

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 Center for HIV Law and Policy (CHLP) appreciates the opportunity to comment on the Administration for Community Living's (ACL) proposed rule on recommended changes, additions, or deletions to regulations for programs authorized under the Older Americans Act (OAA).

For the past 16 years, CHLP has utilized legal advocacy and high-impact policy and research initiatives in collaboration with national partners to fight to end stigma, discrimination, violence, and the criminalization of people based upon their health status or sexual identity. We collaborate with people living with HIV, organizers and base builders, direct service providers, and national organizations to identify, create, and share expertly crafted, intersectional legal and policy resources and advocacy strategies. Our work is nationally respected and recognized, and our expertise around the criminalization of HIV and its commiserate impacts on bodily autonomy are consistently sought out nationwide. We focus our work on those who are most deeply vulnerable to discrimination and criminalization by state actors, amongst others. We are an abolitionist organization that firmly believes that the criminalization of people based on their health status, racial identity, or sexual identity harms rather than protects the public.

We are compelled to provide expert feedback on the OAA rule making and implementation process to make sure that the needs of older Americans living with HIV are centered and holistically addressed. Over 50% of people living with HIV are now age 50 or older, a percentage that will only grow in time with the continued improvement in anti-retroviral

treatment.¹ As of 2018, people ages 50 and older are one in six of new US HIV diagnoses.² Older people living with HIV have very particular, and extensive, needs that must be met in such a way that is responsive to their complexity. Older people living with HIV are more likely to suffer from depression, to have early onset of neurocognitive impairment, and need treatment for a host of comorbid diseases.³ Older Americans, especially members of the LGBTQ+ community, are more likely to lack in family support and assistance and need government resources and support to live out their fullest lives.

S1321.27: State Plans Must Include People Living w/ HIV as Having “Greatest Social Need”

To a certain extent, the creation of categories of greatest social need implicitly recognizes that not every older person is the same; that the intersection of their identities, for example sexual orientation with aging and racial identity, can cause unique issues. The inclusion of people living with HIV in the category of greatest social need is important, as older people living with HIV have specific concerns both medically and due to the ongoing stigma of living with HIV that must be prioritized.⁴ However, this category of greatest social need could be improved by additionally stating that people have intersectional identities within these larger monolithic categories (lesbian, gay, persons who live in rural areas, etc), and that how they are addressed by state plans under s1321.27 must reflect these identities so they are not rendered invisible. Inevitably, if this is not made explicit, our stereotypes and biases will cause plans to be centered, in the case of people living with HIV, towards the needs of white, gay men as HIV, especially in older Americans, is still commonly perceived by people as a white, gay male disease (contrary to the reality that Black Southerners are the fastest growing number of new cases). A state plan

¹ Cahill, S., Geffen, S., Marquez, S., & Wade Taylor, S. (2016). Strategies to Improve the Health of Older Adults Living with HIV. In *Target HIV*. National Center for Innovation In HIV Care. Pg. 10. Retrieved August 15, 2023, from <https://targethiv.org/library/strategies-improve-health-older-adults-living-hiv>

² Bland, S., & S. Crowley, J. (2021). Meeting the Needs of People Aging With HIV: On the Path to Ending the Epidemic. In *O’Neill Institute*. Pg 8. Retrieved August 15, 2023, from <https://oneill.law.georgetown.edu/wp-content/uploads/2021/05/Meeting-the-Needs-of-People-Aging-with-HIV.pdf>

³ Bland, S., & S. Crowley, J. (2021). Meeting the Needs of People Aging With HIV: On the Path to Ending the Epidemic. In *O’Neill Institute*. Pg 4. Retrieved August 15, 2023, from <https://oneill.law.georgetown.edu/wp-content/uploads/2021/05/Meeting-the-Needs-of-People-Aging-with-HIV.pdf>

⁴ “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. The Act directs State agencies and AAAs to focus attention, advocacy, and service provision toward those in greatest economic need and greatest social need.” 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 for 2023, 88 Fed. Reg. 39581(June 16, 2023)(to be codified at 45 CFR Parts 1321, 1322, 1323, and 1324)

centered around that bias will fail to address the needs of, for example, a Black trans woman, as the issues that cause her difficulties in accessing supportive services are vastly different. This reauthorization tries in many parts to make explicit positions that were left murky in the 2020 reauthorization, as to not be explicitly mentioned in the law means to be invisible to it. Acknowledgement of the ways the peoples' intersectional identities impact their needs is therefore vital to meeting those needs.

