Submitted via Regulations.gov

August 15, 2023

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

Re: Notice of Proposed Rulemaking: Older Americans Act Regulations, RIN Number 0985–AA17

Dear Ms. Barkoff:

I am writing on behalf of Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders ("SAGE"), and the undersigned organizations, in response to the Notice of Proposed Rulemaking: Older Americans Act Regulations, RIN Number 0985–AA17.[1] SAGE is the country's oldest and largest organization addressing issues related to lesbian, gay, bisexual, transgender, queer, questioning, and intersex people[2] (LGBTQI+) and aging, as well as older people living with HIV/AIDS. SAGE offers supportive services and consumer resources to LGBTQI+ older adults and their caregivers, advocates for public policy changes that address their needs, and provides training for agencies and organizations that serve LGBTQI+ older adults. In partnership with our constituents and allies, SAGE works to achieve a high quality of life for LGBTQI+ older people, supports and advocates for their rights, fosters a greater understanding of aging in all communities, and promotes positive images of LGBTQI+ life in later years. The implementation of programs authorized by and funded through the Older Americans Act (OAA) by the Department of Health and Human Services' Administration for Community Living (ACL) provides essential support for our constituency to age successfully.

We, and our constituencies, appreciate that ACL is proposing changes that advance the purpose of the OAA, with equity in service delivery placed front and center. Centering equitable service of older adults and family caregivers from underserved and marginalized communities

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[1] *See* Older Americans Act, Titles III, VI, and VII, 88 Fed. Reg. 39568 (June 16, 2023) (to be codified at 45 C.F.R. pts. 1321, 1322, 1323, 1324).

[2] We appreciate ACL's explicit inclusion of intersex older adults in the Proposed Rule. Although there remains a need for more research and data on the experiences of older adults born with intersex variations, available research suggests significant potential for barriers and disparities in needs and supports. *See* Berry AW, Monro S., *Ageing in obscurity: a critical literature review regarding older intersex people*, Sex Reprod Health Matters, 2022 Dec;30(1):2136027.

aligns with the 900 comments submitted in response to the 2022 Request for Information.[3] We are particularly supportive of the explicit inclusion of LGBTQI+ older adults and those living with HIV/AIDS in ACL's definition of a population with greatest social need.

In this comment, we first offer our support for many of ACL's proposed changes to the Rule, and we provide suggestions for additional ways to further improve on said proposed changes, as follows:

- 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;
- 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.

We then outline some unmet needs for ACL's consideration, which we had hoped to see in the Proposed Rule: 1) the need for more robust non-discrimination and cultural competency requirements in various places throughout the Proposed Rule, and 2) the need for the State Long-Term Care Ombudsman to track sexual orientation and gender identity data as part of its official duties (to identify systemic discrimination issues) and to develop certain policies and procedures for residents without the ability to consent to records review.

[3] 88 Fed. Reg. 39568, 39572.

I. Support for Proposed Changes and Additional Areas for Improvement

A. Inclusion of LGBTQI+ Older Adults and Those Living with HIV/AIDS in the Definition of Greatest Social Need

We first applaud the proposed requirement that state plans set forth by State units on Aging (SUAs) define the term "greatest social need," with the "standard expectation" that such definitions will include 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."[4] We also support ACL's inclusion of this requirement in Area agencies on aging (AAAs) in their Area plans, which are submitted to the SUAs for approval.[5]

As we noted in our response to ACL's 2022 Request for Information,[6] LGBTQI+ older adults and those living with HIV/AIDS meet the OAA criteria for greatest social need. The OAA defines greatest social need as:

> [T]he need caused by noneconomic factors, which include—(A) physical and mental disabilities; (B) language barriers; and (C) cultural, social, or geographical isolation, including isolation caused by racial or ethnic status, that—(i) restricts the ability of an individual to perform normal daily tasks; or (ii) threatens the capacity of the individual to live independently.[7]

Lifetime disparities in earnings, employment, and retirement saving opportunities put LGBTQI+ older adults at risk of financial instability and poverty.[8] Many LGBTQI+ older adults are forced to rely on institutional and professional care and support; they are also more likely to live alone and less likely to have children to help them than their heterosexual and cisgender

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[4] 88 Fed. Reg. 39568, at 35981, 39618.

[5] 88 Fed. Reg. 39568, at 39623.

[6] Democracy Forward Found., Comment Letter on Request for Information: Older Americans Act Regulations (June 6, 2022), pp. 3-5, *available at* https://drive.google.com/file/d/1ZM7GbOck9mvQUPMUMzc1BSv6ZrFak0yp/view?usp=sharing [hereinafter Comment Letter on Request for Information].

[7] 42 U.S.C. § 3002(24).

