



# ***MOVING AHEAD TOGETHER***

*A Framework for Integrating HIV/AIDS & Aging Services*



a publication of **GIA** Grantmakers In Aging

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## ***About Grantmakers In Aging***

Grantmakers In Aging (GIA) is a national membership organization of philanthropies. Believing a society which is better for older adults is better for people of all ages, GIA acts as a relevant and responsive network, resource, and champion, amplifying the voices of older people and issues of aging. Our vision is of a just and inclusive world where older people are fully valued, recognized, and engaged in ways that matter. Learn more at [www.GIAging.org](http://www.GIAging.org).

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## ***About the Moving Ahead Together Initiative***

Moving Ahead Together is an initiative of Grantmakers In Aging that seeks to create closer connection, coordination, and expertise sharing between the HIV/AIDS services network and the aging services network with the goal of improving the lives and health of older people living with HIV/AIDS. It is supported by a grant from Gilead Sciences. Learn more [here](#).

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## ***About Gilead Sciences***

Gilead Sciences, Inc. is a research-based biopharmaceutical company that discovers, develops and commercializes innovative medicines in areas of unmet medical need. The company strives to transform and simplify care for people with life-threatening illnesses around the world. Gilead has operations in more than 35 countries worldwide, with headquarters in Foster City, California. For more information on Gilead Sciences, please visit the company's website at [www.gilead.com](http://www.gilead.com).

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### ***Cover art***

*Betsy Poncé, I'm Not Dying From It. I'm Living With It, 2017*

*Pastel on Fabriano paper, 15" x 11"*

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# EXECUTIVE SUMMARY


About 1.2 million people in the U.S. live with HIV, and advancements in treatments now give many of them a life expectancy almost the same as those without HIV. Today, more than 50% of people living with HIV in the U.S. are age 50 or older, and by 2030, that is anticipated to rise to 70%.

Care and services for people aging with HIV/AIDS have not kept pace with this change, however, and the HIV/AIDS services network and the aging services network – both well-developed and mature systems that deliver excellent care – are siloed. This causes serious gaps in care for older people living with HIV (OPLWH), for whom few tailored services exist.

As part of Grantmakers In Aging’s Moving Ahead Together initiative, supported by Gilead Sciences, this document offers a detailed framework of recommendations for strengthening the integration of HIV and aging care and services through increased understanding, more customized programs, closer cross-sector connection, and stronger policymaking.

Review or download a high-level, at-a-glance version of the Framework by clicking [here](#), or find it in this document, in [Appendix A](#).

This document contains three main sections. *Focus Area #1: Complexities and Challenges*, explores the broader social context, including stigma. *Focus Area #2: Integrating and Improving Care and Services*, emphasizes the need for whole-person care and examines medical care, mental and behavioral health care, and social and psychosocial support. *Focus Area #3: The Way Forward*, looks at policy and how to update it to reflect the graying of HIV.

Contextualizing the framework are thought leader reflections from members of the Moving Ahead Together steering committee and from participants in the Moving Ahead Together virtual Summit, all of whom are leaders in the aging and HIV service sectors. The document also includes quotes and videos that tell the first-person stories of many older people living with HIV who were interviewed for this project. All the artwork included in the document is also created by older people with HIV. Programs serving older people living with HIV are designated with this symbol. 




Ronnie Queenan  
*Hidden Soul II*

# INTRODUCTION: THE GRAYING OF HIV

Since HIV (Human Immunodeficiency Virus) was first detected in 1981, it has caused the deaths of more than 700,000 people in the United States - almost twice the number of Americans who died in World War II. Today, the epidemic is approaching its 40th anniversary. About 1.2 million people in the U.S. now live with HIV, but the diagnosis no longer represents the virtual death sentence it once did. Thanks to advances in treatment, the ability to live for decades with HIV has become a remarkable success story.

The graying of HIV introduces a major plot twist. In the early days, life expectancy after an HIV diagnosis averaged just one to two years but today, more than half of people living with HIV in the U.S. are age 50 or older (the age generally termed “older” in HIV parlance). By 2030, that is anticipated to rise to 70 percent.

This longevity should be celebrated. But it also needs other forms of attention. Hundreds of thousands of people are aging with HIV, but the systems, standards, and policies that guide and provide their care have not kept pace with this change.

“Unless you are in our shoes, you would really never understand,” says Pat Kelly, executive director of  A Family Affair in Orangeburg, South Carolina, a great-grandmother who received her HIV diagnosis 35 years ago. “I may look fine, but I may be having things going on in my body that nobody would ever know unless I told them.”

## ***A Framework for Integrating HIV/AIDS and Aging Services***

Aging with HIV is a relatively new phenomenon that is still under explored and under resourced. Grantmakers In Aging (GIA), a national membership organization of philanthropies, began working on the issue in 2019. With support from Gilead Sciences, GIA sought to highlight the issue for philanthropy, offering a plenary session at its annual conference, presenting two national webinars, and publishing a guide targeted to funders titled *Aging Positively: Bringing HIV/AIDS into the Aging Services Mainstream*.

GIA’s Moving Ahead Together initiative grew out of that work and recognition of the paucity of programs and services appropriately tailored for older people living with HIV (OPLWH). Its premise is that the HIV/AIDS services network and the aging services network are well-developed and mature systems that deliver excellent care, but that the two sectors have been siloed, operating almost entirely separately. Both have much to offer their clients, but now that they have begun to serve some of the same people, closer connection and better integration of services are needed. Finally, these two strong systems have much to learn from each other to find more effective approaches to improving the health and wellbeing of older people living with HIV.

