

### NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE

Ashwin Vasan, MD, PhD Commissioner

Testimony

of

### Ashwin Vasan, MD, PhD Commissioner New York City Department of Health and Mental Hygiene

before the

New York City Council Committee on Health, Committee on Aging, and Committee on Hospitals

on

**Older Adults Living with HIV** 

November 17, 2023 New York, NY Good morning, Chairs Schulman, Hudson, and Narcisse, and members of the committees. I am Dr. Ashwin Vasan, Commissioner of the New York City Department of Health and Mental Hygiene. I am joined by Dr. Celia Quinn, Deputy Commissioner for Disease Control, who will speak later on the oversight topic – older adults living with HIV and the related legislation.

Thanks to advancements in HIV screening, treatment, and prevention, as well as institutional and community efforts to reach the last mile and address inequities, we have a clear opportunity, in our lifetimes, to end the HIV epidemic in New York City. Dr. Quinn will speak to our work in this regard. Before the advent of and widespread access to HIV medications, HIV/AIDS was a leading cause of death in New York City until the early 2000s. The dramatic gains in life expectancy experienced in the first decade of this century are in part due to the introduction of antiretroviral therapy. I began my career working to ensure access to HIV treatment around the world to address this leading cause of preventable death. And so I am very glad as well, and I want to thank Chair Schulman, for also providing an opportunity to testify today on HealthyNYC, the City's campaign to improve life expectancy and create a healthier city for all.

The health of New Yorkers is at a major inflection point. As we emerge from the COVID-19 pandemic, New Yorkers are, on average, sicker and dying too soon. Life expectancy — the average number of years a person can expect to live from the time of their birth — dropped more than four-and-a-half years, from 82.6 years in 2019, its highest point ever, to 78 years in 2020. Underneath these overall data, we also see stunning inequities, reflecting that our health challenges are not experienced equally. Black New Yorkers, starting from the lowest baseline life expectancy in 2019 of 77 years, lost 5.5 years in 2020, and Latino New Yorkers, 6 years. This represents the biggest and fastest drop in lifespan in a century.

In 2021, life expectancy rebounded slightly to 80.7 years, accounting for the lessening impact of COVID-19 due to advances in treatment and our vaccination and prevention efforts. However, we are still two years behind in lifespan from where we were in 2019. And there should be no expectation that we will return to our previous baseline or meet our common expectation of healthier, longer lives, without intentional action.

Two weeks ago, Chair Schulman joined myself and the Mayor as we launched HealthyNYC, the City's population health agenda to improve life expectancy and create a healthier city for all. HealthyNYC sets, as a matter of civic planning and civic expectation, that all New Yorkers, year after year, should expect to live healthier and longer in our great city. And it is a plan that demonstrates how the City of New York is stepping up to meet this challenge, along with partners across sectors. We know health is a choice, but it's not just an individual choice; it's an institutional choice and a democratic choice. And that's why we have government, to tackle the problems too big or too complex for us to address on our own.

HealthyNYC sets clear mortality reduction goals to reduce the greatest drivers of overall risk and death: premature death below age 65, which predominantly impacts Black and Latino New Yorkers; excess deaths, which predominantly impact vulnerable groups like older New Yorkers,

disabled people, and people with underlying health conditions or living in vulnerable settings; and the most extreme racial inequities, including unacceptable rates of Black maternal mortality.

The HealthyNYC goals set numeric targets for reducing deaths from chronic and diet-related diseases, screen-able cancers, overdose, suicide, Black maternal mortality, violence, and COVID-19. By 2030, if we are successful in achieving these disease targets, we will reach the highest ever life expectancy recorded in New York City, 83 years.

We want New Yorkers to experience more birthdays, weddings and graduations, more holidays and holy days, more life lived. To do so is an all-hands-on deck moment. It is a civic responsibility, and we will need to engage all parts of our civic infrastructure to achieve. Government, through HealthyNYC, can set the guideposts and goals, and will play a big part in achieving these goals. But we will need nonprofits, community organizations, the private sector, and everyday New Yorkers, to align around these goals. HealthyNYC is how we ensure everyone, across sectors, consider health in every institutional and individual decision they take. It's how we link all these decisions to perhaps the most important single metric we have for our society and our democracy – how well and how long we live.

I am happy that we have the support and partnership of City Council in this campaign. The Health Department proudly supports Introduction 1248, which will require our agency to lead the development of a citywide population health agenda that focuses on improving life expectancy. As well as report on progress towards achieving the goals set in that agenda, and update the agenda every five years, setting new goals to achieve new life expectancy targets, as needed. Under the legislation, the Health Department will consult with stakeholders and provide regular updates to the City Council on progress made.

This bill ensures that planning around health, and life expectancy as the key measure of our collective health, will be a permanent feature in New York City government. One that lasts from mayor to mayor and administration to administration. Because we know that this is long work, and it is hard work, and it is bigger than the ability of any one institution, or any one branch of government, or any one community, to achieve on their own.

Improving life expectancy will require collaboration, energy, and focus from many partners, across the five boroughs. HealthyNYC will not only be a model for civic planning for health for our city, but for our nation, showing once again that New York City is a leader and innovator in public health. Thanks to the Council, the Speaker, and specifically Chair Schulman, HealthyNYC will be an organizing force in government for years to come.

Thank you once again for the opportunity to be here today. I look forward to answering your questions on HealthyNYC and Intro 1248. I will then turn things over to Dr. Quinn.



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November 17, 2023 New York, NY Good morning, Chairs Hudson, Schulman, and Narcisse, and all members of the Committees on Aging, Health, and Hospitals. I also want to thank Commissioner Vasan for speaking on HealthyNYC. My name is Dr. Celia Quinn and I am the Deputy Commissioner for Disease Control at the New York City Department of Health and Mental Hygiene. I am pleased to be here with my colleagues Dr. Emma Kaplan-Lewis from New York City Health + Hospitals and Jocelyn Groden and Anya Herasme from the New York City Department for the Aging, to discuss the important topic of older adults living with HIV and the legislation included on today's agenda.

Before I describe the Health Department's specific programming and services for older people with HIV, I want to mention the advances in HIV treatment that have allowed people with HIV to live longer. HIV antiretroviral medicines are safer and more effective than ever. When taken as prescribed, HIV treatment medicines can reduce the amount of virus in the body to levels so low that the virus is undetectable. People with undetectable HIV *cannot* pass HIV to others through sex. In New York State, HIV treatment is available to anyone who has HIV, regardless of immigration status. As more people with HIV are on treatment and have access to health insurance and patient assistance programs, they are living longer, healthier lives.

In 2021, there were approximately 49,400 people ages 50 years and older with diagnosed HIV in New York City, representing 56% of all people with diagnosed HIV in the city. Among people 50 years and older with HIV, 90% were receiving care, 86% were prescribed HIV treatment medicines, and 83% were virally suppressed, meaning that the amount of virus detectable in a person's blood is very low. The Health Department receives federal funding through the Ryan White HIV/AIDS Program to support the medical and nonmedical needs of income-eligible people with HIV in New York City. In 2021, approximately 48% of our Ryan White clients were ages 50 years and older, and 93% of those receiving Ryan White-funded HIV medical care were virally suppressed. This speaks to the Ryan White program's role as a critical safety net provider for people with HIV who are uninsured or underinsured. Clients benefit from client-centered care coordination and a range of supportive services, including food and nutrition services, mental health services, housing placement and short-term rental assistance, health education, and legal services, among others. The Health Department continues to work closely with our HIV Health and Human Services Planning Council of New York to set program priorities and allocate resources for Ryan White clients.

New York City is also seeing decreases in the number of older people newly diagnosed with HIV. In 2021, 273 people ages 50 years and older were newly diagnosed with HIV, down 21% since 2017 and 67% since 2001 when HIV reporting began in New York State. The sooner people with HIV are diagnosed, the sooner they can be connected to HIV care and treatment. We are encouraged that the federal government is moving towards requiring Medicare to fully cover HIV pre-exposure prophylaxis or PrEP, including long-acting injectable PrEP, and look forward to more information from them on this initiative. We also welcome the final rule issued by the federal government for Medicare to reimburse providers for Community Health Worker services, including Principal Illness Navigation services for those with HIV/AIDS, starting in January 2024. This rule will provide resources for care coordination, patient education, facilitation of social services and health system navigation for older adults with HIV.

In addition to our work to ensure more New Yorkers know their HIV status, the Health Department oversees an array of programming and services for older people with HIV. Our Building Equity: Intervening Together for Health – or BE InTo Health – initiative funds nine HIV clinics across the city to implement evidence-informed HIV care models that support communities most affected by HIV, including three clinics that specifically focus on serving Black and Latino people with HIV who are ages 50 years and older. BE InTo Health's goals include increasing engagement and reengagement in HIV care and decreasing racial and ethnic inequities in HIV outcomes. Since BE InTo Health's launch in 2021, funded clinics have served 267 Black and Latino people with HIV ages 50 years and older.

In April of this year, the Health Department launched a new Ryan White program for older people with HIV, which funds three New York City Health + Hospitals sites to deliver outpatient health services designed to treat the complex needs of older people with HIV. Services include medical history taking, physical examination, diagnostic testing, treatment and management of physical and behavioral health conditions, preventive care and screening, prescription management and treatment adherence, education and counseling on health and prevention issues, and referral to specialty care and other services. Providers also offer social and physical activities addressing isolation among older people with HIV. My colleague Dr. Kaplan can answer more questions about this program.

Last year, the Health Department launched our PlaySure Network 2.0, a network of 18 organizations funded to provide a comprehensive health package of HIV-related services in health care and non-health care settings using an equity-focused, one-stop shop and holistic client-centered model. PlaySure Network 2.0 providers offer universal HIV testing; PrEP and emergency post-exposure prophylaxis or PEP; immediate initiation of HIV antiretroviral treatment; sexually transmitted infection – or, STI – testing and treatment; outreach and navigation services; and mental health, substance use, and other supportive services. Several funded organizations offer programming and services designed for older people with HIV. For example, Exponents offers ARRIVE, an eight-week education and counseling program for older people with HIV who are struggling with addiction; GMHC's Healthy Aging Project and its hub for long-term survivors offer workshops, resources, and referrals to supportive services, and GMHC's Thriving @ 50 group for older Black and Latino people with HIV focuses on reducing social isolation, depression and stigma; and New York-Presbyterian's Comprehensive Health Program offers a wellness program for people with HIV who are 50 years and older.

Last year, the Health Department's Training and Technical Assistance Program launched a training for clinical, non-clinical, and social service providers on enhancing health outcomes for older people with HIV. Participants learn how these clients' unique mental and physical health needs may impact their care, treatment, and health outcomes. Participants learn about the importance of using a strengths-based, health equity approach, and how to transform HIV care settings to better serve older clients with HIV. Since the training launched last February, we have held seven trainings attended by a total of 112 participants. The Health Department's NYC Condom Availability Program delivers condom education trainings at senior centers across the city. Since last April, we have conducted over 17 trainings at senior centers attended by a total of 544 participants.

I am happy to be here with the Department for the Aging which has a broad range of programs serving older adults with HIV. For a quick description, NYC Aging serves older New Yorkers, 60 and over, through a range of programs and services including older adult centers, case management, home-delivered meals, mental health programs, workforce development and supports, and a host of other aging services. All older adults who are physically able are welcome to attend any of the more than 300 older adult centers across the City to participate in programs and activities or receive services, including a daily congregate meal, referrals, and case assistance. Additionally, homebound older adults may be eligible to receive homebased services such as case management, home-delivered meals, homecare, friendly visiting, etc.

Before we answer your questions, I'd like to briefly discuss the legislation being heard today. Regarding introduction 825, which relates to reporting on PrEP outreach and distribution, New York State Department of Health regularly reports on the outreach and distribution of PrEP. They purchase statewide PrEP prescription data and other HIV-related data that are uploaded to the Ending the Epidemic – or ETE – Dashboard annually. The ETE dashboard can be filtered by region and by sex, age, and race/ethnicity. Data on the number of people with PrEP prescriptions in New York City are already publicly available on the ETE Dashboard. The Health Department uses these data to inform our efforts to expand access to PrEP and increase PrEP uptake among specific groups and communities. Requiring the Health Department to report on this data would duplicate the state's efforts.

Regarding introduction 895, which relates to providing rapid testing for STIs in all boroughs, the Health Department has concerns related to the logistics and feasibility of the proposed legislation as written. The Health Department operates Sexual Health Clinics across the city, all of which offer rapid HIV testing. Two clinics, Chelsea and Fort Greene, offer Quickie Express visits for rapid STI testing for people without symptoms, with most HIV, chlamydia, and gonorrhea test results within hours. We are able to process the chlamydia and gonorrhea tests through the use of a special specimen testing machine located on site; these machines are large, stationary, and require specific infrastructure to operate. Other clinics also offer rapid HIV testing and screening and testing for STIs, with immediate treatment initiation if indicated. In addition, we partner with approximately 70 organizations located in all five boroughs to deliver free HIV self-tests directly to New Yorkers at home. And, as I mentioned earlier, the Health Department funds numerous organizations across the City to offer routine STI and HIV testing, including rapid HIV testing, in clinical and nonclinical settings. The Department distributes resources and supports services based on need, taking into account a variety of factors including surveillance data, care access, and equity concerns. Neighborhoods and communities with the highest burden of STIs can change quickly. Additionally, burden of different STIs can vary by population within neighborhoods, at times requiring targeted approaches by gender, race and ethnicity, age group, and geography. Given the constraints around the method of testing, and the infrastructure needed to perform these tests, we do not support this legislation.

Introduction 620 relates to mpox education and prevention efforts and an infectious disease vaccine scheduling portal. The Health Department has incorporated mpox prevention activities into our routine sexual health programming. This includes provider education, assisting providers with mpox vaccination, and partner and community outreach, including during Pride events. The Health Department provides a list of mpox vaccination sites on the City's

vaccinefinder.nyc.gov website, which includes links to the various sites for scheduling and other information. The infectious disease vaccine scheduling portal described in the legislation would take a substantial amount of time and resources considering the lack of standardization across healthcare provider platforms. We are pleased to report that the number of mpox cases in New York City has remained low in 2023 with just 22 cases from October 8 through November 4, 2023, and a total of 133 cases since January 1, 2023. In our view, existing vaccine information and resources are effective and meet the current level of need.

The Health Department remains committed to providing comprehensive services and support to older adults living with HIV, and we are happy to discuss with the Council how we can best support the intention of the proposed legislation. Thank you for the opportunity to be here today to address this important topic. We look forward to answering your questions.



**BRONX BOROUGH PRESIDENT VANESSA L. GIBSON** 

### Testimony of Bronx Borough President Vanessa L. Gibson New York City Council Committees on Health, Hospitals, and Aging November 17, 2023

Thank you to Chair Schulman, Chair Narcisse, and Chair Hudson for convening this important hearing today. Our public health agencies must continue to confront and deter the spread of STIs, HIV, and Monkeypox (mpox) in our city. I am proud to stand with all of you to call for expanded outreach, education, and access to testing and treatment that will help mitigate the proliferation of these diseases.

As Borough President, I am proud that my office has worked to combat the spread of these diseases. I have convened an HIV Roundtable to coordinate our activism, outreach, and education regarding HIV/AIDS. We work closely with our partners at the city and state levels, including the End the Epidemic Committee, the AIDS Institute, and The Bronx Knows, to build partnerships with community members, advocates, and providers to create the connections that keep our residents healthy and safe. We have also joined together to promote HIV testing among vulnerable populations and commemorate World AIDS Day.