[8] 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 [hereinafter Williams LGBT Aging Report]; *see also* M.V. Lee Badgett et al., Williams Inst., *New Patterns of Poverty in the Lesbian, Gay, and Bisexual Community* (2013), *available at* https://williamsinstitute.law.ucla.edu/wp-content/uploads/Poverty-LGB-Jun-2013.pdf. Studies also find that same-sex couples have higher rates of poverty compared to heterosexual married couples. *See* Williams LGBT Aging Report at 10.

peers.[9] Many may also be estranged or concealing their sexual orientation or gender identity from biological families due to fear of rejection.[10] This isolation from traditional family support while aging results in a significant need for informal care and support.[11] ACL's Proposed Rule appropriately incorporates factual findings on the social isolation faced by LGBTQI+ older adults and those living with HIV or AIDS based on sexual orientation, gender identity, and stigma surrounding HIV-positive status.[12]

We are confident the explicit inclusion of LGBTQI+ older adults and those living with HIV/AIDS in the required definitions of "greatest social need" within State and Area plans will encourage SUAs and AAAs to serve these populations more effectively and consistently than we have seen to date.[13] We continue to believe, based on our experience, that implementation of these requirements will be feasible for SUAs and AAAs, as they evaluate the services needed by and effectiveness of services provided to these groups, and as they engage in targeted outreach to the same. Meeting such requirements is feasible through the provision of education, technical assistance, and training to SUAs and AAAs. In this regard, SAGE, SAGECare, and the associated National Resource Center on LGBTQI+ Aging (NRC) are well situated to support SUAs and AAAs in complying with the requirements of a new greatest social needs designation. We provide training, technical assistance, and education resources focused on improving the quality of services and supports offered to LGBTQI+ older adults, older adults living with HIV/AIDS, their families and caregivers.[14]

As part of additional required core elements for State plans on aging, the Proposed Rule

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[9] Williams LGBT Aging Report, *supra* n. 7 at 6, 8.

[10] *Id*. at 8.

[11] A survey based in the Midwest found that LGBT older adults on average received more types of care from families of choice than from their biological families. *See* Mark Brennan-Ing et al., *Social Care Networks and Older LGBT Adults: Challenges for the Future*, 61 J. Homosexuality 21 (2014). With more limited ties to biological family, "family of choice" ties, based on friendship and commitment, are prominent in LGBT communities. *See* Jeffrey Weeks et al., *Same Sex Intimacies: Family of Choice and Other Life Experiments* (Routledge 1st ed. 2001); Judith C. Barker et al., S*ocial Support in the Lives of Lesbians and Gay Men at Midlife and Later*, 3 Sexuality Rsch. & Soc. Pol'y 1 (2006), *available at* https://doi.org/10.1525/srsp.2006.3.2.1.

[12] 88 Fed. Reg 39568, at 39571.

[13] Many State plans do not acknowledge the existence of LGBTQI+ older adults or those living with HIV/AIDS, much less set forth requirements as to data collection or targeting of services. Of 56 SUAs, only seven designated LGBTQI+ older adults as a population of greatest social need, four did so for older adults living with HIV/AIDS, and fourteen states reference LGBTQI+ older adults in State plans, and even fewer reference older adults living with HIV/AIDS. *See* Comment Letter on Request for Information, *supra* n. 3, at 6-7.

[14] NRC receives financial assistance from ACL to do this work. The NRC publishes LGBT aging best practice guides, which have been downloaded more than 120,000 times. From 2015-2020, it helped with nearly 800 requests for technical assistance. Along with SAGECare, another SAGE project, the NRC trained more than 650 ACL-funded organizations on culturally competent services. See NRC, *Celebrating Ten Years of Knowledge* (2020), *available at* https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20NRC%20Top%20Ten%20Final.pdf. Many of SAGECare's trainings, which include trainings on HIV, are available online and on demand. See SAGECare, *Staff Development/Training*, https://sageusa.care/ourservices/coaching-training/ (last visited Aug. 9. 2023).

would require SUAs to explain how individuals with greatest economic need and greatest social need are determined and served, and how SUAs will target services to these populations–including how funds under the Act may be distributed.[15] In order to meet the goals of the OAA, we recommend that this requirement be more specific as to the populations ACL has identified as typically having greatest social need, including LGBTQI+ older adults and those living with HIV/AIDS. SUAs should be required to explain how each population was determined to meet its definition of greatest social need within the State. ACL should require SUAs to explain in detail how targeted approaches for service delivery are tailored for each population, to avoid blanket statements of intention or generalized approaches that lack cultural and social responsiveness.[16] Such explanations should demonstrate that the SUA has investigated the most effective approach for reaching each population identified as having the greatest social need. We echo this suggestion for AAAs, and for service providers contracting with SUAs or AAAs under State and Area plans, which are required to specify how the provider intends to satisfy the service needs of those identified as being in greatest economic or social need, with a focus on "low-income minority individuals."[17] This specific requirement will increase SUA and AAA accountability for the unique needs of LGBTQI+ older adults, those living with HIV/AIDS, and other populations with unique needs, as opposed to planning that doesn't differentiate between the needs of various underserved populations. It has also been our experience that reluctant States will be more likely to comply fully if the requirements are detailed and explicit in all relevant circumstances.