This document offers a detailed framework of recommendations for strengthening the integration of HIV and aging care and services through increased understanding, more customized programs, closer cross-sector connection, and stronger policymaking. Where they are available, this framework also highlights programs and services that are already addressing systemic challenges and filling gaps to provide excellent and equitable care for older people living with HIV.

The framework contains three main sections. *Focus Area #1: Complexities and Challenges*, explores the broader social context, including stigma. *Focus Area #2: Integrating and Improving Care and Services*, emphasizes the need for whole-person care and examines medical care, mental and behavioral health care, and social and psychosocial support. *Focus Area #3: The Way Forward*, looks at policy and how to update it to reflect the graying of HIV.

Review or download a high-level, at-a-glance PDF version of the Framework by clicking [here](#), or find it in this document, in [Appendix A](#).

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## ***Mapping Progress, Assuming Positive Intent***

The process of formulating these recommendations was guided by a distinguished multidisciplinary steering committee of leaders and professionals from the HIV/AIDS and aging services sectors. (Please see a full list of members in [Appendix C](#).) The project was also strengthened, and its secondary goal of building cross-sector connection was advanced, by the Moving Ahead Together Summit, at which leaders in both fields gathered (virtually) in September 2020 to review and contribute to this framework. (Please see the full list of Summit participants in [Appendix C](#).) GIA is extremely grateful to everyone who participated.

The Moving Ahead Together project has repeatedly stated an assumption of positive intent by all parties. The fact that there is work to do should not, and does not, diminish the accomplishments or commitment of the many dedicated people working in HIV and aging and other affiliated services. Indeed, the MAT steering committee and those attending the MAT Summit, all of whom are deeply immersed in these issues, expressed strong agreement about the existence of care silos and the need to reduce them. This document is offered with the sole objective of helping all involved find actionable ways forward to help real people thrive while growing older with HIV.

“I think everybody wants to do the right thing.” observed Meredith Greene, MD, a summit participant who is a geriatrician and HIV specialist at the University of California San Francisco. “They just don’t know what it is.”




*Sister Used Carlotta,  
Transformation,  
2018*


*Pastel on Fabriano  
paper, 15" x 11"*





## Leveraging the Unique Expertise of People Living with HIV

*There are many ways to be heard, and creative self-expression can be a powerful one. All the art featured in this report was created by older people living with HIV.*

*The pastel drawings were generously provided, with the artists' permission, by Diana Sciarretta, an artist who created the Bodyscapes Healing Art Experience at  [The Red & Orange House](#) in San Francisco. Bodyscapes, she explains, "is about people living with trauma and illness and its effects on their body and soul," and gives people a new way to connect. "You're talking about illness but not test results and numbers. It's using colors to communicate the way it feels inside your body," she explains.*

*Also featured are paintings by artists in the  [Healing Art](#) program, which began working with people living with HIV in 1990. Now part of Art League Houston, Healing Art is serious about art (using professional teaching artists for all its classes) but also about community building. "It's close knit. If someone gets too ill to come in or has to take a semester off, we hold their space," explains Eepi Chaad, Director of Community Engagement for Art League Houston. "People get together outside the program. They holiday together, bring each other groceries, become each other's support systems. There are days when people come in and don't even touch the paint."*

*Finally, this initiative recognizes the [Denver Principles](#), first declared in 1983 to assert the right of people living with HIV/AIDS to meaningful involvement in design and decisionmaking about programs and policies that affect them. "I may not have a Master's health in public health. I may not be a Doctor of Psychology. But I do know how I feel," explains Malcolm Reid, director of programs at Thrive Support Services in Atlanta and founder of the  [Silver Lining](#) peer support program for older, same gender loving men of color living with HIV. "I can talk to the guys in my group because they know I'm also living with HIV and I have the same struggles. But if you come to them and dictate, 'this is what we need,' it might not work. There is still nothing better than that empathetic conversation with the people you are trying to help."*

*To raise more authentic voices and perspectives, this framework will include excerpts from original, one-on-one interviews with people living and aging with HIV, both in the text and in a series of short videos. Videos are indicated in the text with this icon. *



Ronnie Queenan

Black Lives Matter II



## HIV and Health Equity in the Era of COVID-19

No public health issue can be examined today without reference to COVID-19. That pandemic has cast a harsh and revealing light on the persistent gaps, shortfalls, and inequities in the U.S. health care and public health systems, and parallels to the HIV epidemic are inescapable. In fact, the theme selected for HIV Long-Term Survivors Awareness Day in 2020 (observed on June 5, 2020) was, “Not Our First Pandemic” (a framing not without controversy, as some long-term HIV survivors feel it diminishes their history.) Ironically, people who have experienced both emergencies have valuable perspective to share but COVID-19 social distancing has made sharing difficult, while increasing the painful isolation that is one of HIV’s unofficial co-morbidities.

Also relevant are the calls for change arising from the Black Lives Matter movement. The disproportionate burden of HIV in Black and Latinx communities is profound and marks one of the shifts that have transformed the epidemic but that have not been fully addressed.



“To me, HIV is a racial justice issue. Period,” says Venita Ray, deputy director of the Positive Women’s Network-USA, who was diagnosed with HIV in 2003 while serving as an Assistant Attorney General for the Office of the Attorney General for the District of Columbia. “People with HIV tend to be people with low income. They tend to be Black and brown. They tend to be the folks that our society marginalizes. So, I see HIV as a racial justice issue and definitely as a social justice issue.”

