



FLORIDA HEALTH JUSTICE PROJECT, INC.

October 3, 2022

Melanie Fontes Rainer
Director, Office for Civil Rights
Department of Health and Human Services
Washington, DC

Submitted electronically via [regulations.gov](https://www.regulations.gov)

Re: RIN 0945-AA17 Nondiscrimination in Health Programs and Activities Impacting Older Adults

Dear Director Fontes Rainer:

Florida Health Justice Project (FHJP) is writing to comment on the notice of proposed rulemaking (NPRM) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) issued by the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS). This comment only pertains to nondiscrimination in Health Programs and Activities impacting older adults. Please note, FHJP is also submitting a more extensive comment on RIN 0945-AA17 Nondiscrimination in Health Programs and Activities today.

FHJP is a nonprofit health advocacy organization whose mission is expanding access to healthcare with a focus on Florida's most vulnerable populations. Accordingly, we have prioritized work on behalf of low-income frail and disabled seniors who require home and community-based services (HCBS) in order to remain safely at home and out of an institution and who are enrolled in the Long-Term Care (LTC) Waiver. Among other things, FHJP has published an *Advocates' Guide to the Long-Term Care Waiver*, see <https://www.floridahealthjustice.org/guide-to-long-term-care-medicare-waiver.html>

(now in its 5th edition) and a consumer video, see <https://www.floridahealthjustice.org/medicaid-hcbs.html> that explains this complex and critical program for vulnerable Floridians and their families. We also provide trainings and technical assistance to other advocates and work with individuals who wish to share their stories See <https://www.floridahealthstories.org/long-term-care>, and we represent individual clients.

The Health Care Rights Law (Section 1557 of the ACA) prohibits discrimination in health care on the basis of race, color, national origin, sex, age, and disability. We appreciate HHS's proposals to restore and strengthen these important anti-discrimination protections for older adults. In the course of our work we have heard from numerous stakeholders who have first hand experience with the LTC Waiver, and we have seen first hand the need for clear rules guarding against discrimination. This comment focuses on the strengthening of the rule's application to prohibiting discrimination based on age and

ensuring its applicability to Medicaid plans and all home and community based services relied on by frail and disabled older Floridians.

These data points highlight the need in Florida: over 20% of Florida's population is 65 or older, and will grow to over 30% by 2030, making Florida the second “grayest” state in the Nation.¹ 12.7% of Florida seniors live in poverty, including 18.6% of Black older adults and 21.6% of Hispanic older adults.² Black and Hispanic older adults in Florida have higher rates of poverty than the national average.³ Over half of older adults in Florida need long term services and support, but Florida ranks 51st for these services.⁴ Until the state stopped tracking COVID-19 data in nursing homes, Florida led the nation in nursing home resident and staff COVID-19 deaths, accounting for 21% of total deaths.⁵

1557 Should Apply Broadly to Health Programs and Activities, Including all Home and Community Based Services (HCBS)

HHS operates many programs, including some that are not “health” programs but are nonetheless vital to older adults’ well-being. A large number of our older Floridians rely on community services and programs, such as congregate meal settings, adult day care centers, and meals on wheels. These programs are extremely important to their well being, not only because they provide the only meal some of these older adults eat a day, but sometimes their only social interaction.

For example, one older Floridian we serve is a low-income 78 year old African American who has severe health issues, no phone, computer, car or family assistance. He is not able to shop or cook for himself. He is still waiting for enrollment into the Medicaid long-term care waiver for Florida. He has to rely on community programs for his meals and has experienced racial discrimination at one of the facilities and has been turned away. He relies on those programs, and sometimes that one meal he could get would be his only for days.

Thus, we urge HHS to work with the Department of Justice and other agencies that administer health programs to develop a common rule to implement section 1557 to ensure nondiscrimination in these programs.

We also support the proposal to incorporate the integration mandate in HHS’s Sec. 504 regulations into Sec. 1557. This provision is necessary to help ensure people with disabilities, including older adults, are able to get the services they need to live in the community and are not institutionalized. In Florida, for example, nursing homes are an entitlement for Medicaid recipients requiring a nursing

¹ <https://www.prb.org/resources/which-us-states-are-the-oldest/>

² https://www.americashealthrankings.org/explore/senior/measure/poverty_sr/state/FL

³ *Id.*

⁴ <https://www.longtermscorecard.org>

⁵ <https://www.baynews9.com/fl/tampa/news/2021/06/15/ltc-covid-data>

home level of care, whereas home and community based services (HCBS) have a capped waitlist currently at 51,901.⁶

The long-term care preferences for older adults resemble those of younger individuals with disabilities. Older adults also want social integration and the ability to receive care at home or in the community, rather than being institutionalized, yet the norm is institutionalization.⁷ This is particularly true for ethnic and racial minorities who are disproportionately represented in nursing homes.

