commonwealth's designation of "populations of greatest social need" under the Older Americans Act. As such, the Massachusetts Commission on LGBT Aging endorses the state legislation as well as the ACL's proposed changes to the OAA.

We are strongly in support of now codifying recognition of LGBTQI+ persons and older persons living with HIV or AIDS as populations of greatest social and economic need on a federal level. The addition of these older adults reflects a greater awareness of the many challenges faced by these communities, such as social discrimination and stigma, limited access to affordable and safe housing, limited access to culturally responsive and affirming healthcare, and food insecurity. Older LGBT people experience greater physical and mental health disparities compared with their heterosexual, cisgender age peers.<sup>1</sup> These include higher rates of kidney disease among LGB and other individuals age 50 or older compared to heterosexual age peers.<sup>2</sup> LGBT people also experience higher rates of chronic conditions such as diabetes,<sup>3</sup> asthma,<sup>4</sup> obesity, and cardiovascular

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<sup>1</sup> Kimmel D. Lesbian, Gay, Bisexual, and Transgender Aging Concerns. *Clin. Gerontol.* 2014;37:49–63.

<sup>2</sup> Chandra M, Hertel M, Cahill S, Sakaguchi K, Khanna S, Mitra S, Luke J, Khau M, Mirabella J, Cropper A. Prevalence of Self-Reported Kidney Disease in Older Adults by Sexual Orientation: Behavioral Risk Factor Surveillance System Analysis (2014-2019). *J Am Soc Nephrol.* 2023 Apr 1;34(4):682-693.

<sup>3</sup> Beach LB, Elasy TA, Gonzales G. Prevalence of Self-Reported Diabetes by Sexual Orientation: Results from the 2014 Behavioral Risk Factor Surveillance System. *LGBT Health.* 2018 Feb/Mar;5(2):121-130.

<sup>4</sup> Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, Chengshi Shui, and Amanda E. B. Bryan, 2017: [Chronic Health Conditions and Key Health Indicators Among Lesbian, Gay, and Bisexual Older US Adults, 2013–2014](#). *American Journal of Public Health* 107, 1332\_1338.

disease,<sup>5</sup> and higher rates of certain cancers,<sup>6</sup> cancer risk factors, and access to preventive screenings and care.<sup>7</sup>

Older PLWH have complex healthcare needs including a higher prevalence of comorbid conditions like kidney disease, geriatric conditions such as frailty, behavioral health issues, psychosocial needs, and disability.<sup>8,9</sup> Older PLWH in the U.S. are almost twice as likely as the general population to have a disability<sup>10</sup> and are nearly two and a half times more likely than older people who are not HIV-positive to experience cognitive decline.<sup>11</sup> Research shows that older PLWH in the U.S. are more likely to live alone and experience elevated rates of loneliness,<sup>12,13</sup> social isolation,<sup>14</sup> and lack of social support.<sup>15</sup> Older gay

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<sup>5</sup> Fredriksen-Goldsen KI, Kim H-J, Emlert CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: University of Washington; 2011.

<sup>6</sup> Cathcart-Rake EJ. Cancer in Sexual and Gender Minority Patients: Are We Addressing Their Needs? *Curr Oncol Rep*. 2018 Sep 13;20(11):85.

<sup>7</sup> Wakefield D. Cancer care disparities in the LGBT community. *Curr Opin Support Palliat Care*. 2021 Sep 1;15(3):174-179.

<sup>8</sup> American Academy of HIV Medicine (AAHIVM). *Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV. Assessing Frailty and Functional Capacity: Managing the Care of Older Adults with HIV*. CME/CE credit available June 8, 2021 - June 7, 2022. <https://aahivm-education.org/hiv-age/contents>

<sup>9</sup> Chowdhury PP, Beer L, Shu F, Fagan J, Luke Shouse R. Disability among adults with diagnosed HIV in the United States, 2017. *AIDS Care*. 2021 Dec;33(12):1611-1615. doi: 10.1080/09540121.2020.1842318. Epub 2020 Nov 10. PMID: 33172311.

<sup>10</sup> Chowdhury PP, Beer L, Shu F, Fagan J, Luke Shouse R. Disability among adults with diagnosed HIV in the United States, 2017. *AIDS Care*. 2021 Dec;33(12):1611-1615. doi: 10.1080/09540121.2020.1842318. Epub 2020 Nov 10. PMID: 33172311.

<sup>11</sup> Deng L, Zhang X, Gao Y, Turner D, Qian F, Lu H, Vermund SH, Zhang Y, Qian HZ. Association of HIV infection and cognitive impairment in older adults: A meta-analysis. *Ageing Res Rev*. 2021 Jul;68:101310. doi: 10.1016/j.arr.2021.101310. Epub 2021 Feb 26. PMID: 33640473.