B. Expansion of the "Family Caregiver" Definition

We support ACL's proposal that the definition of "family caregiver" include unmarried partners, friends, or neighbors caring for an older adult.[18] In our experience, LGBTQI+ older adults and those living with HIV or AIDS often rely on friends and community members rather than family of origin to provide care and companionship, colloquially known as "chosen family" or "family of choice." Focusing on inclusivity in this definition acknowledges the lived realities of those in our constituency, given that 39% of LGBTQI+ adults have faced rejection from their families of origin.[19] This change means that ACL, SUAs, and AAAs will include the real-world "family caregivers" of LGBTQI+ older adults and those living with HIV or AIDS in its administration of support services, which are designed to "assist older persons *and family caregivers* in leading independent, meaningful, and dignified lives in their own homes and

[15] 88 Fed. Reg. 39568, at 39581.

[16] 88 Fed. Reg. 39568, at 39612, 39618.

[17] 88 Fed. Reg. 39568, at 39612, 39626.

[18] 88 Fed. Reg. 39568, at 39573, 39610.

[19] P. Gutierrez, *The Importance of Found Families for LGBTQ Youth, Especially in a Crisis,* GLAAD (2020) https://glaad.org/importance-of-found-families-lgbtq-youth/; *see also* Nina Jackson Levin et al., *"We Just Take Care of Each Other": Navigating 'Chosen Family' in the Context of Health, Illness, and the Mutual Provision of Care amongst Queer and Transgender Young Adults*, 17 Int'l J. Env't Rsch. Pub. Health, Oct. 8, 2023, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7579626/.

communities."[20]

C. Area Agency on Aging Advisory Councils and Area Plans

We support the proposed requirement that AAAs seek public input with respect to Area plans on aging, including the establishment of AAA advisory councils with specified duties in soliciting and incorporating public input.[21] It is integral to the mission of the OAA that Area agencies, which are best suited to understand and meet the needs of local populations, inform their practices and services with input from the public–i.e., those who are directly impacted by such services. ACL notes that AAA advisory council members should include individuals and representatives from or serving the AAA's planning and service area, including those identified as having greatest economic need or greatest social need. This provision will help ensure that AAAs include the perspectives of those communities in their planning. We also encourage ACL to provide AAAs with technical assistance and resources as to how to best work with in-Area communities to identify and invite community members from populations with greatest social or economic needs to serve on AAA advisory councils in meaningful ways–with a particular focus on LGBTQI+ older adults and those living with HIV/AIDS.

We make the same suggestions regarding the proposed requirement that AAAs employ a comprehensive and coordinated community-based system involving collaborative decision-making among public, private, voluntary, faith-based, civic, and fraternal organizations, including trusted leaders of communities in greatest economic or social need, and older persons and family caregivers in the community.[22] We urge ACL to clarify that AAAs should specifically aim to involve individuals from or representatives of the various populations identified as having greatest social need, including LGBTQI+ older adults and those living with HIV or AIDS, in these community-based systems.

As ACL notes, Area plans submitted to the State for approval must identify populations of greatest economic need and greatest social need, and provide an evaluation of unmet needs.[23] As we have suggested above, AAAs and their advisory councils should be required to explain in Area plans how the evaluation of unmet needs was formulated for each identified population. Area plans should also include an explanation of how targeted approaches for service delivery are tailored for each population of greatest social need, to once again avoid blanket statements of intention or generalized approaches that lack cultural and social responsiveness at the Area level. In particular, we recommend that, for AAAs that provide meals to clients, they detail how meal outreach will be intentionally tailored per population.[24] Such additional detail will provide accountability for adequately meeting the differing outreach needs of each population receiving meals, and will prevent AAAs from issuing generalized statements of intent or execution.

[20] 88 Fed. Reg. 39568, at 39611 (emphasis added).

[21] 88 Fed. Reg. 39568, at 39584, 39623.

[22] 88 Fed. Reg. 39568, at 39622.

[23] 88 Fed. Reg. 39568, at 39585.

[24] 88 Fed. Reg. 39568, at 39623-24.

D. Legal Assistance, Guardianship, and Self-Determination

ACL's proposed clarification of and modifications to the legal assistance requirement will further the purpose of the OAA in serving the needs of those with greatest economic or social need, including LGBTQI+ older adults and those living with HIV/AIDS.[25] Our experience reinforces ACL's determination that legal assistance programs play a pivotal role in ensuring that older adults are entitled to freedom, independence, and the free exercise of individual initiative in planning and managing their own lives, full participation in the planning and operation of community-based programs provided for their benefit, and protection against abuse, neglect, and exploitation.[26] For example, SAGE has partnered with organizations to successfully host clinics with local legal aid programs and law schools to promote the completion of Durable Powers of Attorney for Health and Finances. These are valuable arrangements that reduce the need for a guardian or court-appointed conservator in the future. Additionally, SAGE's legal clinic has been operating for more than twenty years, providing free consultation to LGBTQI+ older adults and those living with HIV/AIDS. Many constituents of the clinic seek assistance with landlord/tenant issues, survivorship issues, advance directives, and debt issues–all colored by their identities and experiences.