The Committees' focus today on HIV among seniors is an important topic that will become more essential to discuss over the coming years. The population of people living with HIV is steadily getting older as medicine is evolving to better prevent new infections and finally end the epidemic. In the most recent HIV surveillance report from DOHMH, 31.6% of New York City residents living with HIV were age 60 and up – that's more than the number under age 40 living with HIV. We must continue to improve our understanding of HIV/AIDS among seniors and how we can best provide for the needs of these individuals living with HIV.

The Bronx in particular has a high level of HIV infections and HIV-positive residents. In 2021, The Bronx was second in new HIV infections after Brooklyn, had the highest number of new AIDS diagnoses, had the second-most HIV-positive residents after Manhattan, and had the highest number of deaths among people with HIV. The Bronx needs more targeted interventions that will help reduce the spread in our borough. We need more testing and more access to healthcare and other treatment.

During the spread of mpox last summer, we saw again how the distribution of care in our city is not always done in the most equitable way. The Bronx was not prioritized for mpox vaccinations and, accordingly, we had a low number of people vaccinated. In 2022, The Bronx had 19.5% of the city's mpox cases but only 6% of the people vaccinated. Black and Latino New Yorkers were also significantly underrepresented when it came to vaccinations versus cases.

I am proud to support the bills under consideration by the committees today that would expand access to testing, vaccination, and medication for people who have or who are at-risk of contracting HIV, STIs, or mpox. Int 895 sponsored by Councilmember Pierina Sanchez would help make rapid testing for STIs and HIV more available to New Yorkers, particularly to those living in neighborhoods with the highest rate of STI transmission. Expanding education to residents about the risks of STIs and the availability of testing is essential to stopping the spread and limiting exposure.

It is a critical goal for our city to expand the use of pre- and post-exposure prophylaxis among populations at increased risk of contracting HIV. PrEP is an essential part of the strategy for ending the HIV/AIDS epidemic in our city. Individuals who are on PrEP have a greatly reduced risk of contracting HIV, and thus the use of PrEP helps prevent the spread. New York must work to make PrEP more accessible to our residents. While insurance covers this essential medication, vulnerable and high-risk populations such as the uninsured, those without regular access to medical providers, people with addiction issues, sex workers, and others are all less likely to have access.

Thank you again to the members of the Council who participated in this hearing today. I urge the speedy passage of the bills under consideration to help stem the tide of HIV, STI, and mpox cases in our city. We must do more to protect our residents from the spread of these diseases, and these bills represent a strong step towards achieving that goal.



### Testimony of Kevin Jones AARP New York

### NYC Council Committees on Aging, Health, and Hospitals

November 17, 2023

Contact: Erik Kriss (518) 360-9213 | ekriss@aarp.org

My name is Kevin Jones, and I am the Associate State Director for Advocacy at AARP New York, which counts 750,000 members in New York City and advocates on behalf of them and the 2.9 million city residents over the age of 50. Thank you for the opportunity to testify.

Older adults represent New York's fastest-growing demographic. According to a report we commissioned from the Center for an Urban Future, New York City's 65-and-over population grew by 36 percent, or more than 800,000 people, over the past decade, while the under-65 population shrank by nearly half a million.

Older adults are also more diverse, with more foreign-born, and increasingly income insecure. On top of that, they are less healthy. Life expectancy is down and health problems, including mental health, are on the rise.

The City must do more to support the wellbeing of our older neighbors. They built this city and made it great, and they deserve better.

That's why I'm here today to testify in support of legislation requiring the Department of Health and Mental Hygiene to develop a population health agenda for the purpose of improving public health outcomes, addressing health disparities, and improving quality of and access to health care.

We believe a health agenda must incorporate:

- Robust funding and support for community-based strategies that address the social determinants of health.
- Increased capacity to deliver public health services.
- Sound public health strategies for health promotion, disease prevention, and intervention that are evidence-based and have proven efficacy.

We know from our research that many older New Yorkers lack access to affordable, high-quality clinical medical care as well as preventive services.

Policymakers have found that entrenched socioeconomic factors also affect health and longevity. These factors include income, education, and occupation. Environmental conditions, neighborhood characteristics, and the historical legacy of discriminatory private- and public-sector practices also are factors in determining health outcomes. To that end we encourage the Council to focus on all the social determinants of health that impact wellbeing.

Our older neighbors are struggling and suffering. They deserve better. A population health agenda that is tracked and renewed on a regular basis is the blueprint the City needs to move the needle on health and wellness.



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### New York City Council Committee on Health Jointly with the Committee on Aging and the Committee on Hospitals Oversight – Older Adults Living with HIV

#### **Testimony of EmblemHealth**

#### November 17, 2023

EmblemHealth would like to thank Chair Schulman, Chair Hudson, Chair Narcisse, and the members of the Committee on Health, the Committee on Aging, and the Committee on Hospitals for holding this hearing and providing the opportunity to express our support of the citywide population health agenda aimed at improving life expectancy.

The EmblemHealth family of companies provides insurance plans, primary and specialty care, and wellness solutions. As one of the nation's largest community-based non-profit health insurers, we have over 80 years of local experience, and proudly serve more than two million New Yorkers. We operate 14 EmblemHealth Neighborhood Care centers where we provide free in-person and virtual support, access to community resources, and culturally competent programming to all community members including those who are not EmblemHealth members. Many of our Neighborhood Care centers are co-located with our partner medical practice, AdvantageCare Physicians (ACPNY), which provides primary and specialty care at over 30 offices in the New York area to over 500,000 patients a year, including at 11 offices in designated Medically Underserved Areas and 17 in Primary Care Health Professional Shortage Areas.

Our experience in all of these areas makes us uniquely positioned to advise and coordinate with the City in the efforts to extend the lifespan of New Yorkers and to improve population health. We were encouraged by the announcement of the HealthyNYC plan to advance these efforts and EmblemHealth's CEO Karen Ignagni has committed to aligning to this work. She told the *Washington Post*, "We see this as a social responsibility" and shared our commitment to working with the City to achieve these goals such as through facilitating healthy food access and mental health services at our Neighborhood Care sites and sharing data to support the City's dashboards.

We would like to work closely with you to help shape the City's population health agenda and offer EmblemHealth as a resource as you and other City leaders continue this work. We know that health outcomes are affected by more than just individual actions, and we will continue to work across our family of companies to ensure that all communities, including those that have traditionally experienced inequities in the health care system, have access to the services they need. Our commitment to reducing inequities was recently recognized when we were awarded Health Equity Accreditation from the National Committee on Quality Assurance (NCQA), the first health plan operating in New York to receive this designation across all lines of business. We place health equity at the forefront of everything we do, including through the collection

and use of data to better reach our communities and through comprehensive health and wellbeing programming tailored to meet the needs of each unique community we serve. We hope to bring what we have learned to help HealthyNYC achieve its goals.

We know that improving public health outcomes, addressing health disparities, and improving the quality of and access to health care will require a coordinated effort to ensure that all New Yorkers, especially the most vulnerable and at-risk, have access to public health education, culturally competent health and wellness services, and needed resources. EmblemHealth strongly supports Introduction 1248-2023 and the development of a HealthyNYC population health agenda, as well as the legislation under consideration today related to expanding access and availability of mpox education and vaccines, STI testing, and HIV/AIDS prevention. We hope to continue to be a constructive partner and resource to the City Council and look forward to continuing to work together to keep our neighbors and communities healthy.



### Testimony to the New York City Council's Committee on Aging Jointly with the Committee on Health and Committee on Hospitals

Oversight Hearing: Older Adults Living with HIV Friday, November 17, 2023

Good afternoon, Chair Hudson, Chair Schulman, Chair Narcisse and members of the NYC Council Committee on Aging and Committee on Health, and Committee on Hospitals. Thank you for your leadership and the work of your staff and the committee staff for bringing together the Council's first-ever hearing dedicated to addressing the needs of older people living with HIV (OPLWH).

SAGE is the country's first and largest organization dedicated to improving the lives of lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ+) elders and OPLWH. We have been serving these populations for over four decades, including operating one of the longest-running HIV support groups for LGBTQ+ elders living with HIV through our SAGEPositive program. The SAGEPostive program is for LGBTQ+ elders aged 50 and over who are either living with HIV or otherwise impacted by the epidemic and provides comprehensive services including support groups, social programming, care and case management, and nutrition services.

Right here in New York City, in the face of violence and stigma, the fierce advocacy of ACT-UP not only forced the United States government and the scientific community to fundamentally change the way medical research was conducted, it also played a crucial role in reshaping social service systems. Their tireless efforts resulted in advances in antiretroviral therapies (ART) that keep millions of people alive and sparked transformative changes in how social services are delivered, ensuring better support and care for those affected by HIV and AIDS. Now OPLWH make up the majority of New Yorkers living with HIV, and it is estimated that by 2030, over 70% of New Yorkers living with HIV will be over the age of 50.<sup>1</sup> This growing population is the result of medical advances and the overall aging of our city, but it is also fueled by new HIV diagnoses. Data from the New York City Department of Health and Mental Hygiene 2021 HIV Surveillance Annual Reports shows that over 17% of new HIV diagnoses were of New Yorkers aged 50+.<sup>ii</sup>

It is important to center today's hearing with the understanding that older New Yorkers Living with HIV are diverse in age, gender identity, race and ethnicity, sexual orientation, and socioeconomic status. Older people of color are disproportionally impacted by HIV. Black Americans make up 38% of OPLWH, followed by non-Hispanic Whites (37%), Hispanics/Latinx (18%), people of multiple races/ethnicities (4%), Asians (1%), and less than 1% each who are American Indians/Alaska Natives, Native Hawaiians, and Pacific Islanders.<sup>iii</sup>

Nationally, 77% of OPLWH are male and 23% are female.<sup>iv</sup> Historically, the CDC included transgender women under the misclassification of "men who have sex with men," making it much harder to know the number of older transgender PLWH. However, this issue has been corrected in more recent HIV surveillance data, which has found that transgender women are among the groups most disproportionately affected by HIV in the United States, which we can infer is true for transgender older adults.<sup>v</sup>

When the HIV epidemic emerged in the 1980s, the notion of people living long lives was unforeseen, leaving us ill-equipped to care for older adults and long-term survivors of HIV today. Those who are older and living with HIV were unable to anticipate or prepare for the challenges that lay ahead, even within a few years. Healthcare providers, caregivers, aging services, and government programs are also lagging behind in their capacity to adequately support OPLWH. Consequently, New York City finds itself completely unprepared to meet the pressing needs of this growing population. This testimony will delve into policy and program recommendations that New York City can adopt in order to address the significant issues faced by older individuals living with HIV, as well as those who are vulnerable to contracting the virus.

#### **HIV Prevention and Sexual Health:**

Many older people enjoy active and healthy sex lives and need access to HIV testing, education, and other sexual health services. However, due to ageism and HIV-related stigma, HIV—and sexual health more widely—is not considered an issue that affects older people.

In New York City, the prevalence of HIV diagnoses among individuals aged 50 and above remains a significant concern. Unfortunately, there is still a significant deficiency in overall HIV testing, which poses a direct obstacle for this particular age group becoming aware of their HIV status.<sup>vi</sup> Additionally, healthcare providers rarely inquire about the sexual health of their older patients, leading to a lack of knowledge among many older New Yorkers regarding preventive measures such as PrEP and PEP. This age-related bias further exacerbates the situation, increasing the likelihood that older individuals will progress to AIDS without even realizing they are living with HIV.<sup>vii</sup>

To address this, New York City must increase HIV testing rates among older adults by implementing enhanced and intensified efforts including:

- Allocate resources to develop targeted HIV prevention campaigns that specifically cater to the unique needs of older adults that cover topics including HIV testing, PEP, PrEP, and condoms.
- Explicitly include older adults in all HIV prevention campaigns and work to distribute HIV and sexual health educational information through NYC Aging's network of over 300 older adult centers across the city as well as in long-term care facilities, PACE programs, and senior housing developments.

• Develop and distribute guidelines including best practices for sexual health and wellness programming at Older Adult Centers.

#### Access to Programs and Services:

Older New Yorkers living with HIV are more likely to rely on government and community-based services due to high rates of multimorbidity and behavioral health issues and poverty.<sup>viii</sup> Many long-term-survivors never expected to live into their later years and cashed-in their savings, retirement, and life insurance plans to pay for their immediate needs and support their community during the height of the epidemic.<sup>ix</sup> Additionally, living in poverty—in and of itself— also facilitates HIV transmission among all age groups.<sup>x</sup>

In the face of these high needs, the communities served by New York's HIV and aging services providers overlap more and more each year. Yet these services remain siloed. Absent increased and coordinated collaboration, the growing population of New Yorkers aging with HIV will continue to face negative health outcomes due to untreated mental illness and substance use, lack of consistent HIV and geriatric medical care, lower rates of viral suppression, lack of support for mobility and related housing and transportation needs, and increased effects of stigma and social isolation. Older PLWH also avoid services due to shame or past experiences of discrimination due to HIV status, demonstrating an urgent need for HIV competency training as well as HIV de=stigmatization campaigns focused on older people.<sup>xi</sup>

The following steps must be taken to support the service needs of older New Yorkers living with HIV:

- Establish and fund a new City Council Initiative on HIV and Aging in the FY25 budget, in collaboration with HIV and Aging service providers.
- Direct regular collaboration between NYC Aging and New York City Department of Health and Mental Hygiene to incentivize collaboration between HIV and aging providers. Develop new funding opportunities for community-based organizations that work with OPLWH. This should include the development of trainings on the topic of HIV and aging, self-management education programs targeted at older people with HIV, and the hiring of case managers specialized in HIV and aging.
- Require all staff, subcontractors, subgrantees, and volunteers of City-funded aging services, long-term support services, home and community-based services, and housing services, to receive training on providing care and support to older New Yorkers living with HIV.
- Implement the New York City Council LGBTQIA+ Caucus' *Marsha & Silva Plan*, which calls for the creation of a strong and intentional strategy to improve access to care and service for older New Yorkers living with HIV and long-term survivors.<sup>xii</sup>

#### Healthcare:

Research has demonstrated that HIV has a significant and early impact on the aging process, accelerating biological changes typically associated with getting older.<sup>xiii</sup> Consequently, OPLWH

face difficulties in navigating the complex healthcare system to access and maintain HIV treatments. Given the substantial volume of healthcare services required, barriers to care, and personal factors that can impede accessing necessary services, OPLWH often require additional support to get the services they need. Furthermore, these individuals frequently report high levels of depression and anxiety, yet healthcare settings often overlook these concerns, failing to address them adequately. Additionally, access to essential mental health services is often lacking for this population.

To address these barriers, healthcare providers across New York City need to make the following reforms:

- Recalculate the timeframe and conduct routine age-related assessments earlier, i.e., colonoscopy, cancer screenings, bone density, frailty, and cognitive tests for OPLWH.
- Diversify and employ a similar percentage of staff who are of the same population, gender, and sexual orientation as the communities they serve.
- Allocate longer appointment times for OPLWH to ensure comprehensive healthcare needs are addressed effectively, including thorough examinations, discussions on sexual history, cognition, frailty, diet, exercise, sleep, medication review and adherence, prescription management, and explanation of lab work results, considering the limitations of a 10-20 minute time slot.
- Upon making referrals, coordinating with referral provider office to be certain they accept the patient's insurance carrier to improve access to care.