<sup>12</sup> Karpiak S, Shippey A. Research on Older Adults with HIV (ROAH). AIDS Community Research Initiative of America. (2006).

[https://www.researchgate.net/publication/280291375\\_Research\\_on\\_Older\\_Adults\\_with\\_HIV](https://www.researchgate.net/publication/280291375_Research_on_Older_Adults_with_HIV)

<sup>13</sup> Kim HJ, Fredriksen-Goldsen KI. Living Arrangement and Loneliness Among Lesbian, Gay, and Bisexual Older Adults. *Gerontologist*. 2016 Jun;56(3):548-58.

<sup>14</sup> Grov C, Golub SA, Parsons JT, Brennan M, Karpiak SE. Loneliness and HIV-related stigma explain depression among older HIV-positive adults. *AIDS Care*. 2010;22(5):630-639.

<sup>15</sup> Matsumoto, S., Yamaoka, K., Takahashi, K. et al. Social Support as a Key Protective Factor against Depression in HIV-Infected Patients: Report from large HIV clinics in Hanoi, Vietnam. *Sci Rep* 7, 15489 (2017).

and bisexual men living with HIV are twice as likely to experience depression,<sup>16,17,18</sup> compared to heterosexual and HIV-negative counterparts. Depression is now a leading cause of morbidity and mortality among older people living with HIV, exceeding even that caused by HIV.<sup>19,20</sup>

Successful management of the health care of older PLWH requires the collaborative, coordinated provision of care from multiple specialty areas to manage comorbidities, geriatric conditions, behavioral health, and psychosocial needs.<sup>21</sup> Many older PLWH, especially Long-Term Survivors living with HIV (persons who were diagnosed before 1996, when antiretroviral therapy became available), live alone and have multiple conditions, including diabetes and blindness, that leave them essentially homebound. Home care assistance, home delivered meals, and other services are absolutely essential to these individuals' ability to age in place and stay out of an institutional setting for as long as possible.

In Massachusetts, in 2019 and 2020, we worked with colleagues at the Mass. Department of Public Health to analyze Behavioral Risk Factor Surveillance System Survey data for older LGBT people. We also conducted 9 in-person and virtual listening sessions with LGBT older adults across Massachusetts. Among our key findings were these: Key themes that came up in the listening sessions were:

- Strong anti-LGBT prejudice in rural Massachusetts, and from age peers across the Commonwealth
- Social isolation and lack of connection
- Mental health needs specific to social isolation
- The need for ongoing services and mental health care for LGBT widows and widowers, especially those on Cape Cod and in other rural areas

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<sup>16</sup> Turrini G, Chan SS, Klein PW, Cohen SM, Dempsey A, Hauck H, Cheever LW, Chappel AR. Assessing the health status and mortality of older people over 65 with HIV. *PLoS One*. 2020 Nov 5;15(11):e0241833.

<sup>17</sup> Nanni MG, Caruso R, Mitchell AJ, Meggiolaro E, Grassi L. Depression in HIV infected patients: a review. *Curr Psychiatry Rep*. 2015 Jan;17(1):530.

<sup>18</sup> Bromberg DJ, Paltiel AD, Busch SH, Pachankis JE. Has depression surpassed HIV as a burden to gay and bisexual men's health in the United States? A comparative modeling study. *Soc Psychiatry Psychiatr Epidemiol*. 2021 Feb;56(2):273-282. doi: 10.1007/s00127-020-01938-1. Epub 2020 Aug 12. PMID: 32785755; PMCID: PMC7870461.

<sup>19</sup> Nanni MG, Caruso R, Mitchell AJ, Meggiolaro E, Grassi L. Depression in HIV infected patients: a review. *Curr Psychiatry Rep*. 2015 Jan;17(1):530.

<sup>20</sup> Ogburn DF, Schoenbach VJ, Edmonds A, et al. Depression, ART Adherence, and Receipt of Case Management Services by Adults with HIV in North Carolina, Medical Monitoring Project, 2009-2013. *AIDS Behav*. 2019 Apr;23(4):1004-1015.