We find the following anonymized example from a partner low-income legal services provider to be particularly illustrative of the importance of legal assistance programs for LGBTQI+ older adults. "Tim," a older, gay, disabled man with HIV, reached out to a low-income legal services provider for help navigating the complexities of Medicare Part D prescription insurance options in order to maximize his coverage for his HIV care and other comorbidities. Tim expressed fear about what would happen to his partner "John" if Tim were to pass away. Though they lived together, they were unmarried, and their respective incomes from Social Security Disability differed widely. Tim worried that if he passed away before John, John would be left living below the poverty level. Tim's legal services attorney counseled him on how marriage could potentially protect John in such a situation. Through the attorney, Tim and John learned about the financial effects that marriage would have on their eligibility for various public benefits. Based on this counseling, the couple decided to marry. Tim also executed estate planning documents to ensure his partner John would have the legal authority to care for him in the event of debilitating illness. In 2023, Tim passed away after a long struggle with cancer. The same low-income legal service organization is now assisting John with applying for spousal survivor benefits, getting his SNAP benefit increased, and adapting in other ways to his spouse's passing–implementing the plan the couple put together years ago to secure John's future by means of the advice and assistance they received from their low income legal service provider, for free.

We, and our constituencies, are particularly invested in legal assistance programs as they relate to guardianship and alternatives to guardianship, and the prioritization of person-directed forms of decision support like health care and financial powers of attorney, advance directives and supported decision making, and other tools clients may prefer.[27] We support ACL's

[25] 88 Fed. Reg. 39568, at 39586; 39628.

[26] 88 Fed. Reg. 39568, at 39586.

[27] 88 Fed. Reg. 3956,8 at 39587, 39628.

clarification that the role of legal assistance providers is to promote self-determination and person-directedness in support of older adults making their own decisions in the event of future diminished decisional capacity, and to represent older adults who are or may be subjected to guardianship. The emphasis on self-determination and person-directedness is especially important for LGBTQI+ older adults and those living with HIV/AIDS, many of whom may not have experienced the power of controlling their decisions and their future in their lifetimes thus far.

Consistent with ACL's determination that LGBTQI+ older adults and those living with HIV/AIDS are populations with greatest social need, we strongly suggest ACL consider including language regarding legal assistance providers that refers to the experiences of, for example, transgender older adults who may be subjected to guardianship. In our experience, transgender older adults who may be subjected to guardianship are at risk of having their wishes overruled by families of origin who may not acknowledge or recognize the transgender older adult's gender identity (or sexual orientation). Transgender older adults deserve the dignity of having their authentic selves respected and acknowledged throughout their lives, regardless of their present or future capacity for decision making. Indeed, the National Resource Center on LGBTQI+ Aging published a 2023 guide for Person-Centered, Trauma-Informed Care of Transgender Older Adults which emphasizes the importance of and best practices for person-centered care.[28] Person-centered care focuses on older adults' emotional needs and care preferences, and not solely on the physical health of older adults.[29]

Respect for a guardianship ward's sexual orientation and gender identity is essential to the concepts of dignity and self-determination that have served as guiding principles in efforts to reform guardianship schemes across the country.[30] Transgender older adults subject to guardianship may experience the halt of gender-affirming care, should their appointed guardians be unsupportive of their gender identity.[31] Transgender older adults under guardianship who are placed in assisted living facilities or nursing homes may also experience hostility and mistreatment from staff, or the refusal to refer to a resident by the names and pronouns that represent their gender identities.[32] In the tragic case of *In re Guardianship of Atkins*, a middle-aged member of a gay couple without power of attorney or estate plans in place suffered an aneurysm that rendered him unable to make decisions. His parents, who did not support his sexual orientation, were appointed co-guardians of his estate and refused to allow their son's

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[28] FORGE, National Resource Center on LGBTQI+ Aging, & SAGE, *Person-centered, Trauma-informed Care of Transgender Older Adults* 5 (2023), *available at* https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20Trans%20TIC%20Final.pdf.

[29] *Id.*

[30] Nancy J. Knauer, *LGBT Issues and Adult Guardianship: Comparative Perspectives* 1 (Kim Dayton ed., 2013) http://www.guardianship.org/IRL/Resources/Handouts/Thinking%20About%20Difference%20-%20Legal%20Studies%20Handout.pdf [hereinafter *Comparative Perspectives*].

[31] *Id.*, at 11.

[32] National Citizens Senior Law Center, *LGBT Older Adults in Long-Term Care Facilities: Stories from the Field* 13 (Apr. 2011), https://www.lgbtagingcenter.org/resources/pdfs/nsclc_lgbt_report.pdf.

partner to visit or contact him.[33] We suggest ACL explicitly acknowledge the unique risks all LGBTQI+ older adults–and especially transgender older adults–may encounter in the face of guardianship as essential considerations for legal assistance providers who contract with ACL to provide services.