Gregg Cassin,  
*This Heart*, 2017

Pastel on Fabriano paper,  
15” x 22”

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# 1

## FOCUS AREA #1:

# COMPLEXITIES AND CHALLENGES

An environmental scan of HIV and aging finds numerous complexities and challenges, some longstanding and some the result of change over time. HIV is a medical condition that attacks the body but also unleashes an assault on people’s identity and social status – through stigma, discrimination, isolation, disability, and often, poverty – which continues even decades after diagnosis. It would be difficult to name another virus, even COVID-19, that so forcefully, personally, and lastingly punishes its host.

This negativity has contributed to the struggles of people living with HIV since the earliest days of the epidemic and many people living with HIV say it still defines their experience and creates many of the gaps in their care.

With the graying of HIV, it becomes necessary to add ageism to that list. “Being LGBT people, we have always felt left out of society. But when you get older, that is a monster of another kind. It’s like you disappeared,” says DeeDee Ngozi Chamblee, Executive Director and Founder of  **La Gender, Inc.**, an organization for African American trans women in Atlanta.

As Stephen Karpiak, PhD, Director of the [National Resource Center on HIV and Aging](#) at GMHC, observed during the MAT summit, “This is a uniquely isolated and abandoned population.”



### LISTEN UP

For more first-person perspective on Complexities and Challenges, please listen to excerpts from interviews with older people living with HIV/AIDS in this [video](#).

### Issue #1:

## The epidemic has changed over time.

### ▶ THE SURVIVAL RATE IS MUCH IMPROVED.

Today, the average life expectancy for people with HIV who are in care is nearly the same as people without HIV.

With the advent of highly active [antiretroviral therapy](#) (HAART), many people’s “AIDS cocktail” is now a single daily pill. HAART reduces the viral load, increases the CD4 cell count to improve immune function, and slows the development of opportunistic infections and AIDS. Taken properly, it can render the virus undetectable and untransmittable to others (abbreviated as U=U.)

### ▶ DEMOGRAPHICS HAVE CHANGED.

The perception that HIV primarily affects younger gay, bisexual, and other men who have sex with men (MSM) is outdated. Today, there is more diversity among people who are newly diagnosed: 19% are women (most commonly through heterosexual contact); 8% are heterosexual men; 66% are MSM (2018 CDC [data](#)).



### **THE AGE PROFILE HAS CHANGED DRAMATICALLY.**

Once a cohort that skewed young, today, half (51%) of people living with HIV are age 50+; this is estimated to increase to 70% by 2030. And 17% of new HIV diagnoses are in older people.

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### **GEOGRAPHIC DISTRIBUTION HAS SHIFTED.**

The rate of new infections is now highest in the South (51% in 2018), where cases are highest in rural communities and in the Black community.

## **Issue #2:**

# ***Certain groups bear a disproportionate burden.***

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### **RACIAL DISPARITIES ARE HIGH.**

Among gay, bisexual, and other MSM, 50% of Black men and 25% of Latino men are projected to acquire HIV in their lifetimes (6x and 3x the rate for whites, respectively).

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### **BLACK WOMEN FACE DISPROPORTIONATELY HIGH RATES OF INFECTION.**

About one in five new HIV diagnoses are among women, most attributed to heterosexual contact. Older women (55+) account for 16% of these cases; more than half (58%) are Black women. The risk of contracting HIV for Black women (of all ages) is 17 times the risk for white women. For Hispanic/Latino women, it is more than three times higher than for white women.

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### **TRANSGENDER OLDER WOMEN FACE HIGH RISK OF INFECTION, STIGMA, AND ISOLATION.**

Trans people are under-studied but a CDC meta-analysis concludes that there are about one million transgender adults in the U.S., and an estimated 14% of transgender women have HIV.

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### **TARGETED HIV SERVICES FOR OLDER WOMEN ARE RARE.**

Women face unique issues during aging and menopause but are under-studied, so there is a sparse evidence base to guide their care.

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### **OLDER PEOPLE ARE MORE LIKELY TO HAVE LATE-STAGE HIV AT TIME OF DIAGNOSIS.**

Generally attributed to lack of widespread education and testing, about one third (35%) of people diagnosed after age 50 have both HIV and AIDS.

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### **OLDER PEOPLE AND THEIR MEDICAL PROVIDERS UNDERESTIMATE THEIR RISK.**

Both may mistake HIV symptoms for those of normal aging, may not consider HIV as a cause, and may not consider HIV to be a risk.

### Issue #3:

## Stigma perpetuates discrimination and creates obstacles to care and support.

Perhaps the most commonly-cited barrier to health and wellbeing is stigma, which can drive older people into isolation, causing delays in testing and sabotaging their motivation to stay in care. While stubbornly pervasive, stigma is also widely viewed as difficult to target.

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### **MULTIPLE FORMS OF STIGMA APPLY.**

Ageism, sexism, homophobia, transphobia, and racism are all factors limiting good access and good care. Stigma can be also internalized, causing “self-stigma.”

“You think about the layers of stigmas – stigmas, plural – that this population has to confront. It would paralyze anybody,” observes Moisés Agosto-Rosario, Director of Treatment at [NMAC](#) in Washington, DC, where the mission includes normalizing discussion about race within the HIV movement.