It is of utmost importance that the Federal Government specifically mandate the inclusion of people living with HIV and LGBTQ+ people as groups to prioritize as having the Greatest Social Need. Thirty States have specific laws that target people living with HIV or have them incur additional penalties/sentence enhancements.⁵ Currently dozens of states have anti trans bills passed or pending. If left up to the discretion of the states, we will be left with a patchwork system of states where the needs of LGBTQ+ folks and people living with HIV are prioritized and met, and others where they are not only not prioritized but that their trans identity or the fact that they are living with HIV could be weaponized against them. Especially in light of the push to collect data to identify needs and trends (which must be safeguarded from misuse by law enforcement), vulnerable populations such as LGBTQ+ elders and older people living with HIV must be given as much support and protections as possible. Part of this must include needing to submit to an independent Ombudsman State and Local plans that are subject to their review and approval based upon whether or not they prioritize the needs of people living with HIV and LGBTQ+ folks within the meaning and spirit of the Older Americans Act. These plans must be specific and lay out strategies and the basis for them line by line, point by point, to block any ability to hide indifference and/or bias behind a mere assurance that the needs of ALL of the elders with greatest social need are being prioritized.

S1321 [ent.seq.]: Mandated Trainings Must Include Culturally Competent Sexual Education

CHLP has a history of advocating for comprehensive sexual education, including the requirement that medical professionals be mandated to receive training in how to take a sexual history and counsel a patient on sexual health practices. This background is also what drives our response to the proposed changes to the Older Americans Act. The numbers of older people being diagnosed with HIV is rising, with older Americans comprising a consistently growing percentage of all new HIV diagnoses.⁶ This is due in large part to the fact that generally older

⁵ Center for HIV Law and Policy (2022) *Map: HIV Criminalization in the United States*, CHLP Retrieved August 15, 2023, from <https://www.hivlawandpolicy.org/resources/map-hiv-criminalization-united-states-chlp-updated-2022>

⁶ Cahill, S., Geffen, S., Marquez, S., & Wade Taylor, S. (2016). Strategies to Improve the Health of Older Adults Living with HIV. In *Target HIV*. National Center for Innovation In HIV Care. Pg. 7. Retrieved August 15, 2023, from <https://targethiv.org/library/strategies-improve-health-older-adults-living-hiv>

people are viewed as asexual/not sexually active, which is not the case.⁷ Many older people themselves view STIs and HIV as issues that only impact younger people and are more likely to engage in condomless sex.⁸ Part of the state agencies' policies and procedures under s 1321 [ent seq.] must be to mandate trainings for relevant service providers (such as those responsible for health promotion and evidence-based disease prevention found in s1321.71(a)) on how to discuss older people's sexual health as well as in best practices for addressing the needs of groups designated as having the greatest social need. Providers trained in how to address older American's sexual health will be better able to serve that population and help provide resources geared towards ending the epidemic.

Similarly, to best serve people living with HIV, providers should receive LGBTQ+ competency as well as racial justice trainings. Between 300,000 and 400,000 elders living with HIV are men who have sex with men (MSM).⁹ As of 2016, Black people made up 42% of new HIV diagnoses, and 39% of all older people living with HIV.¹⁰ Black people, specifically black women, are significantly more likely to die from an HIV related issue.¹¹ And, as discussed earlier, many people living with HIV are members of both of those communities. Merely stating that services to people living with HIV will be prioritized, but not providing education to members on best practices renders the intent void. Services must be provided in a culturally competent matter, or people will simply seek to avoid utilizing the resource. Basically, if the intention is to prioritize older people living with HIV and LGBTQ+ folks, and the people offering the supportive services are not trained, then the services will not be utilized by the people who are supposed to be prioritized. And this education must be standardized by the federal government as well as mandatory.

S 1322.3: Definition of “Family Caregiver” Must Include Chosen Family

⁷Aitchison, P. et.al. (2014). Eight Policy Recommendations for Improving the Health and Wellness of Older Adults with HIV. In Diverse Elders Organization. Pg. 6. Retrieved August 15, 2023, from https://www.diverseelders.org/wp-content/uploads/2014/05/DEC-HIV-and-Aging-Policy-Report_web.pdf

⁸ Cahill, S., Geffen, S., Marquez, S., & Wade Taylor, S. (2016). Strategies to Improve the Health of Older Adults Living with HIV. In *Target HIV*. National Center for Innovation In HIV Care. Pg. 7. Retrieved August 15, 2023, from <https://targethiv.org/library/strategies-improve-health-older-adults-living-hiv>

⁹ Cahill, S., Geffen, S., Marquez, S., & Wade Taylor, S. (2016). Strategies to Improve the Health of Older Adults Living with HIV. In *Target HIV*. National Center for Innovation In HIV Care. Pg. 7. Retrieved August 15, 2023, from <https://targethiv.org/library/strategies-improve-health-older-adults-living-hiv>

¹⁰ Sangaramoorthy, T., Jamison, A. M., & Dyer, T. V. (2018). Older African Americans and the HIV care continuum: A Systematic review of the Literature, 2003–2018. *Aids and Behavior*, 23(4), 973–983. <https://doi.org/10.1007/s10461-018-2354-4>

¹¹ Waysdorf, S. (2002). The Aging of the AIDS Epidemic: Emerging Legal and Public Health Issues for Elderly Persons Living with HIV/AIDS. *Elder Law Journal*, 10(47), 63.