E. Client Eligibility for Participation

We support ACL's clarification that SUAs, AAAs, and service providers may adopt additional eligibility requirements, if they do not conflict with the OAA, the implementing regulation, or guidance issued by the Assistant Secretary for Aging.[34] We recommend that this authorization should allow SUAs, AAAs, and service providers to consider adopting a minimum eligibility age other than 60 years old for older LGBTQI+ adults and those living with HIV/AIDS to qualify for benefits and services under the OAA. Older LGBTQ adults and those living with HIV/AIDS experience significant health disparities and reduced resources for social care compared to other older adult populations. In addition, older adults living with HIV/AIDS have higher levels of multimorbidity at younger ages compared with people without HIV/AIDS. Both groups rely heavily on government and community-based services. Thus, chronological age does not adequately reflect the need of these groups for accessing services supported by the OAA. ACL should consider adding explicit language authorizing SUAs, AAAs, and service providers to adopt a lower minimum age for eligibility specifically for older LGBTQI+ adults and those living with HIV/AIDS, given their unique circumstances and needs.[35]

F. Additional Costs for Outreach and Requirements to LGBTQI+ Older Adults

We agree with ACL's finding that there are no associated additional costs for affected agencies now required to conduct outreach to and collect data on specific populations, including to Asian-Pacific American, Native American, Hispanic, African-American older adults, and LGBTQI+ older adults.[36] As previously noted, SAGE and the National Resource Center on LGBTQI+ Aging are available to provide technical support to SUAs and AAAs in their outreach and data collection efforts. Indeed, the National Resource Center on LGBTQI+ Aging has a best practice guide on how to implement low-cost adaptations to current agency outreach efforts in support of LGBTQI+ inclusion.[37]

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[33] *Comparative Perspectives*, *supra* n. 28, at 2-4; *In re Guardianship of Atkins*, 868 N.E.2d 878, 880 (Ind. App. 2007).

[34] 88 Fed. Reg. 39568, at 39591.

[35] Sanchez-Conde, Matilde, Diaz-Alvarez, Jorge, Dronda, Fernando, Branas, Fatima, *Why are people with HIV considered "older adults" in their fifties?*, European Geriatric Medicine (2019) 10:183-188, available at https://www.natap.org/2019/HIV/SanchezConde2019_Article_WhyArePeopleWithHIVConsideredO(1).pdf.

[36] 88 Fed. Reg. 39568, at 39602-03.

[37] National Resource Center on LGBTQI+ Aging, *Inclusive Services for LGBT Older Adults: A Practical Guide to Creating Welcoming Agencies* (May 2020), *available at* https://lgbtagingcenter.org/resources/resource.cfm?r=487.

G. Best Available Data

We recommend enhancing ACL's definition of "best available data," which presently includes the U.S. Decennial Census, American Community Survey, or "other high-quality, representative data available to the State" for the purposes of the intrastate funding formula by pointing to additional examples of the latter.[38] Additional examples and clarification focusing on appropriate data sources that reflect the experiences of older LGBTQI+ adults and those living with HIV/AIDS would help ensure that SUAs and AAAs collect the best available data on these populations. We recommend that ACL point to national examples such as the U.S. Census Household Pulse Survey,[39] the AARP's Dignity 2022: The Experience of LGBTQ Older Adults survey,[40] or to the HealthHIV Second Annual State of Aging With HIV National Survey (2021). ACL could also point to State-level surveys like the Oregon LGBTQI+ Older Adult Survey of 2022,[41] or to the San Francisco Department of Disability and Aging Services' LGBTQ Older Adult Survey of 2021.[42]

H. The Intrastate Funding Formula

As part of a State plan, SUAs must develop an intrastate funding formula that reflects the proportion among the planning and service areas of persons aged 60 and over in greatest economic and social need, with particular attention to "low-income minority individuals."[43] We strongly recommend that ACL require not only that the formula reflect these proportions, but reflect the specific proportions per population predetermined to be in greatest social and economic need, including LGBTQI+ older adults and those living with HIV/AIDS. This population-specific breakdown should also be included in the "descriptive statement of the formula's assumptions and goals and the application of the definitions of greatest economic and social need," as well as in the "source of the best available data used to allocate funding through the intrastate funding formula."[44] As stated above, this requirement would help prevent generalized approaches that lack cultural and social responsiveness in the development of the

[38] 88 Fed. Reg. 39568, at 39609, 39621.

[39] Lauren J.A. Bouton et al., *LGBT Adults Aged 50 and Older in the US During the COVID-19 Pandemic*, Williams Inst. (Jan. 2023), *available at* https://www.census.gov/data/experimental-data-products/household-pulse-survey.html; https://williamsinstitute.law.ucla.edu/publications/older-lgbt-adults-us/.

[40] Cassandra Cantave, *LGBTQ Adults 45+ Are Worried About Discrimination and Support as They Age*, AARP Rsch. (June 2022), https://www.aarp.org/research/topics/life/info-2022/lgbtq-community-dignity-2022/.

[41] Karen Fredriksen Goldsen et al*., Oregon LGBTQI+ Older Adult Survey Report* (Sept. 2021), *available at* https://goldseninstitute.org/health/oregon/; https://goldseninstitute.org/wp-content/uploads/2021/10/Oregon-LGBTQ-Older-Adult-Report_10.06.21.pdf.