Older people may experience “double stigma” – a combination of anti-HIV feeling and ageism.

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### **HIV STIGMA IS REINFORCED BY LACK OF COMMUNITY AND PROVIDER UNDERSTANDING.**

“I know tons of women who go to the doctor and say, ‘I want an HIV test,’ and the doctor says, ‘Why? Aren’t you married?’ or ‘Why? Aren’t you in a committed relationship?’ It comes across in so many ways, the medical bias about who may need a test and who’s living with HIV, and the whole community internalizes that,” says Venita Ray of the Positive Women’s Network-USA.

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### **MISPERCEPTIONS ABOUT HIV INFECTION ABOUND.**

“I have heard from many folks that have wildly wrong ideas about how HIV is transmitted, like touching someone without gloves, or sharing a bathroom or eating utensils,” says Tim Johnston, senior director of national projects for SAGE, who also oversees [SAGECare](#), SAGE’s LGBTQ cultural competency training for aging services providers. “It’s brand new for a lot of them.”

A new SAGECare online education [module](#), HIV and Aging: Confronting Myths, Reducing Stigma, and Aging Successfully, is designed to help anyone who works with older people – from social workers to nursing home aides to advocacy groups to providers of congregate meals – learn to address HIV-related issues.

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### **SOCIAL AND RACIAL JUSTICE CONCERNS ARE COMMON.**

A 2019 national survey, [State of Aging with HIV](#), shows that two out of three respondents living with HIV had annual income under \$50,000, one in four were unable to find a provider who accepted their insurance, and stigma in the healthcare settings troubled many: 50% reported health care stigma, 25% reported ageism, and 24% reported homophobia.

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### **DISCOMFORT IN ACCESSING AGING SERVICES REMAINS AN ISSUE FOR OLDER PEOPLE LIVING WITH HIV.**

Apprehension about an unfamiliar environment can be chilling for even the most confident and accomplished people living with HIV. During the MAT Summit, steering committee member and AIDS United CEO Jesse Milan, Jr., mused about driving past a senior center



near his home that offers line dancing. “I’m thinking, gee, I’d really like to go line dancing, but will I feel welcome? Is someone going to ask me to fill out a medical form? It could be a great opportunity for social engagement and to meet other folks over 50, but am I really going to say to one of them, ‘I just came from a doctor’s appointment about my HIV?’ How do people hear that and how am I going to feel when I get that blank stare?”

Representing the Association of Area Agencies on Aging (n4a), which includes many of the nation’s senior centers, CEO Sandy Markwood (a MAT steering committee member) agreed that many n4a members want and need more help and education. “There is sometimes the thinking that ‘this went away in the ‘80s’ and a lack of awareness that the client base in the aging network now includes people who have HIV,” she said. “I’m happy to be part of this effort because n4a wants to ensure we are serving all people and I would like to amplify this with all of our members, and find ways to ensure they get the help they need to serve people with HIV.”

#### **Issue #4:**


### ***Location matters; most services are local.***

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#### **▶ SMALL TOWNS AND RURAL PLACES MAY HAVE DIFFERENT NEEDS AND RESOURCES THAN URBAN CENTERS.**

Clinics may have only one provider serving a large area and stories of people traveling hundreds of miles to seek confidentiality or care elsewhere are not unheard of.


Unfortunately, cultural norms are not always conducive to good care. MAT Summit participant Ronald “Chris” Redwood, a Nurse Consultant in the Clinical and Quality Branch of HRSA’s HIV/AIDS Bureau and co-chair of its HIV and Aging Workgroup, recalled a work trip to visit a small HIV clinic in Alabama. “I was shocked when we drove past a church with signs on the lawn saying, and I’m paraphrasing, ‘HIV is God’s curse on homosexuality.’ How can people find the compassion and the care they need in that environment?”

Pat Kelly, whose organization  A Family Affair is based at her church in South Carolina, counsels her members to recognize privacy is hard to come by, but also that living openly with HIV is freeing and therapeutic. “I say, ‘You live in a small community. You may not be telling but guess what – people already know! The doctor lives down the street. The nurse lives around the corner. The person looking at your records lives two blocks over.’”

#### **▶ COMMUNITIES’ ABILITY TO OBTAIN PUBLIC FUNDING OR TO PARTIALLY SELF-FUND VARIES SIGNIFICANTLY.**

Local infrastructure and funding may dictate services and many places cannot draw on the kind of funding that supports HIV services in San Francisco, for example, where more than \$16 million for HIV prevention and health services has come from city’s budget in just five years.

#### **▶ VIRTUAL SUPPORT GROUPS AND PROFESSIONAL SERVICES DELIVERED BY TELEHEALTH CAN EXPAND OPTIONS BUT OPLWH’S ACCESS AND CAPACITY TO USE TECHNOLOGY VARIES.**

Telehealth has made tremendous gains during COVID-19 and for some, has improved access to care by eliminating mobility obstacles. Social groups such as the  San Francisco AIDS Foundation’s 50-Plus Network’s Saturday morning coffees for long-term survivors have also gone online and been able to include people from other cities.

The downside is unequal access. The digital divide is real and those without computer or internet access can be left behind. Some participants also worry about preserving anonymity and confidentiality in online social groups.


## Issue #5:

# One size does not fit all in program design.

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### ► **DIVERSITY AMONG OPLWH MAY REQUIRE EXTRA CREATIVITY IN CREATING SERVICES.**

Few programs exist specifically to serve people aging with HIV, but those that do tend to be warmly welcomed.