### State and Federal Advocacy:

There are many needed reforms to support older New Yorkers living with HIV outside of the jurisdiction of the NYC Council that would have deep impacts across the city. We ask for the New York City Council and Mayor Adams' Administration to join the following efforts at the State and Federal level.

- Support lowering the age at which older people living with HIV can access Older American Act (OAA) programs to 45, similar to the bipartisan Younger-Onset Alzheimer's Disease Act, key provisions of which were included in the most recent reauthorization of the OAA. This language could be added to Title I, Section 102 in the 2024 Older Americans Act Reauthorization.
- Support the removal of the upper age limit on CDC's HIV Testing Guidelines, which currently only recommend HIV testing between ages 13-64.
  - Removing this unnecessary and harmful age cap would promote awareness and education on the testing needs of older people and help remove barriers to testing and other sexual health services like PEP and PrEP

### Conclusion:

Today marks the first time that the intersection of HIV and aging has been highlighted in a dedicated NYC Council hearing. We would not be here now if it was not for the ACT-UP and

other HIV activists who fought and were arrested protesting this very body, along with the state and federal governments, during the height of the epidemic.

SAGE also wants to express strong support for Int. 0623-2022, which would require aging services providers to attend anti-discrimination trainings, focusing on discrimination based on sexual orientation, gender identity, and expression and recommends adding anti-discrimination training based on HIV status to this legislation.

This hearing is a vital step, but we cannot stop here. New York City must act now to ensure that services and policies not only acknowledge but fully support OPLWH and New Yorkers 50+ who require HIV prevention services and education.

Thank you, Chair Hudson and Chair Schulman, for creating the platform for this conversation here at City Hall and for advocating for supports for older New Yorkers Living with, and vulnerable to, HIV. We look forward to working with you to implement the recommendations highlighted here in SAGE's testimony along with the additional calls-to-action brought forward today by older New Yorkers living with, and vulnerable to, HIV.

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David Martin, SAGEPositive Program Coordinator, SAGE <u>dmartin@sageusa.org</u>

<sup>&</sup>lt;sup>i</sup> Gilead Sciences, "<u>HIV Age Positively® 2021 Progress Report</u>" (November 2021)

<sup>&</sup>lt;sup>ii</sup> New York City Department of Health and Mental Hygiene, "<u>HIV Surveillance Annual Report</u>" (2021)

<sup>&</sup>lt;sup>iii</sup> Mark Brennan-Ing, PhD, "<u>Emerging Issues in HIV and Aging</u>," Brookdale Center for Healthy Aging at Hunter College (May 2020)

<sup>&</sup>lt;sup>iv</sup> Id.

<sup>&</sup>lt;sup>v</sup> United States Centers for Disease Control and Prevention, "<u>Issue Brief: HIV and Transgender Communities</u>" (April, 2022)

<sup>&</sup>lt;sup>vi</sup> New York City Department of Health and Mental Hygiene, "<u>HIV Surveillance Annual Report</u>" (2021)

<sup>&</sup>lt;sup>vii</sup> Trent Straube, "<u>Urging the CDC to Recommend HIV Testing for People 65 and Older</u>," POZ Magazine (June 2023)

<sup>&</sup>lt;sup>viii</sup> Mark Brennan-Ing, PhD, "<u>Emerging Issues in HIV and Aging</u>," Brookdale Center for Healthy Aging at Hunter College (May 2020)

<sup>&</sup>lt;sup>ix</sup> Aaron Tax, "Issue Memo: Older People Living with HIV," SAGE (2019)

<sup>&</sup>lt;sup>x</sup> Pellowski JA, Kalichman SC, Matthews KA, Adler N., "<u>A pandemic of the poor: social disadvantage and the U.S. HIV</u> <u>epidemic</u>" Am Psychol (May 2013)

<sup>xi</sup> Mark Brennan-Ing, PhD, "<u>Emerging Issues in HIV and Aging</u>," Brookdale Center for Healthy Aging at Hunter College (May 2020)

<sup>xii</sup> NYCC LGBTQIA+ Caucus, "<u>The Marsha & Sylvia Plan</u>," (June 2023)

x<sup>iii</sup> Enrique Rivero, "<u>Study shows HIV speeds up body's aging processes soon after infection</u>," UCLA Health (June 2020)



### TESTIMONY

New York City Council Committee on Aging Jointly with the Committee on Health and Committee on Hospitals Friday November 17, 2023

> Delivered by: David Martin, SAGEPositive Program Coordinator

Good afternoon, my name is David Martin, and I work as the SAGEPositive Program Coordinator at SAGE. I am a volunteer appointee of the HIV Health and Human Services Planning Council for the New York EMA and serve on its Executive Committee. I am also an older New Yorker living with HIV for 36 years.

The issue I want to raise this morning is that significant disparities exist for older New Yorkers living with HIV when seeking timely and comprehensive healthcare and wraparound services.

What is evident through my individual experiences, hearing stories from the community, and from working for the SAGEPositive program is that older New Yorkers with HIV are often unable to get their needs met, and face barriers in doing so.

HIV stigma, ageism, classism, homophobia, transphobia, and racism have all resulted in limited investments in prevention, medical, and social services.

Direct support is needed to navigate a complex healthcare system to even access services. Many older people with HIV encounter a high volume of healthcare needs, high and unaffordable costs, perplexing insurance plans, as well as personal factors that make accessing needed services more difficult such as comorbidities, cognitive difficulties, language barriers, and immigration status.

However, the New York City Council can help tackle these issues by creating a City Council Initiative on HIV and Aging, which includes funding for healthcare navigation in next year's budget.

It must also be stated that challenges do not stop once an individual successfully makes it to an appointment. Current clinical practices fail to best serve older New Yorkers living with HIV. Older people with HIV require more time with our providers and different approaches to address the evolving and already complex intersection of comorbid conditions, yet only a customary 20-minute appointment is allowed.

Oral Health is paramount to nutrition; however, for older adults with HIV tooth loss limits this due to improper food mastication. Implant treatments with greater effectiveness are needed. Sadly, insurances only cover ill-fitting, painful, and less effective devices currently offered.

In closing, we need providers to conduct routine age-related assessments earlier and have the most updated training and resources about the persistent impact that HIV and trauma have on the aging process.

Providers should be required to make certain that insurance covers different doctors or services before they make referrals to help prevent loss or delay of long-awaited appointments.

Social Services and Healthcare have not centered focus on the ongoing needs of older people living with HIV, and it is time to change course.

Thank you so much for the opportunity to testify. We look forward to working with you to address these and other concerning issues.



### New York City Council City Hall Committee on Aging Council Chambers - City Hall

Friday, November 17, 2023

#### <u>Written Testimony</u> Mohamed Q. Amin, Founder and Executive Director, Caribbean Equality Project

Good Afternoon, Chairperson Hudson, Narcisse, Schulman, and the esteemed Committee on Aging. Thank you for the opportunity to testify today.

My name is Mohamed Q. Amin, Executive Director of the Caribbean Equality Project (CEP), a community-based organization that empowers, advocates for, and represents Afro and Indo-Caribbean LGBTQ+ immigrants in New York City. Through public education, community organizing, civic engagement, storytelling, and cultural and social programming, the organization's work focuses on advocacy for LGBTQ+ and immigrant rights, gender equity, racial justice, immigration, and mental health services, and ending hate violence in the Caribbean diaspora.

Caribbean Equality Project fully supports and calls on the council to pass in this session, all the bills discussed in today's hearing.

New York City is home to the largest Caribbean foreign-born population, many of whom live in Caribbean-centric neighborhoods like Richmond Hill, South Ozone Park and Far Rockaway in Queens, Flatbush and Crown Heights in Brooklyn, and Castle Hill, Wakefield, and Soundview in The Bronx. The Caribbean LGBTQ+ immigrant's Caribbean Equality Project serve faces unique challenges, and health inequity should not be one of them. Many of the barriers Queer Caribbeans encounter are rooted in ancestral trauma, recovering from post-colonization, LGBTQ-related phobias within faith-based institutions and diaspora Caribbean communities, HIV stigma, lack of access to culturally responsive mental health resources, and racism. Many of our community members have been abandoned and rejected by their families, fleeing from their home country because of persecution, escaping death threats, employment and housing discrimination, anti-LGBTQ hate violence, and isolation, including lack of access to sexual health and HIV care.

In 2015, we launched Knowing Matters, a Sexual Health and Wellness program that has been breaking the silence about HIV/AIDS through public education, performing arts, and promoting prevention while offering support and care to the Caribbean LGBTQ+ community living with HIV in New York City. Many of the organization's clients are

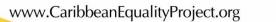
asylum seekers and low-income and undocumented queer and trans Afro and Indo-Caribbean people of color. Health services have been a central component of Caribbean Equality Project advocacy work for over eight years, stemming from a need for increased access to free STI/HIV testing we noticed in our service to community members, particularly asylum seekers who left the Caribbean to live in New York. This correlates with DOHMH's data. According to a 2018 New York City Department of Health and Mental Hygiene HIV Epidemiology research, the highest incidences of new diagnoses for HIV among foreign-born New Yorkers were among people born in the Caribbean, including the Dominican Republic, Jamaica, Haiti, and Guyana. Richmond Hill, home to the largest Guyanese population in NYC, has no community access to HIV and STI testing. A further challenge is finding service providers that are culturally and linguistically competent to serve LGBTQ+ immigrants.

Intro 895 will finally focus on racial disparity in accessing sexual health resources that have long created inequities in Black and Brown immigrant communities. Your neighborhood, immigration status, socio-economic background, race, sexual orientation, gender identity, and sex should not be barriers to health services in NYC. Knowing your HIV status matters, and it starts with getting tested. We have been living within colliding pandemics for decades. If there's one thing, COVID-19 thought is that undocumented, low-income, LGBTQ+, and immigrant communities continue to be disproportionately impacted by health crises. I am calling on the New York City Council to pass Intro 895, Int 620, Int 825, Res 294, and Res 395 so we can safely love and protect each other while living healthy lives with dignity.

Don't hesitate to contact me at <u>Mohamed@CaribbeanEqualityProject.org</u> or by phone at 347.709.3179 if you have any questions. To learn more about the Caribbean Equality Project, visit <u>https://www.caribbeanequalityproject.org</u>.

In Solidarity & Respect,

Mohamed Q. Amin Founder & Executive Director Caribbean Equality Project



# AGING AND HEALTH AMONG OLDER ADULTS WITH HIV IN NEW YORK CITY & TRI-COUNTY REGION

#### Presentation at the Research & Evaluation Meeting

New York State Department of Health AIDS Institute

October 3, 2023

Angela Aidala, Maiko Yomogida, Mary Clare Lennon & Lynn Ngo Columbia University, Mailman School of Public Health

# PROJECT DESCRIPTION

#### **STUDY OBJECTIVE**

 To investigate the interactions among aging processes, length of time living with HIV, chronic disease comorbidities, and social determinants that contribute to clinical and functional outcomes among older persons living with HIV

### **STUDY METHODS**

- Based on the CHAIN Project an ongoing, community cohort study of a racially and economically diverse probability sample of PWH in NYC and the Tri-County Region (Westchester, Putnam, Rockland Counties)
- Information about participants' life contexts, service needs and experience are assessed using a combination of detailed in-person interviews and agency-level information

## Goals of the CHAIN Project

**Community Health Advisory and Information Network (CHAIN)** 

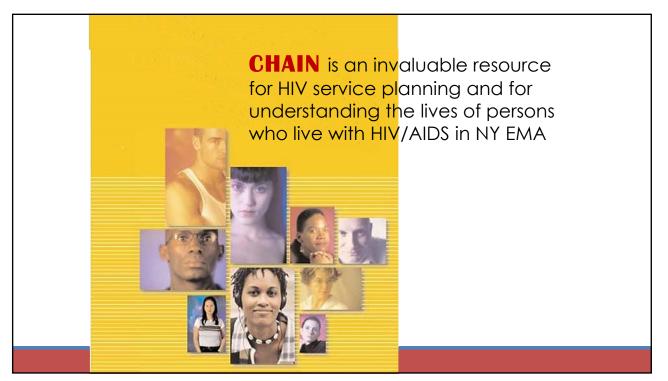
Profiles persons with HIV (PWH) in NYC and the Tri-County region

Assesses the system of HIV care – both health and social services – *from the perspective of PWH* 

Reports on unmet needs, service utilization trends, and HIV health and care outcomes

Makes research results available to the NY HIV Planning Council, its committees, and the wider provider, consumer, and other stakeholder communities

Collaboration with the Planning Council & its committees, NYC DOHMH, NYS AIDS Institute, & Mailman School of Public Health



# SAMPLING AND DATA COLLECTION

Two-stage sampling design yields probability sample representative of PWH who had some contact with a medical or social service provider in the prior year

- $\circ~1^{st}$  stage: randomly select HIV medical and service providers
- 2<sup>nd</sup> stage: randomly recruit participants with agency support

NYC participants are followed over time, interviewed about every 18-24 months

Tri-county participants are recruited every other year under a repeated crosssectional sampling design with about 20% respondents re-interviewed

Data collected by detailed in-person interviews

See: https://nyhiv.org/tdb\_templates/chain-reports-template-12/

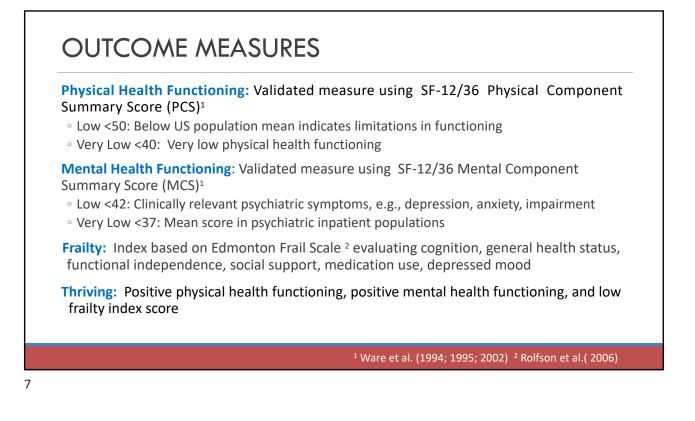
# ABOUT THIS STUDY

Study sample n=2,395 people with HIV (PWH) in New York City and Tri-County Region

Total of 7,764 Interviews conducted between 2002-2020

We are looking at:

- Age differences in sociodemographics, cumulative disadvantage, non-HIV comorbidities, and functional health and well-being among NYC and Tri Co PWH
- The distribution of risks and protective factors for successful aging regarding health/mental health functioning and quality of life shaped by age, time living with HIV, and SDOH
- Implications for program and policy planning





	NYC COHORT <u>2013-2020</u>		TRI-COUNTY <u>2015-2019</u>	
	Age 50+	Age <50	Age 50+	Age <50
Sample (N=)	427	519	176	76
Current Age (mean, stddev) <sup>1</sup>	58.8 (6.7)	35.9 (7.5)	59.2 (6.3)	37.7 (7.8)
Number of Years Living with HIV <sup>1</sup>	20.4 (0.9)	12.8 (7.5)	20.5 (7.5)	9.5 (7.3)
Age at Diagnosis 50+	9%	0%	12%	0%
Year of Diagnosis				
Before 1991	23%	5%	24%	1%
1991-1996	37%	12%	51%	8%
1997-2004	36%	24%	29%	18%
2005-2011	5%	33%	20%	34%
2012 and after	0%	25%	6%	38%