[42] San Francisco LGBTQ Aging Rsch. P'ship, *LGBTQ Older Adult Survey* (June 2021), https://www.lgbtagingcenter.org/resources/pdfs/San%20Francisco%20LGBTQ%20Senior%20Survey%20Report%20Final.pdf.

[43] 88 Fed. Reg. 39568, at 39620.

[44] 88 Fed. Reg. 39568, at 39620-21.

intrastate funding formula.

I. Evidence-Based Disease Prevention and Health Promotion Services

We support ACL's finding that evidence-based disease prevention and health programs improve health and well-being and reduce risk of injury, disease, or disability among older adults.[45] Accordingly, we encourage ACL to promote increased and improved collaboration between SUAs, AAAs, and HIV/AIDS service providers regarding evidence-based disease prevention and health promotion service programs.[46] Increased and improved collaboration is crucial to address the unique needs of LGBTQI+ older adults and those living with HIV/AIDS. For example, ACL should consider fostering collaboration between AAAs and local health departments to address existing health disparities and to promote HIV prevention efforts. Other areas examples of potential improved collaboration efforts include, but are not limited to, the following:

- Cross-Training and Education: Organize training sessions and workshops that bring together aging service providers and HIV prevention experts. These sessions could focus on educating both groups about the specific challenges older adults face regarding sexual health, HIV testing, pre-exposure prophylaxis (PrEP), and post-exposure prophylaxis (PEP).
- Joint Workshops and Webinars: Host joint workshops, webinars, or conferences that provide a platform for both aging and HIV service providers to share their expertise and insights. These events could cover topics such as best practices, effective communication strategies, and innovative approaches to HIV prevention for older adults.
- Resource Sharing: Create a centralized resource hub that includes educational materials, guidelines, toolkits, and research related to HIV prevention and aging. This platform could be accessible to both aging service providers and HIV prevention organizations, enabling them to access relevant information and share resources.
- Integrated Services: Design integrated service models where older adults can access a range of services related to aging, healthcare, and HIV prevention under one roof. This approach reduces the fragmentation of care and encourages a holistic approach to well-being.
- Community Outreach: Organize joint community outreach events that target older adults. This could include health fairs, information sessions, and workshops focused on sexual health education, HIV testing, and preventive measures like PrEP.
- Collaborative Research: Foster research collaborations between aging and HIV organizations to better understand the intersections between aging and HIV prevention. This research could inform the development of evidence-based interventions and strategies.
- Data Sharing and Analysis: Share anonymized data between aging and HIV service providers to gain insights into the prevalence of HIV among older adults, their needs,

[45] 88 Fed. Reg. 39568, 39627.

[46] 88 Fed. Reg. 39568, 39627.

and the effectiveness of prevention programs. This data-driven approach can guide targeted interventions.

II. Unmet Needs for Future Consideration in Rulemaking

A. Non-Discrimination and Cultural Competency Requirements in State plans, Contracts, and Commercial Relationships and in Responsibilities of Service Providers

We had hoped to see more robust non-discrimination and cultural competency requirements throughout the Proposed Rule, as outlined in detail in our response to ACL's Request for Information in 2022.[47] As explained in previous comments submitted by SAGE, LGBTQI+ older adults and those living with HIV or AIDS are highly vulnerable to systemic discrimination. It is vital that OAA services be provided in a non-discriminatory manner, to meet the purposes and intent of the OAA.[48] We understand that the OAA's implementing regulations incorporate some existing non-discrimination protections against discrimination on the basis of race, disability, and age. However, and especially given ACL's predetermination that a number of unique populations have greatest social need, we strongly urge ACL to adopt more robust and comprehensive non-discrimination protections.

We suggest that ACL require State plans on aging to include language stating that the SUA will prohibit discrimination in OAA grant programs on the basis of race, disability, age, religion, sexual orientation, gender identity, and any characteristic that defines a population of greatest social need. State plans should include assurances that discriminatory practices prohibited under the general assurance will include, but not be limited to, the denial of services based on a protected characteristic of the individual and harassment or creation of a hostile environment, including the knowing refusal to use an individual's preferred name or pronouns after being clearly informed of the individual's preferences. As we have previously outlined, implementing more robust non-discrimination language into State and Area plans, and into all contracts with service providers is feasible, and is already being done in various states.[49]

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[47] Comment Letter on Request for Information, *supra* n. 6, at 17.

[48] While the OAA's implementing regulations currently incorporate some non-discrimination protections, those provisions protect only against discrimination on the basis of race, disability, and age. *See* 45 C.F.R. § 1321.5(c), (e), (f).

[49] For example, Georgia's Department of Health and Human Services includes language in its contracts requiring AAAs to provide services in compliance with federal and state anti-discrimination laws. Georgia's contracts also state that if the AAAs engage a subcontractor, the subcontractor is also bound by the relevant non-discrimination laws and regulations. Similarly, Pennsylvania includes the following provision in its three-year contracts with AAAs:

> Neither the Contractor nor any subcontractor nor any person on their behalf shall in any manner discriminate by reason of race, gender, creed, color, sexual orientation, gender identity or expression, or in violation of the [Pennsylvania Human Relations Act] and applicable federal laws, in the provision of services under the contract.