In Chicago, TPAN (Test Positive Aware Network) launched a 50+ program called  [Positively Aging](#), supported by Gilead Sciences, which includes outings and individual and group therapy. “Many of our clients said they’ve never been able to come to a group where they could be with people in their own age bracket and feel comfortable talking about HIV,” reflects TPAN Associate Director of Client Services Ashley Martell.

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### ► **DIFFERENCES MATTER; BUT SCARCE RESOURCES CAN MAKE CUSTOMIZING OR EXPANDING SERVICES CHALLENGING.**

Variations in racial/ethnic identity, socioeconomic status, gender identity, sexual orientation, and community affiliation can all be factors in the success of a program.


Age can be another dividing line. Mark Brennan-Ing, Senior Research Scientist at Brookdale Center for Healthy Aging and a MAT steering committee member, has studied how to maximize psychosocial support for older people living with HIV. “They don’t feel at home in programs with a lot of younger people,” Brennan-Ing recalls. “In one of our focus groups, an older gay man told us he met some young guys in a meeting. Someone called him a ‘grandpa’ and he never went back.”

Some more inclusive programs do succeed, like A Family Affair, which is open to family and friends. “Everybody in the family is affected,” says Pat Kelley. “I have a lot of community members – people that weren’t actually living with HIV but had family members who were – and they wanted to talk!”

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### ► **EXPERIENCE MATTERS; LONG-TERM SURVIVORS’ NEEDS DIFFER FROM THOSE OF OLDER PEOPLE NEWLY DIAGNOSED.**

“There is incredible pain, loss, suffering, and some people are dealing with severe mental and physical health issues because of living through those early days of the epidemic,” says long-term survivor Gregg Cassin.

That’s why he created a series of retreats called  [Honoring Our Experience](#). Workshops maintain a focus on the long-term survivor experience, but over time have successfully integrated younger and newly diagnosed people, trans women, caregivers, families, and friends. “I have never been in a room that diverse and had that much shared experience and that much connection,” Cassin adds.

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### ► **EVEN SUCCESSFUL PROGRAMS MAY NOT BE EASILY REPLICATED.**

Because of the range of experiences and environments, replicating or scaling up successful program may not be easy with some HIV and aging programs, but one of the few funders with deep experience in both sectors doesn’t mind.

“If it works in my community, that’s great,” says Nancy Zionts, a steering committee member and Chief Operating Officer and Chief Program Officer at Jewish Healthcare Foundation. “I don’t need it to be replicable in places that don’t look like mine.”

## Issue #6:

# Underestimating the challenge and overestimating progress.

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### ▶ **“A MANAGEABLE CHRONIC DISEASE”**

That is how some health care and other providers have begun to see HIV, believing that in the age of HAART, it is no longer urgent, particularly complex, or different from the management of an older adult without HIV.

As one of only a handful of physicians who have completed fellowships in both geriatrics and HIV medicine, Meredith Greene, MD, has a different perspective. “My geriatrics colleagues tend to see it as a chronic illness,” she says. “But that does not recognize the stigma and history that goes along with it, and the trauma many have experienced, so that’s the one thing I try to educate my colleagues on.”

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### ▶ **LESS PUBLIC FOCUS.**

HIV has dropped dramatically in public perception from 1987, when surveys show 68% of people rated it “the nation’s most urgent health problem, to 2011, when that view shrank to 7%.

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### ▶ **MULTIPLE CO-MORBIDITIES AND ACCENTUATED AGING ARE PART OF THE EXPERIENCE.**

As Focus Area #2 will explore, aging with HIV tends to be accompanied by a cascade of other conditions at higher rates than people without HIV (known as accentuated aging), which must be co-managed but is not widely understood.

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### ▶ **RECRUITING NEW HIV PROVIDERS IS GETTING HARDER AND OLDER SPECIALISTS ARE STARTING TO RETIRE.**