 $^1\mbox{Current}$  age and number of years with HIV at most recent interview

## RESOURES, DISADVANTAGES

		NYC COHORT <u>2013-2020</u>		TRI-COUNTY <u>2015-2019</u>	
		Age 50+	Age <50	Age 50+	Age <50
Sample	e (N=)	427	519	176	76
Education Less Than High School		37%	32%	37%	40%
Income Below Poverty Level		59%	66%	48%	48%
Precarious Housing /Homeless		8%	33%	7%	18%
Living in Disadvantaged Neighborhood		49%	53%	100%	100%
Food Insecurity		46%	56%	52%	57%
Financial Hardship		52%	70%	72%	76%
Experienced HIV Stigma Discrimination		36%	55%	45%	41%
Ever Jail Or Prison		49%	30%	33%	16%
High Stress Score		42%	54%	46%	58%

Note: Data from most recent interview

	NYC COHORT <u>2013-2020</u>		TRI-COUNTY <u>2015-2019</u>	
	Age 50+	Age <50	Age 50+	Age <50
Sample (N=)	427	519	176	76
CVD-related conditions High cholesterol, hypertension, heart disease	86%	49%	56%	23%
Chronic respiratory diseases Asthma, COPD, emphysema, etc.	64%	53%	43%	20%
<b>Cancer</b> Lung, rectal/anal, cervical, liver, other non- HIV related	37%	20%	31%	21%
Diabetes	27%	8%	19%	4%
Hepatitis C	21%	8%	23%	5%
Conditions associated with increased mortality isk among PWH <sup>1</sup> 0 1-2 2+	5% 12% 83%	22% 33% 45%	24% 22% 54%	56% 74% 17%

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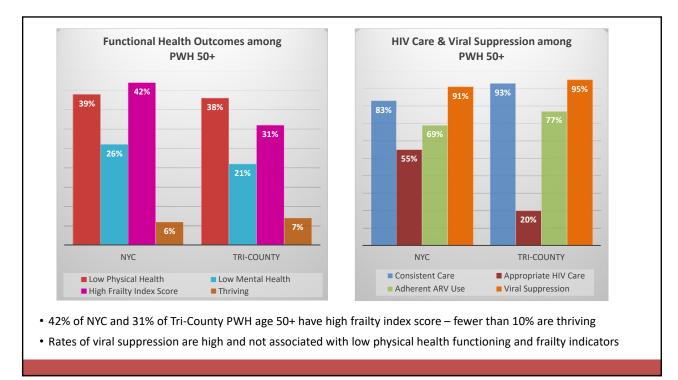
# Health Functioning, Frailty, and Thriving by Aging indicators

### MENTAL & PHYSICAL HEALTH FUNCTIONING, FRAILTY & THRIVING BY AGE

		ow I Health		ow Il Health	High Frailty Index Score		Thriving	
	OR	AOR	OR	AOR	OR	AOR	OR	AOR
Current age	1.074	1.055	0.972	0.985	1.076	1.063	0.951	0.956
Age Group (ref 35-49)								
Under 35	0.233	0.337	1.506	1.308	0.388	0.555	1.760	1.563
Age 50+	1.721	1.563	0.737	0.840	2.023	1.741	0.515	0.526
Current Age among 50+	ns	1.041	0.966	ns	1.117	1.118	0.960	0.950
Age 50+ at diagnosis	ns	ns	0.669	ns	2.316	2.521	ns	0.440
Years of HIV Diagnosis								
1991 - 1996	ns	ns	ns	ns	ns	ns	1.680	1.574
1997 - 2004	0.463	0.636	ns	ns	ns	ns	1.674	ns
2005 - 2011	0.124	0.367	1.458	ns	0.411	ns	2.203	ns
2012 and after	0.038	0.180	2.201	1.616	0.247	ns	4.385	ns
Years living with HIV	1.049	1.028	0.985	ns	1.085	1.053	0.951	0.976

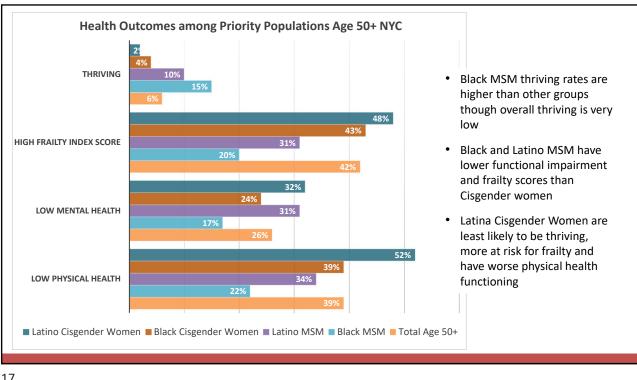
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Functional Health and HIV Outcomes among PWH Age 50+

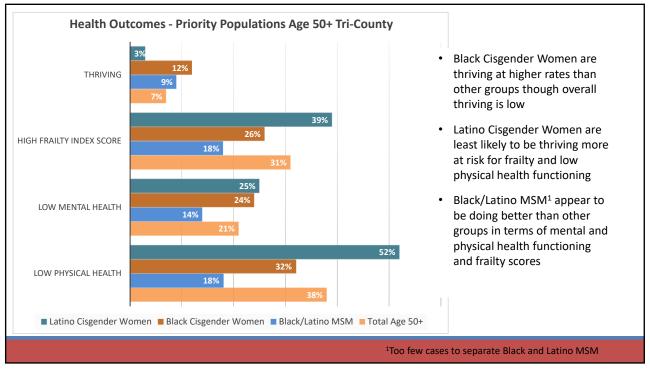












# Predictors of Health Functioning, Frailty, and Thriving

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Predictor	AOR
Current age	1.036*
Number of years living with HIV	1.012
Female	1.241
Transgender	0.300
Black	0.875
Latino/a	0.918
Tri-County Region	1.126
Less than HS Education	0.839
More than HS Education	0.632
Income below poverty threshold	1.247
Precarious housing, homeless	1.569*
Ever jail or prison	0.920
Area deprivation index	1.069
HIV Stigma, discrimination	1.807
Life Stress Scale Score	1.135*
Past smoker	0.849
Current Smoker	1.148
past problem substance use	1.217
Current problem substance use	1.360
Number of comorbidities	1.465*
HIV Medical Care meets clinical practice standards	1.393*
Social Services case management	1.488*

### Predictors of Low Physical Health Functioning

Current age, precarious housing, stress, number of comorbidities and appropriate HIV medical care and case management are associated with higher odds of **LOW physical health functioning** controlling for other variables in the model

Gender, low education, poverty income, smoking, problem drug use, HIV stigma also associated with risk of low physical health functioning in bivariate analyses – but not statistically significant in the full adjusted model

Random effects logistic regression among PWH age 50+ n= 911 individuals, 2530 observations

Predictor	AOR
Current age	0.985
Number of years living with HIV	1.002
Female	1.078
Transgender	2.567
Black	0.816
Latino/a	1.352
Tri-County Region	0.772
Less than HS Education	1.027
More than HS Education	1.370
Income Below poverty threshold	1.032
Precarious housing, homeless	0.871
Ever jail or prison	0.935
Area deprivation index	0.984
HIV Enacted Stigma	0.888
Life Stress Scale Score	1.331*
Past smoker	0.932
Current Smoker	1.030
past problem substance use	0.776
Current problem substance use	1.108
Number of comorbidities	0.966
HIV Medical Care meets clinical practice standards	0.739*
Social Services case management	1.090
Random effects I	ogistic regre

### Predictors of Low Mental Health Functioning

Life stress is the strongest predictor of **LOW mental health functioning**. Receiving HIV medical care that meets clinical practice standards is negatively associated with low or poor mental health functioning

Current age, race/ethnicity, education, smoking, problem drug use, HIV stigma associated with risk of low mental health functioning in bivariate analyses – but not statistically significant in the full adjusted model

ssion among PWH age 50+ n= 912 individuals, 2533 observations

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Predictor	AOR
Current age	1.107*
Number of years living with HIV	1.031*
Female	0.989
Transgender	2.487
Black	1.036
Latino/a	1.174
Tri-County Region	0.669
Less than HS Education	1.516*
More than HS Education	1.130
Income Below poverty threshold	1.489*
Precarious housing, homeless	1.354
Ever jail or prison	0.793
Area deprivation index	0.989
HIV Enacted Stigma	0.828
Life Stress Scale Score	1.197*
Past smoker	0.894
Current Smoker	0.784
Past problem substance use	1.134
Current problem substance use	1.727*
Number of comorbidities	1.385*
HIV Medical Care meets clinical practice standards	0.791
Social Services case management	1.574*

### Predictors of High Frailty Index Score

Current age, number of years living with HIV, low education, poverty, higher stress score, current problem drug use, number of comorbidities, and social service case management are associated with higher odds of **high frailty score** 

Years living with HIV, race/ethnicity, below poverty income, and smoking, are associated with higher odds of frailty in bivariate analyses – but not statistically significant in the full adjusted model

Predictor	AOR
Current age	0.950*
Number of years living with HIV	1.006
Female	0.728
Transgender	0.453
Black	2.002
Latino/a	0.817
Tri-County Region	1.054
Less than HS Education	0.619
More than HS Education	1.030
Income Below poverty threshold	0.819
Precarious housing, homeless	1.039
Ever jail or prison	1.424
Area deprivation index	1.038
HIV Enacted Stigma	0.331
Life Stress Scale Score	0.722*
Past smoker	1.207
Current Smoker	1.069
past problem substance use	0.897
Current problem substance use	0.503
Number of comorbidities	0.693*
HIV Medical Care meets clinical practice standards	1.210
Social Services case management	0.624*
Random ef	fects logi

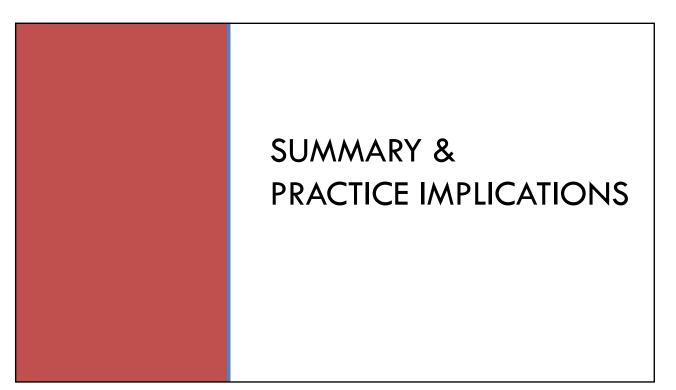
### Predictors of Thriving

Current age, higher stress score, number of comorbidities, and social service case management are associated with lower odds of **thriving** 

Female gender, Latino/a ethnicity, low education, poverty, HIV stigma associated with lower odds of thriving in bivariate analyses but not statistically significant in the full adjusted model

c regression PWH age 50+ n= 909 individuals, 2526 observations

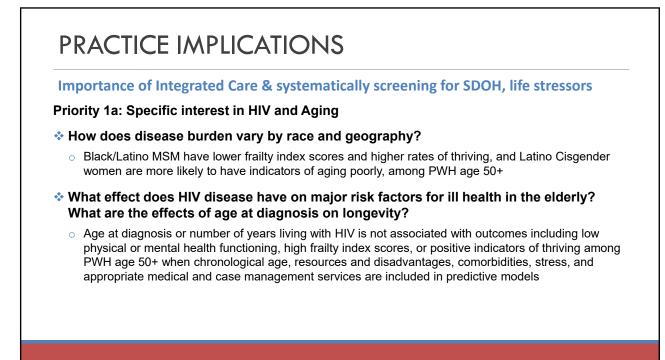
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# Predictors of Frailty, Thriving, and Health Functioning: Summary

- Life Stress Scale Score, Chronological Age, and Number of Comorbidities are the most consistent predictors of aging-related challenges indicated by Low Physical Health Functioning and High Frailty Score, and negatively associated with Thriving
- Strongest predictors of high Frailty Index Score which includes social functioning as well as physical health functioning are indicators of cumulative disadvantage including low education, poverty, and life stressors
- Contrary to expectations, Low Mental Health Functioning is not consistently associated with Chronological Age
  - Younger persons, especially those under 35, have lower Mental Health Functioning scores than older PWA including those over age 50

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# Thank You

In addition to the NYS AIDS Institute's mini-grant, this research was supported through a contract with the NYC DOHMH as part of its Ryan White HATEA grant, H89 HA00015, from the Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau (HRSA HAB)

Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the HRSA HAB, the NYC DOHMH, or NYS AIDS Institute

We are especially grateful to the staff of the many agencies in New York City who help introduce the project to their clients and patients

Without our dedicated, community-based interviewers, there would be no CHAIN project

Most importantly, we thank the many persons living with HIV who have shared their time and experience with us as CHAIN project participants since 1994

Contact for CHAIN study: aaa1@columbia.edu or my2278@cumc.columbia.edu

Comments on HIV and Seniors.

The National Black Leadership Commission on Health (Black Health) fully supports our LGBTQIA senior communities. We support free HIV testing and access to care for all New Yorkers. We call on all stakeholders to get involved in conversations that promote good health, fellowship, and community engagement. We call for and support a strong and professional Community Health Workers (CHWs) network to support all New Yorkers, particularly our seniors. CHWs play a vital role in communicating personalized health information from a place of trust and empathy. It is time to empower and strengthen CHW networks.



# Testimony from Queens Community House/Queens Center for Gay Seniors In Support of Int 0623-2022

Thank you, Council Member Marte, for inviting Queens Community House (QCH), sponsor of the Queens Center for Gay Seniors (QCGS), to testify before the New York City Council Committee on Aging on behalf of proposed Int 0623-2022. Queens Community House is a not-for-profit CBO dedicated to offering social and economic opportunities for the diverse communities of Queens. With over 50 programs that range from youth and family services to adult education to older adult centers, including QCGS. QCH supports the families and communities of Queens through every stage of life.

The Queens Center for Gay Seniors is a New York City Aging funded Older Adult Center located in Jackson Heights, Queens, and it offers a diverse range of programs from a daily hot lunch and exercise, health education, arts & recreation workshops and events, to friendly visiting, referrals, and benefits & entitlements assistance in both Spanish and English. These programs are designed for and tailored to the interests and needs of LGBTQ older adults.

On this Day of Transgender Remembrance in this season of Transgender Awareness it feels particularly fitting that QCH should be submitting this testimony in support of this particular legislation. My name is Thomas Weber and I am the Multi-Site Director of Older Adult Services at QCH. In this role, I oversee the work of QCGS. Prior to my coming to QCH, I worked for 16 years at SAGE, where I was, at various times, Director of Community Services and Director of Care Management.

LGBTQ older adults remain one of the most invisible and at-risk populations among our nation's elders. LGBTQ older people are twice as likely to live alone; half as likely to be partnered; half as likely to have close relatives to call for help; and more than four times more likely to have no children to help them. As a result of these thin support networks, many LGBTQ older people have

nobody to rely on. In fact, nearly 25% of LGBTQ older adults have no one to call in case of an emergency.

LGBTQ older people are more likely to face discrimination around their sexual orientation and gender identity when accessing health care, social services or mainstream senior centers – yet they are among the most in need of care as they have few places to turn. In addition to the traditional challenges associated with aging including declining health, diminished income, and ageism, LGBTQ older adults also face invisibility, ignorance, and discrimination. This is now also compounded by the polarized political situation in this country and the fact that multiple states and locales around the nation have started proposing and passing legislation that is discriminatory and restricting of the rights of LGBTQ people, particularly transgender and gender-non-conforming people. This has put a political target on individuals in some of these communities making them less safe and more open to victimization. This has put more stress on a population and community that was already marginalized.