Likewise, the State of Maine includes non-discrimination language in its contracts similar to that used by Pennsylvania. These examples demonstrate a mechanism by which states can provide some protections.

ACL's proposal that State agencies, AAAs, and service providers entering into contracts and commercial relationships for OAA-funded services must develop policies and procedures to promote fairness, inclusion, and adherence to the requirements of the OAA is a step in the right direction, but is not adequate to protect vulnerable populations.[50] We strongly suggest that ACL require all contracts and commercial relationships entered into by SUAs, AAAs, and service providers to include identical non-discrimination protections as described above in all contractual provisions to ensure that contractors provide older adults with the same quality of non-discriminatory service as SUAs and AAAs.

We are also disappointed that the Proposed Rule does not include any requirements for cultural competency training. As we previously explained, cultural competency training is essential to enhancing and supporting robust non-discrimination requirements, and to providing SUAs, AAAs, and service providers with comfort addressing issues relevant to groups with greatest social or economic need. We strongly suggest that ACL require State plans to provide assurances that the state will develop a program that requires all service providers—including the SUA, AAAs, and any subgrantees, contractors, or commercial relationships—to undergo appropriate and ongoing training to provide services and collect data in a culturally competent and non-discriminatory manner. State plans should also describe how the training program will address sensitive cultural issues relating to all populations of greatest social need. Further, ACL should require State plans to describe how they will ensure that AAAs and other subgrantees will comply with the training program requirements. ACL should also consider requiring that the information and referral programs offered by AAAs must include cultural competency training. It should do the same for ACL-funded eldercare locators. Any such training programs should also be required at reasonable intervals (e.g., once every two years). ACL should provide SUAs, AAAs, and service providers with best practices for how to target underserved communities. As we have noted, SAGE and the National Resource Center on LGBTQI+ Aging are available to support SUAs and AAAs in their training efforts.

As for Grants to Indian Tribes and Native Hawaiian Grantees for Supportive, Nutrition, and Caregiver Services,[51] we make the same recommendations as above regarding the responsibilities of service providers to implement non-discrimination language and cultural competency training.[52] We further recommend ACL consider the adoption of explicit language referring to LGBTQI+ Indian and Native Hawaiian older adults, Two-Spirit older adults, and Indian and Native Hawaiian older adults living with HIV/AIDS and including such language in all non-discrimination provisions and in cultural competency training requirements.[53]

B. The State Long-Term Care Ombudsman

We would have liked to see ACL include a requirement that the State Long-Term Care

[50] 88 Fed. Reg. 39568, at 39578, 39615.

[51] 88 Fed. Reg. 39568, at 39632.

[52] 88 Fed. Reg. 39568, at 39636.

[53] Indian Health Service, *Two-Spirit*, https://www.ihs.gov/lgbt/health/twospirit/ (last visited Aug. 9, 2023).

Ombudsman track and collect data on complaints raised by residents of long-term care facilities (or other sources of underlying complaints), which are related to discrimination on the basis of sexual orientation, gender identity, and HIV/AIDS status as part of the Ombudsman's official duties. An analysis of such data could be incorporated into the annual submission of both the National Ombudsman Reporting System report and the independent Long-Term Care Ombudsman's report as required by ACL.[54] Tracking this data would allow ACL to better understand whether there are systemic issues of discrimination on the basis of sexual orientation, gender identity, and HIV/AIDS status. ACL should also provide guidance as to how to remedy these issues on a systemic level.

We would further propose, in similar fashion to prior recommendations, that ACL and State agencies require all representatives and staff of the Office of Long-Term Care Ombudsman Programs, as well as local Ombudsman entities within a State or State agency, to undergo not only training for certification and continuing education, but also training in non-discrimination and cultural competency principles as they relate to the duties of the office.[55] Such a program should involve training at reasonable intervals, and should address sensitive cultural issues relating to all residents from populations of greatest social need as served by the Ombudsman. As discussed previously, some states have enacted laws that require LGBTQI+ cultural competency training at regular intervals for licensed long-term care facilities. It follows that the office responsible for investigating complaints of maladministration in long-term care facilities should undergo training in the unique issues that could face residents with marginalized identities, like LGBTQI+ older adults and those living with HIV or AIDS. As previously noted, ACL can and should offer technical assistance to help the State Long-Term Care Ombudsman implement such training programs, in cooperation with SAGE and the National Resource Center on LGBTQI+ Aging who offer the training, technical assistance, and education resources needed to make a cultural competency training program successful. We also suggest such training be grounded in the long-term care rights as enshrined by the Nursing Home Reform Act of 1987–especially as they pertain to populations predetermined to have greatest social need.[56]

We applaud ACL's proposal to require the establishment of policies and procedures to

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[54] 88 Fed. Reg. 39568, at 39643.