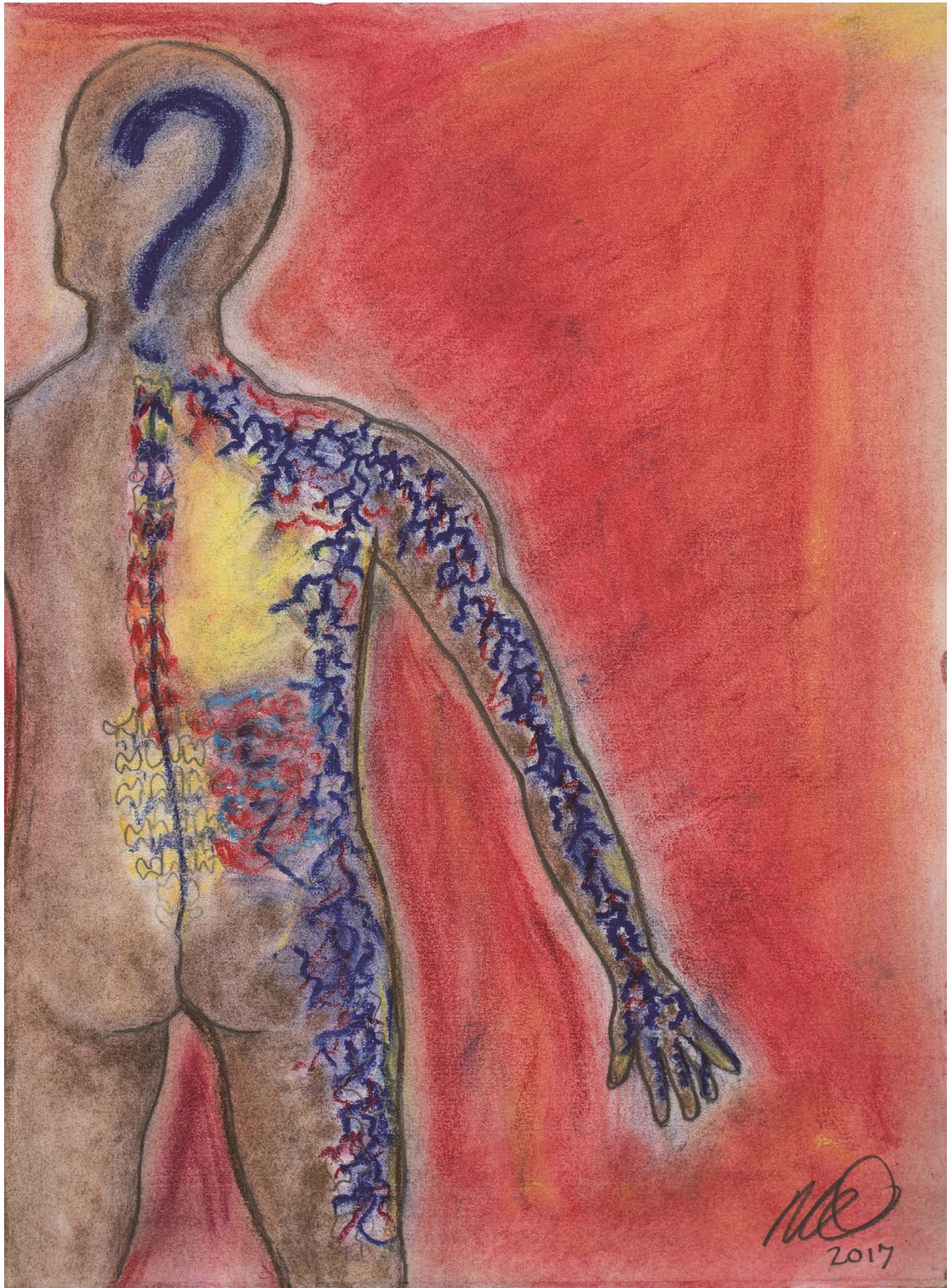
“The field is burning out,” says Maile Karris, MD, a MAT steering committee member, Owen Clinic Research Director, and Associate Director of the San Diego Center for AIDS Research Clinical Investigations Core at UC San Diego. “There is high administrative burden, many of the older HIV doctors don’t want to do chronic conditions, and many of the younger HIV docs went into a specialty because they didn’t want to do general primary care.” [Read more.](#)

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### ▶ **OVERTAKEN BY COVID-19?**

Concern is growing in the HIV field that funding and attention will be co-opted by COVID-19.





*Marcus Oliphant, Inside Me, 2017*

*Pastel on Fabriano paper, 11" x 15"*

# 2

## FOCUS AREA #2:

# INTEGRATING AND IMPROVING CARE AND SERVICES

American health care, social services, and aging services are usually delivered by disparately located and credentialed providers, which is counterproductive for older people living with HIV (OPLWH), whose challenges tend to be complex and intersecting.

Medically, people with HIV often age into “no man’s land.” They may receive good care from an HIV clinic or specialist but their needs evolve with age and these providers may not manage geriatric syndromes or the many non-HIV co-morbidities. (People living with HIV who are in care are more likely to die of cancer than anything else.)

Having a specialist or primary care physician manage multiple conditions makes sense but transitioning to a non-HIV setting can be traumatizing and fear of stigma or being “outed” scares some people away.

Good care encompasses more than medicine, but seeking suitable behavioral and mental health care, psychosocial support, and help with daily challenges such as securing housing, applying for disability benefits, or finding long-term services and supports can be hard. Older people may feel they have “aged out” of HIV support groups, which tend to be youth- and prevention-focused.

Compounding it all: the sprawling systems that deliver insurance, health care, social services, aging services, and long-term care, offer little or no coordination or navigational support.

In looking at these issues, this section examines specific types of care. This does not imply that one type is more important than another; rather, all forms of care should receive equal consideration and these recommendations focus on strategies for making care more interdisciplinary and holistic.



### **LISTEN UP**

For more first-person perspective on Integrating and Improving Care and Services, please listen to excerpts from interviews with older people living with HIV/AIDS in [this video](#).

## **Focus Area #2A: Core Principles**

### **Issue #1**

## **Health equity principles should inform HIV and aging programs and care.**

*“What is critical when using an equity perspective is ensuring all people have access to their full health potential,” says Karen Fredriksen Goldsen, PhD, Principal Investigator of the National Health, Aging and Sexuality/Gender Study at the University of Washington and a MAT steering committee member.*



▶ **ACKNOWLEDGE THE HEALTH DISPARITIES, RACIAL AND SOCIAL INEQUITIES, STIGMA, MARGINALIZATION, AND DISCRIMINATION THAT MANY OPLWH EXPERIENCE.**

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▶ **LEVERAGE THE SOCIAL DETERMINANTS OF HEALTH.**

Emerging awareness, policies, and funding that address the social determinants of health can promote the shift from a traditional medical model toward a more holistic approach to meeting the complex health and social needs of OPLWH.