In order to prioritize LGBTQ+ folks, including those living with HIV, the definition of family caregiver must be expanded to include ones “chosen family.” This is contemplated by the expansive proposal, “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.” Where 85% of all elder care nationally is provided by younger family members (related by blood or marriage), spouses, partners and friends provide 90% of the care for LGBTQ+ adults (only 3% is provided by adult children).¹² The demand for informal, “chosen family” caregiving is exacerbated by the fear of anti-LGBTQ+ bias in congregate care.¹³ And that fear is based in reality, as there is no national law protecting LGBTQ+ folks of all ages from discrimination in the private sector (there are protections under the ADA for discrimination based upon a person living with HIV). As falling under the definition of Family Caregiver gives people access to resources and support under the Older Americans Act that they would not otherwise have, it is imperative that the definition encompass the reality of LGBTQ+ peoples’ lives.

S 1321.93 All Older Americans Must Have Counsel Provided if Guardianship Is Sought

Access to comprehensive legal services is key to promote the goal of older Americans having equal access to full and free enjoyment of the best physical and mental health.¹⁴ The web of programs that an older person may utilize to meet their daily needs, from Medicare to federally funded senior housing, are governed by a complex interlocking regime of federal, state, and sometimes even city laws. Being incorrectly denied access to any of these services could be the difference between life and death for an older American, which is why they need prompt legal assistance to correct the error. It is further necessary for these advocates to undergo rigorous anti-bias, racial justice, and LGBTQ+ competency trainings. When dealing with the vulnerable, but resilient, aging population it is important for attorneys to know how to keep their own biases in check when helping clients navigate these systems. Furthermore, having this background will assist lawyers in creating trust and rapport with their clients.

Where access to counsel is of particular vitality for older Americans living with HIV and LGBTQ+ folks is during guardianship proceedings. Many people in either or both of these groups are estranged from their family, and their chosen family cannot make legal decisions on

¹² Nancy Knauer (2016), *Lgbt Older Adults, Chosen Family, and Caregiving*. *Journal of Law and Religion*, 31 (2), 151.

¹³ Nancy Knauer (2016), *Lgbt Older Adults, Chosen Family, and Caregiving*. *Journal of Law and Religion*, 31 (2), 155.

¹⁴ Bland, S., & S. Crowley, J. (2021). Meeting the Needs of People Aging With HIV: On the Path to Ending the Epidemic. In *O’Neill Institute*. Pg 18. Retrieved August 15, 2023, from <https://oneill.law.georgetown.edu/wp-content/uploads/2021/05/Meeting-the-Needs-of-People-Aging-with-HIV.pdf>

their behalf.¹⁵ Even as guardianship laws and standards have evolved over the last few decades, to this author's knowledge, they have not integrated in any protections or safeguards for LGBTQ+ elders. This means that during a guardianship proceeding, if unrepresented, an LGBTQ+ elder may be forced to navigate the courts hostility and bias alone. "Capacity doctrines typically take into account an individual's ability to engage in deliberative decision making and, in some instances, the perceived reasonableness of the individual's actions."¹⁶ If the court is under the impression that identifying as trans is proof of some sort of "mental defect," how is the court likely to rule as to that individual's capacity? Or, for an elder recently diagnosed with HIV and subject to all of the stigma and judgement that such a diagnoses causes, what will the court determine about that elders' ability to make healthy decisions for themselves? Although mandating counsel is not a perfect solution, it should help older Americans protect themselves from specious losses of their independent decision making authority.

Conclusion

CHLP applauds many of the changes contemplated for the 2023 revisions to the Older Americans Act. That said, in our climate of criminalization and stigma against people living with HIV, and growing dogmatic hatred of LGBTQ+ folks, it is important to make sure that the provisions are as protective of older folks who hold those identities as possible. As has been shown through the misapplication of such statutes as the Religious Freedom and Restoration Act, or through the misuse of previous OAA funds to *bring* guardianship proceedings, the protections of the law depend on the details.

Thank you for your consideration. We look forward to hearing from you. If you have any questions about these comments, or would like to schedule a follow up meeting, please reach out to Kae Greenberg, Esq., Staff Attorney at CHLP, kgreenberg@hivlawandpolicy.org.

Sincerely,



Kae Greenberg, Esq.

Staff Attorney

Center for HIV Law and Policy

¹⁵ Knauer, N. J. (2012, November 8). LGBT Issues and Adult Guardianship: A Comparative perspective. <http://ssrn.com/abstract=2147988>

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