QCH heartily endorses this proposed legislation because I have witnessed first-hand the need for it. I have facilitated many presentations on the history and needs of LGBTQ older adults, who grew up in a time of massive discrimination and invisibility. These presentations have been to many different kinds of audiences, both locally and nationally, including senior service providers. Two things I heard frequently from providers at various times, were:

- 1. We don't have any of those people here, and
- 2. We treat everyone the same

These were dismaying responses because of course, 1) they had LGBTQ people accessing their services and they just weren't aware of them, and 2) a policy of treating everyone "the same" just doesn't work for anyone. I believe there is a need for this education on both the provider level, as well as the participant level. I recently overheard a loud conversation taking place between participants in an older adult center in which LGBTQ people were being openly derided and ridiculed as the result of someone's religious beliefs. In the mind of one of these participants, this discourse was justified under the rubric of 'free speech.' This was immediately addressed by the administrators once it was brought to their attention, but of course, made very clear to me the need for precisely the kind of education your proposed bill would put in place enabling older adult centers to be safe spaces for all individuals, including those who identify as, or are perceived as being LGBTQ.

Thank you for holding this hearing. We at Queens Community House and the Queens Center for Gay Seniors add our voices to support for Int. 0623-2022, mandating training for senior center staff and participants about LGBTQ issues of discrimination and also the resources for addressing them. Additionally, we saw recently in Gay City News that the Aging Committee of the NYC City Council is creating a Commission on LGBTQ Older Adults. We respectfully request to be included on this Commission.

Thank you.

### Testimony of Housing Works Before The New York City Council Committees on Aging, Health, and Hospitals Regarding Oversight: Older Adults Living with HIV November 17, 2023

Thank you, Chairpersons Hudson, Schulman, and Narcisse, and Committee Members, for the opportunity to testify today. My name is Valerie Reyes-Jimenez, and I am the NYC Community Organizer for Housing Works, a healing community of people living with and affected by HIV, and a 42-year long-term survivor of HIV. Founded in 1990 with a mission to end the dual crises of homelessness and AIDS, Housing Works currently provides a full range of integrated medical, behavioral health, housing, and support services for over 15,000 low-income New Yorkers annually, with a focus on the most marginalized and underserved—those facing the challenges of homelessness, HIV, mental health issues, substance use disorder, other chronic conditions, and incarceration. As you know, over half of New Yorkers living with HIV are over the age of 50, and Housing Works, like other NYC HIV service providers, work to identify and meet the unique medical, housing, and psycho-social needs of older people with HIV like me.

I came to Housing Works homeless, and at the lowest point in my life in August of 1991, and now I work full time as part of Housing Works Advocacy Department. Like many other older people with HIV, I give back to my community and society every day. I am proud to report that in the years since I lost my husband to AIDS and was diagnosed with HIV myself, I have raised two terrific kids, become a grandmother, and for the last nine years have worked full time in the Housing Works Advocacy Department.

Housing Works is deeply thankful to the Council for its consistent support implementing New York's historic plan for Ending the HIV Epidemic (EtE), and for today's focus on the unique challenges facing older adults living with and vulnerable to HIV. We support the initiatives and resolutions before you today and urge your continued support for the Council's Ending the Epidemic initiative, including opposing all proposed cuts to this initiative. This initiative helped make it possible to "bend the curve" of the New York epidemic by the end of 2019, decreasing HIV prevalence for the first time since the epidemic began. But while the most recent data shows continued overall progress, it also shows that stark and unacceptable disparities persist in HIV's impact in certain communities, including older New Yorkers.

I am a Native New Yorker as are my children and grandchild. I never expected to be pushing sixty. I never expected to see my son turn two years old, much less thirty-five. My daughter, age forty, is a NYC High School math teacher with the DOE, who once worked at our syringe exchange program, and I have a fierce, beautiful 21-year-old granddaughter, that is beyond my wildest dreams.

There are four simple steps to stopping the HIV virus. Four! Testing, Treatment, Prevention and Housing. Homelessness was, and still is, a major social driver for becoming HIV positive and not being able to receive appropriate medical treatment. Then there is the stigma associated with HIV. Everyone has an HIV status. You're either positive or negative. If you're positive, welcome! You can now get early treatment and thrive. If you're negative, congratulations! There are things you can do to remain that way, including taking PrEP and testing annually to maintain your status. HIV testing must

become routine. Until it is, HIV stigma will continue to be perpetuated. Everyone must be offered an HIV test regularly and must become part of every patients' annual blood panel.

Because, yes, older people are still human beings that are hormone driven like everyone else. We have sex. Albeit not as bendy or flexible but it happens. We at Housing Works are deeply concerned by the continuing inequities in PrEP access, and the overall lack of sexual health services for all New Yorker, including those over 50. PrEP uptake has been slow among persons of color, women, and among New Yorkers over 50. The 2021 New York State HIV/AIDS Annual Surveillance Report found that 18% of all new HIV diagnoses were among New Yorkers age 50+, and over one-third of persons concurrently diagnosed with HIV and AIDS are over age 50. Yet prevention services, testing, and education seldom reach these populations due to ageism.

Most older people with HIV that I know don't have the finances needed to retire or grow old. I certainly never planned for a future. Why should I have? I should not even be alive, but I am. I can't retire. I have to work until I die or until my body says I can't anymore. I take one pill a day for HIV which ironically enough, is the least of my problems. The other fistful of medications I take daily are for severe chronic pain, depression, anxiety, nerve damage, muscle spasms, migraines, and high cholesterol. On top of getting older and things slowly and painfully breaking down, the lipodystrophy my body has developed is one of the worst symptoms I grapple with. It's like permanently having a twenty-pound bag of rice strapped to the front of my body. As a result, my body dysphoria and self-esteem has taken a big hit.

I consider myself healthy despite increasingly these complex medical issues – many HIV related and others simply the result of aging. But I am fortunate to have a stable, affordable place to live, a loving family, work that I care passionately about, and colleagues who share and support my commitment to social justice and health equity for the thousands of New Yorkers living with HIV who struggle daily to survive and thrive in the face of homelessness or housing instability, extreme poverty, and social isolation.

I come before you today to emphasize the importance of safe, stable, and appropriate housing for older people with HIV. Housing Works is an organization that for thirty-three years, has fought for safe and stable housing for people living with HIV and AIDS and for people at-risk for HIV transmission, including those with substance use and mental health complexities. We know that housing is healthcare. Housing is the key to helping HIV-positive people live healthy, fulfilling lives, while also helping prevent the further spread of the virus. It is proven that we have not yet ended HIV/AIDS because we have not ended homelessness, a crisis rooted in structural racism and political disregard for people who are Black, Latinx and poor. The challenges posed by homelessness and housing instability, food insecurity, lack of appropriate healthcare, employment, stigma, and other factors are what make it harder for our community to access HIV testing, prevention, and care.

The most basic need for older adults living with HIV is stable housing, a safe and secure place to live. With enhanced rental assistance or support paying a mortgage, many, if not most, older adults living with HIV can live successfully in the community, maintaining their existing friendships, service relationships, medical provider relationships, and vocational involvement, whatever that might involve. Assuming they were doing a good job managing their HIV and other health issues, they are likely to be able to continue to maintain their self-care.

My own experiences and the need for housing supports are underscored by a recent research report from the Columbia University School of Public Health based on their ongoing cohort study of persons with HIV in New York. Interviews with a representative sample of with over 900 PWA age 50+ revealed that:

- 60% struggle to survive on household incomes below the poverty threshold;
- Over half report financial hardship (not enough money in the household for rent, utilities, food, out-of-pocket medical or dental care, or transportation);
- More 50% have a history of precarious housing/homelessness;
- 99% require housing assistance, and almost all have serious housing needs (are seriously rent burdened even with a voucher, do not enough money for utilities, need an accessible unit, are in unsafe living situations, and or are facing eviction); and
- 95% are diagnosed with at least one of the following non-HIV co-morbidities: cardio-vascular conditions, cancer, chronic respiratory disease, diabetes, and liver disease.

Not surprisingly, the researchers found that 70% of PWH over 50 have low physical health functioning, and almost half (46%) have low mental health functioning indicating clinically significant mental health symptoms such as depression and anxiety. Over 40% score high on a frailty index (a measure of cognition, general health status, functional independence, social support, medication use, and depressed mood), and fewer than 10% are "thriving" (based on physical and mental health functioning, and frailty).

The authors of that report stress what we know from experience at Housing Works: that older PWH require integrated care that includes regular screenings and interventions to identify and address the cumulative economic and social disadvantages that contribute to inequities in aging.

We are proud that in 2016 New York City became the first jurisdiction in the world to offer housing assistance for every homeless or unstably housed low-income person with HIV. Yet, given our extreme shortage of affordable housing and housing that enables aging in place, in NYC older people with HIV continue to find safe and appropriate places to live in the current market. We need this now to end this epidemic once and for all.

My written testimony includes more information and proposals on meeting the housing needs of older people with HIV. Please consider my voice and those of your constituents during any discussions and future budget negotiations.

Thank you for your time.

Valerie Reyes-Jimenez reyes-jimenez@housingworks.org

### Meeting the housing needs of older PWH

Older people may need supportive housing to address behavioral health issues or one or both of two other conditions. The first is medical frailty. The second, often related, is social isolation. As medical frailty sets in, people may need assistance just maintaining their apartment. Medication administration may be a need. They may well need case management as well as escort and even transportation to

appointments. On-site supportive services make all this much easier to structure and maintain, flexible to folks' changing needs.

Social isolation often accompanies aging. As one gets older, friends die away even while not having as much opportunity to form new relationships. Meanwhile, as older people become frail, they often become more physically isolated. Even simple activities like going for a walk around the block may become difficult. The lack of elevators in older apartment buildings such as we have in New York City, may leave an older person even more confined. Social engagement opportunities that are customarily made available for older people, such as senior centers, may be seen as uninviting to someone whose life has been defined by their gay sexual orientation or who has focused for years on surviving HIV. This isolation can lead to loneliness, depression, and loss of vigor. Living in community is one way to help people stay engaged and build new and enduring relationships with other people facing similar challenges.

In all these circumstances, supportive housing may be a welcome living environment. The challenge is finding or creating supportive housing that works well for people living with HIV. One option may be to move folk into existing supportive housing for people living with HIV, especially if these folk have behavioral health needs. In fact, many supportive housing facilities developed in the 1990's and early 2000's have already been converted into senior housing simply by being effective at keeping people housed. Housing Works operates two such congregate residences that we opened in the mid-1990's whose residents now average over 60 years of age. These residents in these two facilities have largely aged in place. Younger folk generally don't want to live in an "old folks' home", so they tend to relocate pretty quickly, while people who are older tend to welcome such a placement.

In addition to these two facilities, Housing Works is developing a mixed housing facility at 802 9<sup>th</sup> Avenue (between 53<sup>rd</sup> and 54<sup>th</sup> Streets) in the Hell's Kitchen neighborhood of Manhattan. This building will have a total of 112 apartments. Of these, 59 units will be supportive housing for long-term survivors of HIV, defined as living with HIV for 20 or more years. We anticipate that these will overwhelmingly be older adults, or families that include older family members, based on the requirement to demonstrate the need for supportive services as well as living with HIV for a long period of time. Another eight units will be for people who are leaving the New York City shelter system, and 44 units will be for families who qualify as low income but in which the adults are employed and making up to \$120,000 or more per year per household.

All supportive units will be fully furnished and include full kitchens and bathrooms with there being a mixture of studio, 1- and 2-bedroom units. The low-income units will also come with full kitchens and bathrooms and be a mixture of 2- and 3-bedroom units. All residents will have access to an array of building amenities which include a garden terrace, community room, laundry, bike storage and fitness center. All utilities will be included for the supportive units. Onsite case management will be provided to all supportive residents.

The building will also offer commercial space, with a portion of the building being designed for MTA offices with plans to fill the remaining commercial space with a grocery store as well as a flagship Housing Works Branded Store (like a Thrift Shop)! We have a pre-development loan for this project that will be paid off at the closing with permanent financing. In other words, this project is being funded through the standard channels for low-income housing as opposed to capital funding that targets people living with HIV such as HOPWA.

Another option for housing older people living with HIV is housing that is built with funds from the HUD Section 202 Supportive Housing for the Elderly Program. Through this program, HUD provides capital advances to finance the construction, rehabilitation, or acquisition with or without rehabilitation of structures that will serve as supportive housing for very low-income elderly persons, including the frail elderly, and provides rent subsidies for the projects to help make them affordable.

The Section 202 program helps expand the supply of affordable housing with supportive services for the elderly. It provides very low-income elderly with options that allow them to live independently but in an environment that provides support activities such as cleaning, cooking, and transportation.

HUD provides interest-free capital advances to private, nonprofit sponsors to finance the development of supportive housing for the elderly. The capital advance does not have to be repaid as long as the project serves very low-income elderly people for 40 years. Project rental assistance funds are provided to cover the difference between the HUD-approved operating cost for the project and the tenants' contribution towards rent. Project rental assistance contracts are approved initially for 3 years and are renewable based on the availability of funds.

Occupancy in Section 202 housing is open to any very low-income household comprised of at least one person who is at least 62 years old at the time of initial occupancy. Several organizations have used Section 202 to develop housing that markets to older members of the LGBT community. While they cannot legally prefer members of the queer community, openly marketing to that community often serves as a deterrent to heterosexual folk, making the resident composition almost exclusively LGBT. Some of these facilities already include set-asides for homeless people. There is no apparent reason why the same set-asides could not be made for older people living with HIV.

In New York, SAGE operates two such programs, Stonewall House in Brooklyn, and Crotona Senior Residences in the Bronx. SAGE has created senior centers on the ground floor of both facilities, making a welcoming space for older LGBT adults who live in near-by neighborhoods. Here are similar residences now operating in California and other parts of the country. Generally, sponsors of this kind of housing have assumed that, with other funding available, housing is not a need for older people living with HIV and have made no plan to recruit or accommodate people with HIV in their residences. But this an approach we can change through education.

The bottom line is that older adults, like other people living with HIV most often just need safe secure housing with a rent or mortgage burden they can afford. We are not going to be able to meet their needs without meeting the needs of thousands of other people living with HIV who also lack permanent housing.

Clearly, there are some older people living with HIV who need supportive housing or would function better in a congregate setting. HOPWA and Continuum of Care dollars could both support this, especially if combined to maximize funding. However, Section 202 Supportive Housing for the Elderly is probably the best long-term source of funds whether folding people living with HIV into LGBT-oriented housing or developing housing for elderly people that markets to older people living with HIV.



Testimony to the New York City Council Committee on Aging Regarding Resolution 791 13 November 2023 Submitted by Katy Bordonaro, Corresponding Secretary

Thank you for convening this hearing on Resolution 0791. A resolution calling on the New York State Legislature to pass, and the Governor to sign, S 2960/A 5741, to provide for annual adjustment of the maximum income threshold eligibility for the Senior Citizen Rent Increase Exemption (SCRIE), Disability Rent Increase Exemption (DRIE), Senior Citizen Homeowners' Exemption (SCHE), and Disabled Homeowners' Exemption (DHE) by any increase in the Consumer Price Index.

The Mitchell-Lama Residents Coalition (MLRC) has supported the passage of this legislation at the state level for many years. We are very grateful that Councilmember Gale Brewer has introduced this resolution in order to communicate to the State Legislature and Governor the importance of providing for annual increases in the maximum income threshold eligibility for the above exemptions. Many of the residents of Mitchell-Lama developments are senior citizens, some are disabled. These groups need the protection from rent increases that these exemptions provide.