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▶ **BRING A SOCIAL AND RACIAL JUSTICE LENS TO HIV AND AGING PROGRAMMING AND ADVOCACY.**

HIV's impact in minority communities is critical (in 2018, Blacks accounted for 42% of HIV diagnoses and Hispanics/Latinos accounted for 27%), as is the high degree of marginalization in the lives of other high-risk groups, such as sex workers and people who inject drugs.

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▶ **EMPLOY A VALUES-BASED APPROACH TO BUILD INTERGENERATIONAL, INTERSECTIONAL, AND MULTI-SECTOR APPEAL.**

Finding common ground can help engage younger people living with HIV, as well as intergenerational, philanthropy, legal services, racial and social justice, and service organizations.

One successful example at the San Francisco AIDS Foundation is  [Bridgemen](#), in which men living with HIV join other gay, bi, and trans men of all ages to do public service projects around the city, with a chance to socialize and provide mentoring and support.

**Issue #2:**

***Promote person-centered care by connecting HIV, aging, and social care providers.***


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▶ **OFFER OR CO-LOCATE COMPLEMENTARY SERVICES WHERE POSSIBLE.**

While not easy, co-location is highly effective and can include geriatric consults offered in HIV clinics, social workers embedded in health care settings, or social support programming based in health care settings. Local infrastructure and funding may dictate services, so an HIV provider may not be able to bill from a geriatric clinic, or vice versa.

An alternative strategy is to maximize the contribution of other office staff to help with things like Advance Care Planning paperwork, rather than leaving it to a physician who may face strict time limits on visits. “There are medical assistants that would like more of a role, for example, but they would have to be trained,” offers steering committee member Maile Karris, MD.

The leader in co-location is San Francisco's  [Golden Compass](#), which has earned high patient and provider satisfaction for its many onsite services: cardiology; cognitive evaluations; brain health and exercise classes; geriatric consultation; dental, hearing, and vision screenings and linkage to care; and social activities.


In the aging services network, co-location of HIV services also remains extremely rare. One Area Agency on Aging (AAA) that does it is Region One in Phoenix, which has offered  [HIV Care Directions](#), using Ryan White funding, since 1992. (Ryan White is the HIV safety net program run by the Health Resources and Services Administration (HRSA) that provides a comprehensive system of HIV care, support services, and medications for low-income people who are uninsured and underserved.)



▶ **ESTABLISH SYSTEMS TO INCREASE COMMUNICATION, EXPERTISE SHARING, AND REFERRALS BETWEEN HIV, GERIATRIC/PRIMARY CARE (PC) PROVIDERS, AND SOCIAL SERVICES.**

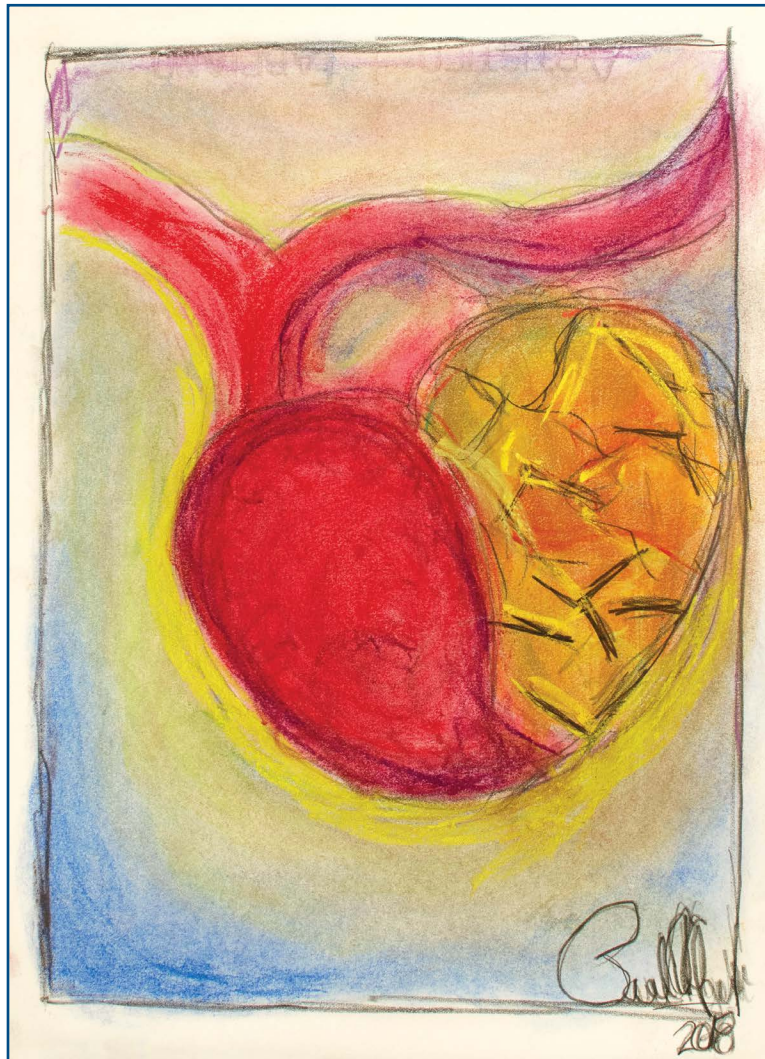
Simply making a referral may not be enough, observes Kristine Erlandson, MD, a MAT summit participant and professor in the Divisions Infectious Diseases & Geriatric Medicine at the University of Colorado. “We also need to facilitate the implementation of recommendations for patients and providers to follow-up, without creating a burden for either.”