<sup>21</sup> American Academy of HIV Medicine (AAHIVM). *Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV. Assessing Frailty and Functional Capacity: Managing the Care of Older Adults with HIV*. CME/CE credit available June 8, 2021 - June 7, 2022. <https://aahivm-education.org/hiv-age/contents>

- The need for social activities that create a sense of community and belonging
- Transportation needs, especially in rural Massachusetts
- Anti-LGBT discrimination in assisted living
- Anti-gay harassment in businesses and health care facilities in the Berkshires
- The centrality of trauma in people's lives
- The need to address racism within the LGBT community
- A dearth of LGBT-competent and -affirming health care in rural Massachusetts
- Struggling to pay for health care
- Economic hardship in general
- The need for LGBT-friendly elder housing
- The need for targeted support groups and services
- The need for assistance with end-of-life planning
- The need for hardware (computers, tablets), internet access, and technical assistance to isolated, low-income LGBT elders so that they can access virtual support groups and other services.

Key findings from the BRFSS data include the following statistically significant differences between LGBT people 50-75 and straight/cisgender people 50-75:

- LGBT elders reported higher rates of fair/poor overall health, and
- Were nearly twice as likely to report ever having been diagnosed with a depressive disorder,
- Were about as likely to be a veteran and to have children in the household,
- Were more likely to have four or more years of college education
- Were more likely to rent and less likely to own their home
- Were nearly three times as likely to report difficulty paying for housing or food in past year
- Were more likely to report serious difficulty concentrating, remembering or making decisions
- Were near twice as likely to fall and be injured in a fall in the past year
- Reported four times the rate of suicidal thoughts in past year
- Reported three times the rate of lifetime sexual violence victimization
- Lesbian and bisexual women were more likely to be obese and less likely to be of normal weight than heterosexual women in Massachusetts.<sup>22</sup>

Older LGBTQI+ people and older PLWH have unique needs and experiences and are significantly more likely to be aging alone without spouse, partner, children or extended family, the informal caregiving networks upon which many older adults rely. This lack of informal caregivers means many are in greater need of formal elder services. At the same

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<sup>22</sup> Cahill S (2020). *LGBT Aging 2025: Strategies for Achieving a Healthy and Thriving LGBT Older Adult Community in Massachusetts*. Boston: The Fenway Institute, LGBT Aging Project. <https://fenwayhealth.org/wp-content/uploads/LGBT-Aging-2025-Report-December-2020.pdf>

time, they may be less likely to access these services due to fear of experiencing stigma and discrimination in elder services, either by age peers or by service providers themselves. Designating them as populations of greatest social need would encourage aging adult service providers to think more explicitly about how they are meeting the needs of these populations, and how they are ensuring that they can provide affirming, culturally responsive services. Codifying these groups as populations of greatest need into federal regulation would go a long way toward ensuring that LGBTQI+ older adults and older PLWH can access nondiscriminatory, affirming elder services to help them thrive and age in place. We are supportive of adding these groups in all mentions of populations of great social and economic need throughout the Act.

*II: In addition to meeting the requirements of section 307, a State plan shall include:*  
*(d) A description of how greatest economic need and greatest social need are determined and addressed by specifying: (1) How the State defines greatest economic need and greatest social need, which shall include the following populations... (iv) Lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; (v) Persons living with HIV or AIDS... ”*

We support this inclusion, which would require states to develop strategies to address the discrimination and disparities that older LGBTQI+ people face through the development of programs and services that are uniquely suited to LGBTQI+ older adults and their allies. This provision would also encourage collaboration and partnership with stakeholders, including community based and grass roots organizations, advocacy groups like the LGBTQIA+ Aging Project, and healthcare providers like Fenway Health. These are organizations that are specialized in providing care for these populations of older adults, and that could also provide training and technical assistance to help mainstream aging organizations seeking to better meet their needs. Creating these partnerships will not only benefit the older LGBTQI+ people that they serve but will also encourage community partnerships.

*III: State policies and procedures regarding area plan requirements will at a minimum address the following... (2) That the area agency shall identify populations within the planning and service area at greatest economic need and greatest social need, which shall include the following populations... (iv) Lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) persons; (v) Persons living with HIV or AIDS;*

We support this proposal. All AAA plan requirements should address the needs of older LGBTQI+ people and older PLWH and incentivize creating programs and services that meet the needs of these and other populations. This can be done through focused, culturally responsive outreach to LGBTQI+ older people, collecting data on their unique needs and experiences, and collecting data on whether the aging network is meeting their needs.

Over the past twenty years the Aging Project has provided LGBTQI+ cultural competency training and technical assistance for program development to many of the Area Agencies on Aging across Massachusetts and commend them for their LGBTQI+ inclusive initiatives. Currently, Massachusetts hosts 30 community meals and programs for LGBTQI+ older adults and their friends.