The importance of this annual cap increase has been shown in the last few years when inflation has driven up so many prices. MLRC is hearing of annual increases in rent and maintenance of 9%. The groups covered by these exemptions are on fixed incomes which are already stretched thin by the rising cost of food and other necessities. The income cap was last raised to \$50,000 in 2014. In today's dollars \$50,000 is closer to \$69,000. If this legislation had been in place then the cap would have risen accordingly. Instead the cap has been stuck as prices have increased and those on fixed incomes are finding it harder and harder to make ends meet.

Providing for annual increases in the income threshold eligibility is the first step in allowing more of our residents to stay in their homes.

Founded in 1972, the Mitchell-Lama Residents Coalition has as its mission to work and organize for the preservation and future expansion of the Mitchell-Lama housing program (both co-op and rental), as well as, all other affordable housing programs and to identify, clarify, and solve common concerns of current and former Mitchell-Lama residents working with elected officials and government agencies at all levels.

We are the only Mitchell-Lama group representing both Co-ops and Rental buildings statewide. Over the years, we have worked with the federal department of Housing and Urban Development (HUD); New York State Department of Housing and Community Renewal (DHCR); and New York City Department of Housing Preservation and Development (HPD) as well as local advocacy groups.

# **Mitchell-Lama United**

The Brooklyn Mitchell-Lama Task Force, Cooperators United for Mitchell-Lama, and the Mitchell-Lama Residents Coalition, working together to protect, preserve, and build more ML cooperatives and rentals

# TESTIMONY TO THE NEW YORK CITY COUNCIL COMMITTEE ON AGING ON RESOLUTION 0791 NOVEMBER 17, 2023

This testimony is being submitted on behalf of Mitchell-Lama United, which is a legislative advocacy coalition of the Brooklyn Mitchell-Lama Task Force, Cooperators United for Mitchell-Lama, and the Mitchell-Lama Residents Coalition. Our members comprise residents of Mitchell-Lama cooperatives and rental apartments, and we strongly support City Council Resolution 0971, which calls on the New York State Legislature to pass, and the Governor to sign, S.2960/A.5741, that will provide annual adjustments to the maximum income eligibility by any increase in the Consumer Price Index for recipients of the various exemption benefits for renters and homeowners: the Senior Citizen Rent Increase Exemption (SCRIE), Disability Rent Increase Exemption (DRIE), Senior Citizen Homeowners' Exemption (SCHE), and Disabled Homeowners' Exemption (DHE).

A significant proportion of those living in Mitchell-Lama developments are eligible for these exemptions due to their age and/or disability, and are faced with increasing costs of living (food, housing, clothing, medical expenses to name a few) while receiving fixed incomes. Therefore, any income-based requirement that is continually consistent with Consumer Price Index increases would provide much-needed relief to this population, as well as a sense of security from staying in their homes where many of them have lived for many years.

As Mitchell-Lama United has worked with the State Legislature and delivered presentations to the City Council and Borough Boards advocating for the protection and preservation of our deeply affordable housing program, we also extend our support for this resolution to protect the residents living in these highly desirable developments.

Respectfully submitted by Warren Harding,

Steering Committee Chair of Mitchell-Lama United

# Older & Elderly HIV+ are NOT Getting their Care Needs Met in NYC Despite Millions in Funding

Hello

My name is Jules Levin.

I am the Executive Director & founder of NATAP (National AIDS Treatment Advocacy Project). Founded by me in 1996, and now the largest HIV organization in terms of how many people we reach. Our website at <u>www.natap.org</u> is the leader in HIV in traffic with 3 million monthly hits.

I am 74 years old and have had HIV for almost 40 years. The problem I am here to discuss is the inadequate HIV are older & elderly PWH (people with HIV) are receiving at the NYC Ryan White major hospital & other clinics. There is a serious well known problem around Aging & HIV that everyone is aware of but the HIV patient needs fir this group are ignored.

The population of people with HIV is quickly aging, as everyone knows: with nationally 50% over 50 years old & 250,000 over 60 years old; in NYC 60% are over 50 but 32% are over 60. Nationally it's expected that by 2030 75% will be over 50 & 40-50% over 60, and in NYC 60% will be over 60 by 2030.

Our HIV care system is unprepared for the epidemiologic current surge in aging & certainly even more unprepared for the greater surge expected.

I get my HIV care at the largest Ryan White Clinic system in NYC where care is horrible for aging & elderly PWH. WHY ? Because there are no geriatric screenings & care, despite that they are recommended by NYS Clinical Guidelines as well as the IAS-USA Guidelines and other guidelines. Plus, the care at large hospital based Ryan White Clinics is beset by a system unable to meet many of our needs for the aging & elderly: communication with you doctor or clinic is extremely difficult - the portals are patient unfriendly & make communications impossible with doctors - often don't answer questions in a timely way, or don't answer questions at all; there is a "telephone tree" where you cannot get through to doctors anymore. The hospitals "abuse" the doctors, making them fit in more patients than they can handle & give good care & attention.

Everyone knows the data & research that Aging & elderly PWH have premature onset of comorbidities compared to the general population & have these comorbidities at higher rates including heart disease, cancosteoporosis & fractures, chronic kidney disease, peripheral artery disease & physical & mental impairments for wgich mental & physical services & care are very difficult if not impossible to secure & keep. HIV doctors & the care system is so unduely restricted – there is not enough time to adequately discuss all one's conditions with your doctor; the visits are often 15-20 minutes; the doctors are unable to knowledgeably discuss those comorbid conditions; and o course they don't have the time to discuss hem often they simply dismiss your concerns around these conditions – only viral suppression seems to be ther concern.

The problem appears to be "bottom line", the 20 minute visit ad all other systems are designed simply to meet the clinic or hospital bottom line. The health priorities of older & elderly PWH are deprioritized or ignored. These Guidelines aforementioned include recommendations for all

PWH over 50 years old to receive bone mineral density testing for osteoporosis; frailty screening for frailty; cognitive function screening, as well as vision, hearing & balance.

With the fast aging HIV population the system is simply not meeting the needs of our aging & elderly population and unnecessary heart attacks, fractures, and physical & mental disability, and deaths are a result of this. I call for a reorganization of the HI care system in NYC & particularly Ryan white fnded HIV clinics to assure that the aging & elderly get the care they need & deserve.

Jules Levin Executive Director, NATAP NYC



Eugenia L Siegler, MD Mason Adams Professor of Geriatric Medicine Professor of Clinical Medicine

November 27, 2023

Re: Testimony for the 11/17 Committee on Aging Oversight Hearing on HIV and Aging

To the Committee members:

I am a geriatrician on the faculty of Weill Cornell Medicine, and I have a special interest in HIV and Aging.

I was a resident in internal medicine at Bellevue in the mid 1980s, when often a quarter of the inpatient medical service were people with AIDS; afterwards, I pursued a career in geriatrics, and had little experience in HIV care until about 10 years ago, when one of my colleagues from infectious diseases gave a lecture on the changing demographics of HIV. Since that time, I have provided geriatric consultation for older people with HIV and have developed a scholarly interest in care for people aging with HIV and other long-term survivors.

I have been working with members of the NYS AIDS institute and with people with lived experience, and I am the lead author on the AI Clinical Guidelines Program's <u>Guidance Addressing the Needs</u> of <u>Older Patients with HIV</u>. I am one of the co-chairs of a joint consumer and clinician subcommittee on aging, long-term survivors and perinatally diagnosed people with HIV, and we recently published the <u>results</u> of our statewide survey – a survey that has led to a successful pilot of a simple <u>tool</u> (based on the <u>WHO ICOPE</u> model) to screen people with HIV for functional deficits and that offers ideas for other quality improvement projects.

At the <u>city</u>, <u>state</u>, and <u>national</u> level, funding has been made available to pilot innovative programs for people aging with HIV. But everyone deserves high quality care. Not just those who go to university-based clinics, not just those who are living independently in the community and who can advocate for themselves. In addiditon, even as we catch up to provide adequate clinical care, we must prepare for long term care needs. I encourage City Council to:

- 1) Recognize that higher rates of frailty and multimorbidity in people with HIV necessitate reimbursement for longer clinic visits and increased care coordination;
- 2) Fund increased mental health services and cognitive assistance programs for older people with HIV;
- 3) Create incentives for <u>older adult centers</u> to partner with HIV programs and provide exercise, socialization, nutrition, and other services for older people with HIV in a safe environment;
- Enable <u>Special Needs Plans</u> to create capitated models of care focused on the needs of older adults with HIV – especially people between 50 and 65, by improving opportunities to socialize, exercise, and learn;
- 5) Ensure that long term care services are a) available at all levels home, assisted living and

Weill Cornell Medicine| 525 E. 68<sup>th</sup> Street, Box 39, New York, NY 10065 | T. 212.746.1729 | E. <u>els2006@med.cornell.edu</u> Center on Aging | T. 212.746.7000 nursing home; b) providing state-of-the-art care (e.g., it is essential that skilled nursing facilities continue antiretroviral therapy – <u>many do not</u>); and c) free of stigma. No one should have to hide who they are just because they need help.

I am grateful that you are addressing this essential topic. Please feel free to reach out to me if you have any further questions.

Sincerely,

Eugenia L. Siegler, MD



## <u>Testimony to the Joint Oversight Hearing on Older Adults Living with HIV, New York City Council, November</u> <u>17th, 2023</u>

For 20 years, VOCAL-NY has been engaged in grassroots organizing to end the war on drugs and overdose crisis, mass incarceration, the HIV/AIDS pandemic, and the homelessness crisis. **VOCAL-NY's Positive Leaders Union** is dedicated to ending the HIV/AIDS epidemic in New York State and beyond by guaranteeing access to housing for People Living with HIV/AIDS (PLWHAs), strengthening medical care and support services, and a guarantee for our elders to age with dignity.

Today, we submit written testimony for our membership on the need to improve and create an infrastructure of care and compassion for Older Adults Living with HIV. In 1999, our organization was founded as the **New York City Aids Housing Network** by **Joe Bostic** and **Joe Capestany**, two black men living with HIV committed to ending the epidemic and homelessness. Unfortunately, our founders did not live past 2004, with both Joes not living past 52 years old. Still, their visions for building a movement of low-income people fighting for systemic change rooted in justice, compassion, and love define our work today.

As reported by <u>Gilead</u> and others, by 2030, up to 70% of people living with HIV will be over 50 in the United States. We're still reeling from the families and friends we lost from the beginning of the HIV epidemic and must continue to honor them by fighting for those that have survived. New York City must rapidly invest and create an infrastructure of care and compassion that addresses the challenges people living with HIV will face.

As such, New York City, alongside all levels of government, must invest in the following:

- 1. Enact the following recommendations from **The Marsha & Sylvia Plan** put forth by NYC Council's LGBTQIA+ Caucus:
  - a. **Expand NYC Aging's Outreach to LGBTQIA+ and HIV-affected older adults** to guarantee that older adults are aware, connected, and provided with city resources.
  - b. **Mandating HIV competency training for older adult service providers** on the best ways to provide care and support for older adults living with HIV by easing barriers like stigma and insensitive or unrelatable language, among others.
  - c. **Increasing HIV Testing Rates among older adults** by improving free sexual health and wellness programming at older adults centers alongside testing.
  - d. Housing is health care and provides much-needed stability and better health outcomes; thus, the city must **Build more LGBTQIA+-specific & set-aside housing for HIV-affected older adults.**
- 2. The HIV/AIDS Service Administration (HASA) is a crucial life-saving program that helps eligible clients living with HIV/AIDS with individualized service plans by connecting them with vital public assistance benefits. To fully support the housing, nutritional, transportation, and care coordination needed by older adults living with HIV, we have to **make HASA More Effective and Recipient-Oriented** by:
  - a. **Strengthening the HASA Advisory Board:** Int. No. 0419 (Richardson-Jordan): Presently, the chairperson of the HASA advisory board is the only one with the power to call a meeting. The legislation, once enacted, will allow the majority of the HASA advisory board to call for a meeting and requires the NYC Human Resources Administration (HRA) Commissioner to consult the advisory board before updating the policy and procedures manual and the client bill of rights. Lastly, the client's bill of rights will be provided to HASA recipients upon their first meeting with a caseworker and annually or upon any revision.
  - b. **Shifting Caseworker and Recipient Interactions:** Often, HASA recipients interact with caseworkers who aren't understanding and/or empathetic to recipients' lived and current

experiences. Training alone is insufficient in correcting this issue. The City must revamp the grievance process to include complaint tracking and recipient inclusion in resolving the grievance.

- c. **Hiring Recipients as Caseworkers:** With New York City experiencing historic staff vacancies across governmental agencies, the City must establish a recipient-to-caseworker pipeline to help shift recipients' interactions with HASA. A recipient-centered approach is led by recipients supporting fellow recipients in accessing and maintaining vital services offered by HASA and the city overall.
- d. **Establish a HASA Recipient Advisory Board:** The HASA Advisory Board comprises members appointed by the Mayor and the Council who advise and recommend changes to the policies and procedures for overseeing and monitoring the delivery of services that HASA is supposed to provide to its recipients. Establishing a recipient advisory board is crucial in creating space and opportunities for everyday recipients to share their experiences with HASA and provide recommendations to the HASA Advisory board and HASA itself on improvements to the agency.
- e. **Removing barriers to permanent housing:** A significant barrier to securing housing that voucher holders face is source of income discrimination; thus, the City must commit to restaffing the City Commission on Human Rights to pre-pandemic levels if it hopes to guarantee housing for all voucher holders.
- f. **Ensuring the ongoing quality and health of housing placements:** The City must support HASA recipients in their housing search and ensure that housing placements are free of hazardous code violations. Through interaction with HASA, recipients are already in communication with the city, and a recipient's housing complaint to a case worker should initiate the same response as a 311 call. HASA must work alongside Housing Preservation Development, the Department of Health and Mental Hygiene, and the Department of Buildings in proactively addressing code violations in private market apartments instead of recommending clients call 311.
- g. **A Guarantee to Dignified Supportive Housing:** Supportive housing is a crucial and essential life-saving model that all levels of government must heavily invest in to create more units and support existing ones. HASA recipients and other supportive housing tenants should be guaranteed supportive housing placements free from threats of eviction, access to quality onsite care, and dignified living conditions.
- h. A Homes Guarantee for Older Adults Living with HIV: Housing has always been and will continue to be a crucial life-saving tool in the fight against the epidemic. As more New Yorkers living with HIV/AIDS live past 50, NYC must prioritize housing placements via set-aside and/or build specific housing for HIV-affected older adults.
- i. Access to Wifi and Technology for Telehealth Services: Within the last couple of years, medical care and agencies at all levels of government have shifted their services online. Given this new reality, the City must provide HASA recipients with free Wifi and essential technological equipment to ensure access to quality medical care and other services. HASA recipients must be included in the telemedicine accessibility plan as defined in Local Law 59 of 2023.
- 3. Calling on our State Partners to **Fully Ending Homelessness for all New Yorkers Living with HIV** by:

a. **Rest of State AIDS Housing** <u>S.183</u>/<u>A.2418</u>: Via the HASA program, eligible PLWHAs receive support with a 30% rent cap and the other benefits outlined above. Unfortunately, PLWHAs living outside of New York City are not provided with this infrastructure of care that's proven to save lives and reduce transmission rates. Passing S.183/A.2418 will ensure that all PLWHAs, regardless of zip code, will be supported with a 30% rent cap, intensive case management, public assistance benefits, and robust care coordination.