In Florida, we have found that White women over the age of 65 are overrepresented in receipt of HCBS in Florida, accounting for the highest number of recipients.⁸ Conversely, the percentage of ethnic and racial minorities in nursing homes has increased over the last 20 years, while the number of White individuals in nursing homes has declined.⁹

Based on National data, Black older adults are more likely to be moved to a nursing home facility, whereas White older adults are more likely to be moved to an assisted living facility.¹⁰ Older Black adults are also overrepresented in Nursing homes¹¹ and more likely to receive lower quality care. The same is true for low-income Hispanic older adults, as they are more likely than White older adults to “reside in nursing homes that are characterized by severe deficiencies in performance, understaffing, and poor care.”¹²

COVID highlighted these profound disparities, as nursing homes with higher percentages of Black and Hispanic residents had higher rates of COVID and COVID related deaths.¹³ Nursing home residents, especially members of minority ethnic or racial groups were disproportionately represented in COVID deaths.¹⁴ This underscores the importance of HCBS and choice of where someone can receive care. Low staffing levels in nursing homes are also associated with COVID-19 infections and deaths. Florida nursing homes led the country for much of the last 2.5 years in both COVID-19 infections and deaths.¹⁵ Insufficient staffing leads to greater infection control violations and issues, which lead to

⁶ Public Records Request to the Florida Department of Elder Affairs for current waitlist data. Current waitlist number as of September 21,2022.

⁷ <https://pubmed.ncbi.nlm.nih.gov/11816651/>

⁸ https://ahca.myflorida.com/medicaid/Finance/data_analytics/BI/docs/Quarterly_SMMC_Report_Winter_2014.pdf

⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3785292/>

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7566960/>

¹¹ Harris-Kojetin L., Sengupta M., Lendon J. P., Rome V., Valverde R., & Caffrey C (2019). Long-Term Care Providers and Services Users in the United States, 2015–2016 (Vol. 3). Retrieved from <https://www.cdc.gov/nchs/nsltcp/index.htm>

¹² <https://pubmed.ncbi.nlm.nih.gov/20048362/>

¹³ <https://www.kff.org/coronavirus-covid-19/issue-brief/racial-and-ethnic-disparities-in-covid-19-cases-and-deaths-in-nursing-homes/>, <https://www.nytimes.com/2020/05/21/us/coronavirus-nursing-homes-racial-disparity.html>

¹⁴ <https://www.cdc.gov/mmwr/volumes/69/wr/mm6942e1.htm>

¹⁵ <https://www.tampabay.com/news/health/2021/09/15/florida-leads-nation-in-nursing-home-resident-and-staff-covid-19-deaths/>

greater risk of spread and death. Infection control deficiencies are more common at homes that have fewer nurses and aides than at facilities with higher staffing levels, based on an analysis of data from the past two regular inspection periods.¹⁶

Prohibiting Discrimination in Automated Decision-Making

As HHS has noted, clinical algorithms can be discriminatory and particularly harmful to Black patients, as they often dictate that Black patients must be more ill than white patients before they can receive treatment for life-threatening conditions such as kidney disease and heart failure. We support the proposed provision to prohibit discrimination through the use of clinical algorithms in decision-making. Additionally, in Florida we note that algorithms tend to discriminate against immigrants and non-English speaking applicants and enrollees, as well as Black individuals in HCBS programs.

We are further concerned with the use of algorithms in the application process for placement on the state's LTC wait list. For older adults and others, there are concerns of discrimination in decision-making tools and systems, like our screening tools for our Medicaid HCBS services, referred to as the Long Term Care Waiver. When older adults and persons with disabilities apply for the Medicaid Long-Term Care Waiver in Florida they are required to complete a screening interview on the phone and get assigned a priority score based on their answers to the screening questions. The problem is that the answer choices and options do not always accurately reflect their reality. This can be due to the individual not understanding how to accurately answer the question. For example, one of our clients with severe health issues, e.g. who was unable to walk by himself and couldn't hear the interviewer on the phone due to hearing issues deafness, so he answered that he was able to dress himself, shop, cook meals, and otherwise take care of himself despite this not being the case. This example demonstrates how the current process can unfairly and negatively impact their priority score, and thus their ability to access much needed services

Thus, we request that HHS broaden the prohibition to include any form of automated decision-making system. While the screening tools may fall outside the term "clinical algorithm," any assessment tools for home and community-based services for both level of care determinations and services allocation that discriminate against groups or deny services needed to maintain community integration should be subject to the protections of 1557.

Thank you for considering these comments.

Sincerely,

Melissa Lipnick

Equal Justice Works Fellow Sponsored by the Florida Bar Foundation

¹⁶ <https://khn.org/news/coronavirus-preparedness-infection-control-lapses-at-top-rated-nursing-homes/>

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