*IV: We later propose to define “older relative caregiver.” With this inclusive approach to defining “family caregiver,” we include those populations specified in the National Family Caregiver Support Program, as set forth in Title III–E of the Act. For example, this includes unmarried partners, friends, or neighbors caring for an older adult.*

We support the inclusion of “unmarried partners, friends or neighbors” in this definition as it acknowledges and validates the diverse relationships and support systems that exist in the LGBTQI+ community. Historically, many LGBTQI+ individuals have faced legal and societal barriers that have prevented them from traditional, legally-recognized partnerships or marriages. Also, many older LGBTQI+ people and older PLWH are widowed, single, and/or live alone. Therefore, unmarried partners and close friends frequently play significant roles as caregivers providing emotional, physical, and financial support. With the inclusion of these caregivers in the definition, LGBTQI+ people can receive caregiving support without fear of discrimination or exclusion. Additionally, it helps ensure legal, healthcare, and social support systems recognize the contributions of unmarried partners or friends and allows them the ability to secure the legal documentation needed to make medical decisions, and to access resources for their loved ones.

*V: Section 307 49 of the Act requires the collection of data and periodic submission of reports to ACL regarding State agency and AAA activities. ACL has implemented a national reporting system and reporting requirements that must be used by all State agencies to ensure timely and consistent reporting.*

We support the importance of collecting data and reporting to the ACL. Data plays a critical role in understanding the evolving needs and experiences of older Americans, including those from diverse backgrounds like LGBTQI+ individuals. ACL should encourage state and local aging departments and AAAs to routinely collect sexual orientation, gender identity (SOGI), and sex characteristics data from all older adults and report de-identified, aggregate data publicly to better understand LGBTQI+ older adults’ access to elder services. With robust data collection and reporting, the ACL will be able to address specific needs effectively. Additionally, data can ensure the equitable distribution of resources and services. By identifying geographic areas or demographic groups with higher needs, the ACL can allocate funding to address disparities in



healthcare utilization, social isolation and economic well-being that may disproportionately affect LGBTQI+ older adults, or Black LGBTQI+ older adults. Data can also allow the ACL to monitor the impact existing programs have on the populations they aim to serve. Moreover, through continuous data collection, the ACL can monitor emerging or escalating issues to take proactive measures to respond to the needs of the groups they aim to serve.

Specifically, regarding the collection of sexual orientation and gender identity, this data needs to be flexible and able to adapt over time as standards and language evolve. Research and testing of questions and answer options is essential to collecting accurate information. Several federal agencies and organizations have provided guidance on best practices on the collection of data. One example of this can be found in the 2022 National Academies of Sciences, Engineering and Medicine “Measuring Sex, Gender Identity and Sexual Orientation” report.<sup>23</sup> The Fenway Institute and the Williams Institute can also provide suggested measures for SOGI and sex characteristics questions and response options.

*VI: 1321.9(c)(2)(xvii). Monitoring of State and Area Plan Assurances. The Act sets forth many assurances to which States must attest as a part of their State plans and to which AAAs must attest as a part of their area plans. We propose to specify that the State agency must have policies and procedures to monitor compliance regarding the assurances to which the State and area agencies attest.*

We support monitoring compliance as a critical component to accountability and transparency, the effective use of funding, assuring quality of services, as well as equity and inclusion. Requiring a transparent framework allows for oversight to ensure the State and area agencies are fulfilling the commitments and responsibilities in serving their communities. Moreover, it also ensures funds provided to the State and area agencies are being used in efficient and effective ways to enhance the lives of older adults, including older LGBTQI+ adults and older PLWH. Monitoring compliance can also establish standards of quality so gaps can more readily be identified. Finally, policies and procedures to monitor compliance can also confirm services are provided equitably, regardless of location or demographics of the populations they serve. This is especially important when serving communities that have historically been marginalized and overlooked.

Thank you for the opportunity to comment on the proposed rule, RIN: 0985-AA17, 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. This proposed rule represents an essential step towards addressing the

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<sup>23</sup> National Academies of Sciences, Engineering, and Medicine. 2022. Measuring Sex, Gender Identity, and Sexual Orientation. Washington, DC: The National Academies Press

disparities faced by older LGBTQI+ people and older PLWH. Through the implementation of these changes, we can work towards a more equitable and inclusive elder services and care system that meets the diverse needs of our aging population. Should you have any questions about this comment, please contact Lisa Krinsky, LICSW, Director of the LGBTQIA+ Aging Project, at [krinsky@fenwayhealth.org](mailto:krinsky@fenwayhealth.org). Thank you.

Sincerely,  
The Fenway Institute  
The LGBTQIA+ Aging Project  
The Massachusetts Commission on LGBT Aging