### 4. Creating an Infrastructure of Preventative & AfterCare by:

a. VOCAL-NY fully supports the legislative package discussed at the November 17th Hearing and hopes that Speaker Adams, Council Members Crystal Hudson, Lynn Schulman, Mercedes Narcisse, and the bill sponsors pass these vital pieces of legislation before the end of the year.

Thank you for organizing this vital hearing, and we look forward to the investments made by the New York City Council that will allow our elders living with HIV to live long and dignified lives.

For More Information Contact: Adolfo Abreu Housing Campaigns Director adolfo@vocal-ny.org Good morning, my name is Dr. Antonio Urbina. I am a Professor of Medicine at the Icahn School of Medicine at Mount Sinai and have over 30 years of experience treating patients with HIV. I currently serve as Medical Director for the HIV and Primary Care Center of Excellence of the Clinical Education Initiative of the New York State Department of Health AIDS Institute.

Early in my career, I treated patients with severe opportunistic infections at the height of the HIV epidemic at St. Vincent's Hospital. I was at the forefront of applying cutting edge antiretroviral therapies from clinical trials to save lives. From 2007-2009, I served on the Presidential Advisory Council on HIV/AIDS advising the White House. And from 2014-2015, I served on Governor Cuomo's Task Force to end the AIDS epidemic in New York.

With this background, I am here today to speak about the important issue of HIV and aging. As someone who has dedicated his career to HIV care and treatment, I understand the unique challenges facing older adults living with HIV

While great progress has been made in HIV treatment and care, more needs to be done to support this vulnerable population. As people with HIV live longer, they are experiencing higher rates of comorbidities, social isolation, mental health issues, and financial insecurity.

The city must take action to address these needs through expanded services and programs tailored to older adults with HIV. I urge the Council to make this a priority by creating and funding a new City Council Initiative on HIV and Aging in the FY25 budget.

This initiative would provide vital resources to two types of organizations that serve people aging with HIV: medical organizations and community-based organizations. The funding could support services offered by both types of organizations, including case management, mental health services, self-management programs, skills training, peer support groups, support group programs, and importantly exercise and physical therapy programs. Providing resources to medical organizations and community groups would improve health outcomes and quality of life for individuals aging with HIV.

Investing in the social and medical needs of those aging with HIV is both a moral imperative and wise long-term strategy. With a dedicated City Council Initiative on HIV and Aging, New York can lead the way in caring for this important yet often overlooked group.

The time is now to make a change. I applaud the Council for holding this hearing and urge you to take the next step by establishing and funding a new initiative to address HIV and aging. Together we can ensure older New Yorkers with HIV live healthier, more empowered lives.

Thank you for your time and consideration. I am happy to answer any questions.

# Testimony in Support of New York City Council Resolution 0791 Diane F. Stein

I live in Independence Plaza, a former Mitchell-Lama rental whose eligible tenants have only recently been able to apply for SCRIE and DRIE. I would like to urge the City Council to support Resolution 0791, Council Member Brewer's resolution telling the New York State legislature that New York City supports NYS S2960/A5741 which will automatically raise the cap for SCRIE/DRIE and SCHE/DHI by the Consumer Price Index on an annual basis. The Mitchell-Lama community has been urging this change, among others, for many years.

On July 1, 2014, the maximum income threshold increased from \$29,000 to \$50,000 per household. The proposed legislation would allow increases to occur automatically. It would also prevent seniors and disabled people from losing their eligibility if their Social Security annual cost-of-living increase pushed them a few dollars over the limit.

New York City is losing its housing affordability. Independence Plaza is a case in point. We need to help seniors and disabled people to be able to remain in the communities they helped build and have put down roots. I hope the City Council will support this resolution.

1	
2	New York City Council
3	HIV and Aging
4	November 17, 2023
5	
6	Jan Carl Park
7	Testimony
8	·
9	Good Morning.
10	
11	My name is Jan Carl Park.
12	
13	I come before you today to share my experiences as a seventy-six year old man
14	living with HIV.
15	
16	Yes I am an elder, a senior, some would say a sage, but in all honestly I never
17	thought I live beyond 40.
18	
19	I moved to New York City in the fall of 1979.
20	
21	All shiny and new, fresh from graduate school, ready to begin a career as a
22	journalist.
23	<b>TT71 '1 1' 11' 1</b> , , , , , <b>1' 1 , T 1</b> , 1
24	While working odd jobs, to get a start in the industry, I volunteered as a
25	reporter at a small gay newspaper, the New York Native.
26	Within moder of mer aminal the Native reported on a meretarious illuser among
27	Within weeks of my arrival the <i>Native</i> reported on a mysterious illness among gay men as death reports filtered in.
28 29	gay men as death reports intered in.
29 30	How to write an obituary became a challenge, many friends and families
31	wanted no mention of the cause of death.
32	wanted no mention of the cause of death.
33	While covering a story I met a male nurse who worked at St. Vincent Hospital
34	in Greenwich Village.
35	
36	He talked about young gay men dying from streptococcus pneumoniae, covered
37	with Kaposi sarcoma lesions, overcome by fevers and headaches caused
38	cryptococcosis meningitis.
39	51 0
40	He said the hospital's beds were full, people were on laying on gurneys in the
41	hallways, some were dying in the emergency room even before they had a
42	chance to see a doctor.
43	
44	The illness soon had a name, GRID, Gay Related Immune Deficiency.
45	
46	GRID was renamed HIV in 1983.

- HIV was infecting gays and straights, African Americans as well as whites, Asians as well as Latinos and Hispanics, women as well as men. Stigma became HIV's cousin. It took years to develop a blood test to detect HIV – it would take weeks to find out the results. Then a treatment for HIV AZT was developed – a handful of pills, taken throughout the day and night, offered limited but ineffective hope. Without health insurance I joined a study of gay men and STDs at Columbia University. Every six months I would have my blood drawn and talk with a medical provider who offered the most basic medical care if needed. As part of that study researchers sent our blood samples to France, one of the first countries to offer HIV testing. I became one of the first one-hundred New Yorkers to be tested for HIV. My results came back positive. My life changed, in the days, months and years that followed, I witnessed first-hand the stigma and discrimination of being HIV positive. Although experiencing no symptoms myself I could not say that of my friends. I buried over eighty of them. My first lover, Art Allison, a psychotherapist. My best friend, David Feinberg, a writer. My roommate, Donald O'Leary, an actor. My doctor, my dentist, my therapist. The memories of these tragic deaths, like those I recall of the Vietnam War, will in my old age remain with me forever. I entered government service in January 1987 an openly gay man living with HIV determined to work within the system to create change.

I soon found myself working at City Hall addressing the growing anger over the 92 93 government's lack of response to the HIV epidemic. 94 95 I served during the Koch and Dinkins administrations from 1989 to 1994 in 96 the Office of LGBTQI Constituency Services at City Hall. 97 98 AIDS activist shouted me down in public meetings, I was called a collaborator, 99 but I knew I had the ear of the Mayor and worked from within to pressure the 100 government to respond. 101 102 From 1994-1996 I served during the Giuliani administration in the Office of AIDS Policy Coordination at City Hall. 103 104 105 Expanding services for people living with HIV and AIDS became far more difficult in an administration that paid lip service to helping those with HIV and 106 107 AIDS. 108 109 I took a break from government service moving to Cambridge to earn a Masters Degree in Public Administration, specializing in Public Health Policy, from the 110 Kennedy School of Government at Harvard University. 111 112 113 Following my time at the Kennedy School I worked as a constituency representative at the National Association for People Living with AIDS in 114 Washington, D.C., traveling across the country studying the nation's largest 115 116 cities response to the AIDS crisis. 117 I returned to government service in 2000 serving in the Bloomberg 118 administration as the Co-Chair of the NY EMA HIV Planning Council at the 119 120 Department of Health & Mental Hygiene. 121 122 I retired on World AIDS Day, December 1st, 2019. 123 124 Today I am but one of 40,984 men, women and transgender New York City 125 residents over the age of 60 living with HIV as of December 31st, 2021. 126 127 I don't consider myself an AIDS expert just someone who is an expert in living 128 with HIV for the past thirty-eight years -- or half of my life. 129 130 As reported in the NYC DOHMH HIV Surveillance Annual Report for 2021, as of 131 December 31, 2021 there were 40,984 (31.6%) people over 60 living with HIV. 132 133 During that same reporting period 1,121 (51.5%) people over 60 died of AIDS related conditions. 134 135

- 136 I believe one of the biggest challenges to elders living with HIV and also living
- on fixed incomes are the costs of health insurance coverage and prescriptiondrug coverage.
- 139
- All New Yorkers, regardless of age, living with HIV with incomes below \$72,900dollars qualify for New York State AIDS Drug Assistance Program (ADAP).
- 142
- ADAP pays for both insurance premiums and pharmaceuticals.
- For New Yorkers living with HIV earning over \$72,900 there is no assistancewith the cost they incur with insurance premiums and pharmaceuticals.
- 146 147
- I earn just over that amount when my social security and pension paymentsare combined.
- 150
- 151 By the fifth month of each year I enter what is known in insurance jargon as
- 152 catastrophic coverage which requires me to pay 5% of the retail cost of
- 153 prescription drugs in the highest tier categories.
- 154
- Along with my monthly health insurance co-payments, I find myself paying
  \$1,234.97 a month in prescription costs fully 34% of my monthly pension.
- How many retirees who have worked 20, 30, 40 years, contributing to a
- 159 pension and social security, are blindsided by the sudden expenses incurred
- 160 when reaching catastrophic coverage definitions of their health insurance and
- 161 prescription plans is a question unanswered.
- 162
- 163 Today there are over 350,000 active members and retirees of the NYC
- 164 Employees' Retirement System.
- 165
- 166 A dozen health insurance plans for retirees are made available to them by the
- 167 Office of Labor Relations Health Benefits Program all with catastrophic168 coverage limitations.
- 169
- For those facing retirement choosing a health insurance and prescription drugplan that is affordable and can accommodate chronic conditions becomes an
- 172 onerous challenge for those unfamiliar with how these plans work.
- 173
- 174 Much good could come from a City Council review, assessment and adjustment 175 of catastrophic coverage limitations that are part of health insurance plans, not 176 only offered to City retirees but to all New Yorkers over 60+ years.
- 177
- Thank you again for offering me this opportunity to address is challengingtopic.
- 179 top 180
- 181

Testimony in Favor of Local Law Int. No. 620

Dear Council Members,

My name is Jonathan Martinez, and I am a student at CUNY School of Public Health and Health Policy, as well as a worker at NYU Langone. I am writing to express my strong support for Int. No. 620, a local law aimed at amending the administrative code of the City of New York. This law focuses on several critical aspects of public health, particularly regarding monkeypox (mpox) education and prevention efforts and the establishment of an infectious disease vaccine scheduling portal.

Int. No. 620 addresses the pressing issue of mpox, particularly the recent mpox outbreak and the associated state of emergency declared by Mayor in Emergency Executive Order Number 158 on August 1, 2022. This law establishes a framework to ensure that the Department of Health and Mental Hygiene is well-prepared to respond effectively to such public health crises, while actively addressing health inequities and issues related to homophobia, transphobia, and racism in healthcare.

The provisions of this local law are designed to benefit New York City in several keyways:

Improved Preparedness: By mandating that the Department of Health and Mental Hygiene develops a mpox response plan, this law ensures that the city is better prepared to address future outbreaks of infectious diseases promptly and efficiently. Importantly, it integrates strategies to combat health inequities, homophobia, transphobia, and racism in healthcare.

Community Education: The law emphasizes the importance of public education and outreach to inform the public about mpox, how it is transmitted, how to prevent infection and its spread, and how to obtain vaccination and treatment. This will empower individuals to protect themselves and their communities, addressing health disparities.

Accessibility to Vaccines: The law places a strong emphasis on equitable vaccine access, particularly for communities most at risk of contracting mpox. It ensures that those who may have limited access to healthcare facilities are not left behind in vaccination efforts, actively addressing health disparities.

Moreover, a recent <u>article</u> highlights the importance of continued vaccination efforts. While the number of mpox cases has dropped significantly in the U.S., the virus remains a concern, and there are cases reported daily. The article underscores the importance of mpox vaccination, especially for high-risk groups, including LGBTQ+. The data emphasizes the importance of sustained efforts to combat mpox and to encourage vaccination, ensuring that the virus does not resurge.

In conclusion, Int. No. 620 is a comprehensive and forward-thinking piece of legislation that addresses pressing public health concerns, promotes health equity, and lays the groundwork for a more responsive and equitable healthcare system in New York City. I urge you to support and pass this law for the benefit of the city's residents and their overall well-being.

Thank you for your time and dedication to the health and safety of our city.

Sincerely,

Jonathan Marinez



# Testimony from Lillibeth Gonzales for T2023-3558 Oversight - Older Adults Living with HIV November 17, 2023

Hello,

Thank you, Chair Schulman, Chair Hudson, and committee members, for the opportunity to testify. My name is Lillibeth Gonzalez, I am a 68-year-old woman who has lived with AIDS for 31 years. I also work at GMHC's HIV and Aging program.

I have already lived past my so-called expiration date, and I have faced many physical and mental challenges. We in the HIV and aging population just want to be able to live long and healthy lives. But more support is needed to ensure we can do so.

New York City must do a better job meeting the needs of older people living with HIV and AIDS by expanding access to vital services like affordable healthcare, food security, accessible housing and long-term care facilities, and mental health and substance use counseling.

Two of the most pressing needs are housing and food security. Without them, it's impossible to care for ourselves, access healthcare services, and maintain treatment.

Support groups and connection to other community members, as well as technology such as laptops, iPads, and smart phones, are also necessary to combat social isolation and depression, as well as to participate in virtual programs and telemedicine. Seeing this need, I created and facilitate a support group at GMHC called Thriving at 50 and Beyond, which is for people over age 50 living with HIV. We need more funding for programs like this across the city in safe spaces that we can call "home."

Another major issue that I and others have experienced is that society does not often think about older people with HIV. This hearing is a good step, but we must consistently be part of the conversation to inform elected officials and community leaders about developing more solutions. These solutions include increasing HIV testing for older adults, requiring training on the topic of HIV and aging for medical and social service providers, and advocating **with** us to ensure we can access the medical treatments we need to thrive.

Thank you again for the opportunity to testify. I look forward to more discussions.

Written Testimony to the NYC Council Committee on Aging Jointly with the Committee on Health Oversight Hearing on Older Adults Living with HIV June 29, 2023 Written by Marc Cail

> <u>Student Loan Pause Is Ending, With Consequences for Economy</u> <u>Three years of relief from payments on \$1.6 trillion in student debt allowed for</u> <u>other borrowing and spending — and will shift into reverse.</u>

This article is in today's New York Times, June 21, 2023. I had spoken about this very subject, a few days back, with my husband. I told him that I felt bad for people who must pay back their loans. I mentioned that it's nice when people in authority take the time to view a subject, carefully, and demonstrate sensitive understanding to what's truly behind a situation and then offer, in an equally sensitive manner, to <u>rectify a societal wrong</u>.

People who are young and, mostly, able bodied and took out the loans with informed knowledge of having to pay them back, I thought. That's *magnanimous*.

My husband pauses and shares, "Yeah. Not like us."

My husband, Frank, and I have been married for 10 years. A legal marriage where before, gay men, weren't allowed to be <u>married</u>. And before that, <u>weren't even allowed to be gay</u>.