[55] 88 Fed. Reg. 39568, at 39598-99, 39643. We believe ACL has the authority to make such a requirement under § 1324.11(e):

> Where the Ombudsman has the legal authority to do so, he or she shall establish policies and procedures, in consultation with the State agency, to carry out the Ombudsman program in accordance with the Act. Where State law does not provide the Ombudsman with legal authority to establish policies and procedures, the Ombudsman shall recommend policies and procedures to the State agency or other agency in which the Office is organizationally located, and such agency shall establish Ombudsman program policies and procedures. Where local Ombudsman entities are designated within area agencies on aging or other entities, the Ombudsman and/or appropriate agency shall develop such policies and procedures in consultation with the agencies hosting local Ombudsman entities and with representatives of the Office. Further, State agencies shall provide training for the Ombudsman and representatives of the Office as authorized by § 1324.15(c).

[56] *Rights & Protections in a Nursing Home*, Medicare.gov, https://www.medicare.gov/what-medicare-covers/what-part-a-covers/rights-protections-in-a-nursing-home (last visited Aug. 9, 2023).

provide direction for the Ombudsman and representatives of the Office as to how to address a situation where a resident is unable to communicate consent to the review of their records in the course of an investigation and they have no legal or resident representative who can communicate consent for them.[57] As discussed previously, LGBTQI+ older adults and those living with HIV/AIDS may face unique and complex issues regarding guardianship and other forms of third-party representation–wherein those designated to represent their best interests may be hostile to their sexual orientation, gender identity, or HIV/AIDS status. We suggest ACL consider implementing a framework for LGBTQI+ older adults and those living with HIV/AIDS in long-term care facilities–one that is sensitive to preserving the dignity and authenticity of LGBTQI+ residents or residents living with HIV/AIDS. ACL might consider instructing the Ombudsman to develop specific procedures in these scenarios (where an LGBTQI+ resident is unable to communicate consent and has no resident representative) that prevents families of origin, who may be unsupportive of or hostile to a resident's sexual orientation or gender identity, from involvement in the investigative process. SAGE is willing to offer technical assistance in developing such a framework.

III. Conclusion

Thank you for taking the time to consider our views, and the impact these proposed revisions will have on the communities of LGBTQI+ older adults and those living with HIV/AIDS that we serve and on whose behalf we advocate. We support the prompt finalization of the Proposed Rule, which we hope will include the recommended changes and enhancements discussed in this comment. Please do not hesitate to reach out with any questions.

Sincerely,

Aaron Tax (he/him)
Managing Director of Government Affairs & Policy Advocacy, SAGE
atax@sageusa.org
www.sageusa.org

Agape, NFP
AIDS Alabama
AIDS Project Los Angeles (APLA) Health
AIDS United
Albany Damien Center
Albemarle Commission Area Agency on Aging
The Aliveness Project
American Psychological Association (APA) Services
BiNet USA
Brandermill Woods Retirement Community
The Brookdale Center for Healthy Aging, Hunter College, CUNY
Callen-Lorde

[57] 88 Fed. Reg. 39568, at 39598-99, 39639-40.

CenterLink: The Community of LGBTQ Centers
Chicago Black Gay Men's Caucus
Coalition on Positive Health Empowerment
Equality California
Equality Federation
Equality Michigan
Equality North Carolina
FORGE, Inc.
Gay Elder Circle
Georgia Equality
GLMA: Health Professionals Advancing LGBTQ+ Equality
HealthHIV
HIV + Aging Research Project, Palm Springs
Hope In The End
JSI
Justice in Aging
Latino Commission on AIDS
Let’s Kick ASS: AIDS Survivor Syndrome
Let's Talk About It! An Educational Journey
LGBT Community Center of Greater Cleveland
LGBTQ Community Center of the Desert
Los Angeles LGBT Center
Mazzoni Center
MiGen - Michigan LGBTQ+ Elders Network
Movement Advancement Project
MPact Global Action
National Alliance of State and Territorial AIDS Directors (NASTAD)
National Coalition for LGBTQ Health
National HIV and Aging Advocacy Network
National LGBT Cancer Network
National Working Positive Coalition
NMAC (f/k/a National Minority AIDS Council)
North Dakota Human Rights Coalition
One Colorado
One Iowa
Oregon LGBTQ+ Aging Coalition
Out Wilmington LGBTQ Seniors/LGBTQ Center of Cape Fear
OutNebraska
PCAF (Pierce County AIDS Foundation)
The Phoenix Center (Central Illinois)
Positive Living, Houston
Pride Action Tank
Pride Center of Maryland
Pride In Aging Rhode Island
Professional Association of Social Workers in HIV/AIDS
Puerto Rican Cultural Center

Rainbow Connections ATX, Part of Family Eldercare
Rainbow Health Minnesota
Ribbon Organizing Center for HIV and Aging (ROC4A+)
San Francisco Community Health Center
Silver State Equality, Nevada
Social Welfare Action Alliance of Connecticut
The National Coalition for LGBTQ Health
The Reunion Project
The TransLatin@ Coalition
The Well Project
THRIVE SS
Treatment Action Group (TAG)
U.S. People Living with HIV Caucus
UTOPIA PDX
Waves Ahead Puerto Rico
Whitman-Walker Health
Whitman-Walker Institute
William Way LGBT Community Center
Zappalorti Society