I asked Frank what he meant, and the wisdom of his 76 years beamed bright. "Most with student loans are young, or younger, have their good health, and have capacities to find and keep jobs. And for decades." He thought that it was nice that government is thinking of lending a helping hand to this specific group.

He continued with me and explained about being gay and shared that it is still tough in some places to find work, to keep it, and to be liked in the workplace, much less to advance. I, myself, can think of many men my age, born in the 1960s and before, who did not do as well as, say, their other family members did in similar workplaces. <u>The workplace for men our age and older was not a safe space for many. Yes, I've been fired for being gay</u>. Or, maybe, for even talking about it...

And this has had a thousand little, yet brittle and real, consequences.... Another truth is just being gay in the 1970s and until today. Gay men, older gay men today, have had to face <u>rough and negative journeys</u> in many life aspects. The workplace. Education. Jobs. Careers. Money. Opportunity. Families. Friends. Colleagues. Neighborhoods. <u>Life.</u>

Again, this too has had a thousand little, brittle, and real consequences....

I, and my husband, are all we have for each other. Neither of us have had children; our family relationships are strained (at best) yet courteous. We've found out many times – many times – that financially, emotionally, and otherwise that there is no help. Others – heterosexuals – who were able to marry, had blessings from employers, family, religion, neighbors – neighborhoods! – and their education, jobs, advancement did (and still do) much better than us – the LGBTQIA+ community – as minorities do often lag badly behind those who are *exalted* by society and others.

Gay men, I can speak about that, are not exalted. It's been a rough road and the literature backs that up, in abundance. Drug use, disparate medical treatment, discrimination in housing, employment, education. Over time, it adds up, badly, and makes facing old age, daunting, and frightening for so many of us.

That in itself would be enough – "just" to be gay in an, at times, very hostile and unforgiving society's culture. That our society would eventually see the need to help marginalized groups that had had a very rough journey, only because of who and what they are. And much like the good sense seen today by leaders of our city and country, a clear and conscious shift is taking place to assist and aid <u>minorities for the past wrongs of that society</u>, reparations for some for example, comes to mind, this too must be considered for the LGBTQIA+ targeted minority. And it must be considered in its full extent and with clear vision; we cannot be squeamish of the horrors endured by our elders, our people, our chosen family.

Oh. Yes. And now add HIV and AIDS to the picture. Was it not "bad enough" for us to deal with society as members of a hated minority? <u>I cannot adequately give voice to the evisceration</u> of a person on all levels when given an HIV diagnosis at a time when there was no hope at all. <u>Utter desperation</u>. It defies description using today's language. No surprise why then so many friends and others killed themselves upon getting their HIV results. It was too much.

# The 1980s and beyond were a bloodbath.

Loss is a very small word that describes so much. Yet, here, it's not enough. Catastrophic loss. Better. I was in medical school when my catastrophic loss hit. I lost weight, I had trouble concentrating, and I was sick. Long story, I was put on SSDI and for 15 years of my life, I drifted on a tiny income and constrained existence. 15 long and bitter years of not working, not able to, not achieving within a workplace at a career or a profession, not gaining any type of work place knowledge or skill set. Not getting a paycheck, no Roth, no 401K, no retirement savings at all. This too is hard to explain. The cost of disease is <u>enormous</u> when you think about it. For the present, of course, and for your *future*.

I lost friends, family. I was alone, lonely. Luckily, I had good doctors. Doctors who cared and still do. Luckily, medications improved, regimens, mental health.

Seven plus years ago, I reentered the work force and have been working since. My health is very good, as is my stamina.

But what is not good, is my future. Finances, for instance. My husband feels the same. I have only been able to contribute, sometimes modestly, sometimes more to my future for about the past 5 years. Only 5. What happens when I retire? I won't have 40 years of work under my belt; I won't have savings, and I won't have a paid mortgage. Rather, I'll have 10 years in. Not much safety; but real expenses.

## If I'm lucky. What happens if I my drug regimen fails?

My husband and I are a great support for each other. We've traveled the same path – as gay men and as HIV+ men – separately and then together. I think of those in our community, so many, who have not. Who are alone, financially, and otherwise.

So, it's great, really, that our government wants to lend a hand to able bodied young people with student loans, who chose to take out their loans, and have many decades of work and income in front of them. I stand 100% for that type of help or assistance because <u>if can be done</u>. But what about those, like us, who did not choose – in any way – to have what happened <u>happen</u> to us? What about those who lost out <u>catastrophically by society's closed</u> notions and prejudices that crippled good people into second class citizenship? And for <u>decades</u>. What happens to those of us who were corralled into poverty and struggled then, and now, to view a safe and secure future for ourselves.

I would ask that the same sentiment seeking to help those with their student loans, cast a sharp and caring, compassionate eye toward older members of the LGBTQIA+ community who equally deserve a good future, as well.

Thank you, Marc Cail

As a 67-year-old person living with HIV for 30 years, I want to address three of the most pressing needs I see in the Elder HIV community. First is the continued need for high quality nutrition that is also accessible. Thankfully GMHC has recently reopened two days a week for lunch, and the NYC SAGE Centers are continuing to serve dinners nightly. However, accessibility remains an issue. The GMHC pantry which supplies groceries to HIV clients, often issues too much for an Elder to handle. Seven-pound bags of potatoes and five-pound heads of cabbage as well as other canned goods and produce is very difficult to maneuver in the subway and on buses, even with my grandpa wagon. At the Edie Windsor SAGE Center in Chelsea, some members collect leftover food and unopened milk, orange juice and fruit to take home with them. This is true also at GMHC lunches. Is it possible that NYC could fund a program that helps LGBTQ+ Elders living with HIV actually carry and get nutritional food delivered? Recently, I have heard of a similar program called "Meals on Heels," where drag queens do this work. It needn't be drag queens perse, but able-bodied people paid a small stipend, (much like a Medicaid Care Giver stipend). They could pick up these foods at GMHC and SAGE and deliver or actually walk with their Elder client to take the foods to their home.

The second most pressing need in the Elder HIV LGBTQ+ community that I see is isolation. This isolation is due to many factors. Friends who have passed from HIV/AIDS, often leaves those still living, without the support and camaraderie they crave. Often mobility issues like living on the sixth floor or fifth floor of a walk up building make this worse as it does for two friends of mine, both HIV positive, LGBTQ+ and elderly. Given this accessibility problem, is it possible that NYC could fund an outreach program, perhaps something like "Positive Friends, that would provide periodic visitations, or maybe "Friends in the Arts," a program that would provide free "extra" tickets to cultural events? Again, these programs could pay a stipend to visitor/companion who visits or attends an event with the LGBTQ+ HIV Elder. Many of the Elder NYC LGBTQ+ population living with HIV came to NYC just for that reason, for the Arts. The city's vibrant offerings and great culture were what made the move from small towns around the country worth it to these young LGBTQ people. In later life, it is still what they crave, and again accessibility is the key.

And finally, the third need I see is increased psychological outreach and counseling. After experiencing the trauma of years of watching our lovers and friends dying horrible deaths from AIDS, the reliving of the trauma during Covid was much more damaging to LGBTQ+ Elders with HIV than even they truly realize. My husband reminds me that each day I would write the Covid death count on the wall calendar in our bedroom.

NYC already provides some of the best services in the country for people living with HIV. But as the HIV population among LGBTQ+ Elders continues to grow, there is so much more the city can do. None of these three ideas costs an inordinate amount of money, but their implementation could have a profound effect on the quality of life for LGBTQ+ Elders living with HIV.

# Sincerely,

Michael Erp

From:	tanya walker <ladeshia5@icloud.com></ladeshia5@icloud.com>
Sent:	Friday, November 17, 2023 1:04 PM
То:	Testimony
Subject:	[EXTERNAL] NYC Council Oversight Hearing on HIV and Aging

CAUTION: This email originated from outside of the organization. Do not click links or open attachments unless you recognize the sender and know the content is safe. Report suspected phishing emails with the Phish Alert Button or forward them to phish@oti.nyc.gov as an attachment.

Good morning. My name is Tanya Walker, and today I stand before you not just as an individual but as a living testament to resilience and the power of community. Twenty-six years ago, my life took an unexpected turn when I received a diagnosis that changed everything—I was diagnosed with HIV. It's a journey that has been both personal and shared, shaped by the experiences of those I've lost, and it's a journey that I believe began long before the official diagnosis.

The catalyst for my decision to get tested was curiosity, born out of the devastating losses of many close friends right here in the heart of New York City. Their deaths were a stark reminder of the urgency surrounding HIV, a virus that doesn't discriminate based on friendship or familiarity. It can touch anyone, and it touched my inner circle deeply.

Today, I bring forth not only my story but a passionate plea for change. As we confront the complexities of HIV, it becomes evident that the battle extends beyond medical interventions—it is a battle against discrimination, against the barriers that hinder our ability to provide care, support, and understanding.

One crucial aspect of this battle is the dire need to invest in low-income housing. For individuals living with HIV, stable housing is not just a basic necessity; it is a cornerstone for effective management of health. Without stable homes, individuals face increased challenges in adhering to treatment plans, managing their health, and sustaining a quality life. Investing in low-income housing is an investment in the overall well-being of those affected by HIV.

Moreover, our efforts must extend to the realm of culturally competent service providers. Discrimination, whether subtle or overt, can be a formidable obstacle for those seeking care. Culturally competent service providers understand the nuances of diverse communities, creating an environment where individuals feel respected and understood. This not only fosters trust but also eliminates the additional burden of discrimination that many individuals living with HIV already carry.

To truly combat discrimination, we must prioritize the training and education of service providers, ensuring they are well-versed in the cultural nuances of the populations they serve. This investment is not just financial; it's an investment in compassion, empathy, and the human connection that is essential in healthcare.

In conclusion, as we navigate the complex landscape of HIV, let us remember that the fight goes beyond medical treatments. It's a fight for dignity, equality, and a future where no one has to face discrimination because of their health status. Invest in low-income housing to provide stability, and empower service providers with cultural competence to dismantle the barriers of discrimination. Together, we can build a community that supports, understands, and embraces every individual on their journey toward health and healing. Thank you. Sent from my iPhone

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	Name: Sam Sheldon Address: I represent: SAGE
	Name: Sam Sheldon

THE CAUNCH	
THE COUNCIL THE CITY OF NEW YORK	
Appearance Card	
I intend to appear and speak on Int. No Res. No	
in favor in opposition	
Date: (PLEASE PRINT)	
Name: RUTH FINKELSTEIN	
Address: BROOKLYN	
I represent: BROOKDALE CTR. FOR HEALTHY AGING Address: 2180 32 AV, 8TH FL, NYC 10035	
Starten and and the second	2
THE COUNCIL	
THE CITY OF NEW YORK	
Appearance Card	
I intend to appear and speak on Int. No Res. No	
🗌 in favor 🔲 in opposition	
Date: (PLEASE PRINT)	
Name: CHRISTIAN GONZÁLEZ-RIVERA	
Address: TROUTMAN ST. BROOKLYN 1-1206	
Address: 2180 312 AV, 8th FL, NYC 10035	
Address: <u>22000-110,010,010,000</u>	
THE COUNCIL	-
THE CITY OF NEW YORK	
Appearance Card	
I intend to appear and speak on Int. No Res. No	
in favor in opposition	
Date: (PLEASE PRINT)	
Name: DENECK Martinet	
Address: 13th Ltc,My	
I represent: <u>Myself</u> . <u>110</u>	
I represent: <u>MySelF</u> . <u>11107</u> Address:	

an Santa Marina Antonio	
	THE COUNCIL
THE	CITY OF NEW YORK
	Appearance Card
I intend to appear and	speak on Int. No Res. No
	in favor in opposition
	Date:
Name: Prof.	(PLEASE PRINT)
Address:	
I represent:	
Address:	nl
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	THE COUNCIL
THE	CITY OF NEW YORK
	Appearance Card
I intend to appear and	speak on Int. No Res. No
	in favor in opposition
	Date:
Name: Whene	REYES - TIMENEZ
Address: B1110	ughby St. Bklyp 1/2.01
represent: Older 1	People w/ HIV + Housing works
Address :	
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IHE	CITY OF NEW YORK
	Appearance Card
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	in favor 🔲 in opposition
	Date:
Name: RELINAL	PLEASE PRINT)
Address: W	1.42 MM
I represent:	

THE COUNCIL
THE CITY OF NEW YORK
Appearance Card
I intend to appear and speak on Int. No Res. No in favor in opposition
Date:
Name: Arthur Filler
Address: 220 2 9211 SP
I represent: <u>VNSHeath</u> Address: <u>ZZO E YZNA</u> ST NYC.
and the second
THE COUNCIL
THE CITY OF NEW YORK
Appearance Card
I intend to appear and speak on Int. No. 1248-23 Res. No.
in favor in opposition
Date: 11/17/23
(PLEASE PRINT)
Name: MICHOLAS MONTEDORD
Address:
TT INT ALL
Address: <u>51</u> WAICR STREET IV
THE COUNCIL
THE CITY OF NEW YORK
Appearance Card
I intend to appear and speak on Int. No Res. No
🗌 in favor 🔲 in opposition
Date:
(PLEASE PRINT) Name: Anya Herasme
Address: Associate (ummissioner for
I represent: (mmunity semce
Address: NYC Dept. of Aging
Please complete this card and return to the Sergeant-at-Arms

THE COUNCIL
THE CITY OF NEW YORK
Appearance Card
I intend to appear and speak on Int. No Res. No
🗌 in favor 🔲 in opposition
Date:
Name: JUCELUD GVODED
Astronomic of the second for the first for the
and Acture Acuroa
I Tepresent.
Address: NYC Dept of Aging
Please complete this card and return to the Sergeant-at-Arms
THE COUNCIL
THE CITY OF NEW YORK
THE CITY OF NEW YORK Appearance Card
Appearance Card         I intend to appear and speak on Int. No.         I in favor         I in opposition
Appearance Card         I intend to appear and speak on Int. No.         I in favor         In favor         In opposition         Date:
Appearance Card         I intend to appear and speak on Int. No.         I in favor         In favor
Appearance Card         I intend to appear and speak on Int. No.       Res. No.         in favor       in opposition         Date:       (PLEASE PRINT)         Name:       DY. (Cha Guino
Appearance Card         I intend to appear and speak on Int. No.       Res. No.         in favor       in opposition         Date:       (PLEASE PRINT)         Name:       DY. (CELA GUIDD         Address:       DEGUTY (Immissioner, DIMSICA A
Appearance Card         I intend to appear and speak on Int. No.       Res. No.         in favor       in opposition         Date:       (PLEASE PRINT)         Name:       DY. (Cha Guino

THE COUNCIL THE CITY OF NEW YORK
Appearance Card
I intend to appear and speak on Int. No Res. No in favor in opposition Date:
(PLEASE PRINT)
Name: Dr. Emma Kaplan-Lewis
Address: <u>HIV Charad Guality Director</u>
I represent: NYC Health + Hospitals
Address:
Please complete this card and return to the Sergeant-at-Arms
THE COUNCIL THE CITY OF NEW YORK Appearance Card
I intend to appear and speak on Int. No.       Res. No.         In favor       In opposition         Date:
I intend to appear and speak on Int. No.       Res. No.         In favor       In opposition
THE CITY OF NEW YORK         Appearance Card
Intend to appear and speak on Int. No.       Res. No.         In favor       In opposition         Date:       Intender         Operation       Description         Name:       Dy. Ashum Vasan