▶ **LEARN FROM ONE-STOP-SHOP INTEGRATION USED IN MANY RYAN WHITE PROGRAMS.**

Geriatrician Eugenia Siegler, MD, who created the  Aging with HIV Program at Weill Cornell Medicine’s Center for Special Studies, has researched the few other integrated HIV and geriatric care models, concluding that, to date, “we do not know how best to care for this population.”

▶ **LEVERAGE THE TRUST THAT OPLWH FEEL WITH PROVIDERS AND SETTINGS IN THEIR “COMFORT ZONES” WHEN ADDING, INTEGRATING NEW SERVICES.**

Even the best system can’t be effective if people don’t feel comfortable, and mistrust is widespread among older people living with HIV. “I’ve been to clinics where the people had no historical knowledge of the AIDS epidemic,” recalls Tez Anderson. “Honey, this is not how this works.”



*Paul A. Aguilar,  
cracked but not  
really, 2018*

*Pastel on Fabriano  
paper, 11” x 15”*

## Focus Area #2B: Medical Care

### Issue #1

## Help primary care providers and geriatricians build their knowledge of HIV issues.

*As the cohort of older people living with HIV continues to grow, many more non-HIV specialists will see people with (or at risk for) HIV and other conditions, and need to prepare accordingly. It is essential to raise the question of whether physicians and other providers “know what they don’t know.”*

#### ▶ “COULD IT BE HIV?”

Encourage physicians and other providers to consider this possibility in diagnosis, and to track the impact of HIV on non-HIV-related comorbidities, such as heart disease, liver disease, cognitive impairment, and frailty.

#### ▶ **CREATE AND DISSEMINATE EDUCATIONAL RESOURCES AND PROFESSIONAL DEVELOPMENT OPPORTUNITIES TO HELP GERIATRICS AND PC PROVIDERS BUILD HIV EXPERTISE.**

One valuable reference for general practitioners is [Care of People Aging with HIV: Northeast/Caribbean AETC Toolkit](#), compiled by geriatrician Eugenia Siegler, which covers fundamentals of geriatric assessments, HIV care, caregiving, polypharmacy, elder mistreatment and financial abuse, Medicare and Medicaid, legal problems, and community-based resources.

#### ▶ **INCREASE HEALTH CARE PROFESSIONALS’ KNOWLEDGE OF THE POTENTIAL FOR POLYPHARMACY IN PATIENTS LIVING WITH HIV AND OTHER CONDITIONS.**

The American Academy of HIV Medicine offers a useful [overview](#) that includes the American Geriatrics Society’s Beers Criteria of drugs and drug combinations that are contraindicated for older people.

#### ▶ **ENCOURAGE HIV-RELATED CONTINUING MEDICAL EDUCATION (CME) CURRICULUM, MENTORING, ATTENDANCE AT CONFERENCES AND SPECIALIZED TRAININGS.**


The American Academy of HIV Medicine, in partnership with the American Geriatrics Society and the AIDS Community Research Initiative of America (ACRIA), offers a suite of CME titled [Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV](#). A pioneering group of interdisciplinary research-focused specialists has led the annual [International Workshop On HIV & Aging](#) (held in the U.S.) since 2009.

### Issue #2:

## Include sexual health in primary and specialty care for older adults.

*Many older adults continue to be sexually active, but sexual health is often overlooked in primary care by both practitioners and patients. With HIV infection at stake, this missed opportunity becomes dangerous.*

▶ **ENCOURAGE AND SUPPORT REGULAR TAKING OF SEXUAL HISTORY FROM OLDER ADULTS.**

Many older people report that their providers either do not ask about their sexual health or seem uncomfortable. “Doctors underestimate the sex lives of older adults. We still have sex!” says Miriam Whitehead Brice, a member of  Older Women Embracing Life (OWEL), an HIV support group in Baltimore.

Older people may also be unaware they are at risk for other sexually transmitted infections or stop using condoms once preventing pregnancy is not an issue.

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▶ **ENCOURAGE, SUPPORT, AND PROVIDE APPROPRIATE TRAINING FOR PROVIDERS ON “DIFFICULT CONVERSATIONS” ABOUT OLDER ADULT SEXUALITY AND HIV, POTENTIAL RISK FACTORS, HIV TESTING, KNOWING HIV STATUS, AND PREVENTION OPTIONS.**

The failure of HIV testing in the older population is stark: an estimated 83% of sexually active older adults are never tested for HIV, according to [Too Old to Test?](#) Even the U.S. Preventive Task Force recommendation for HIV testing [ends](#) at age 65.

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▶ **PROMOTE GERIATRIC AND PC PROVIDER AND STAFF AWARENESS OF PREP AND PEP MEDICATION AND U=U.**

People who are HIV negative but at risk of exposure can protect themselves with medication called [PrEP](#) (pre-exposure prophylaxis), which reduces the likelihood of infection by an estimated 99%.

People who have been exposed to HIV can try to prevent infection by taking antiretroviral medications called [PEP](#) (post-exposure prophylaxis) soon afterwards. An emergency measure, only for people who are HIV negative.

People whose HIV is suppressed through medication [Undetectable] should be counseled that they cannot pass the virus to others [Untransmittable], abbreviated as [U=U](#).

**Issue #3:**

***Build primary care providers’ and geriatricians’ cultural competency on HIV issues.***

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▶ **ACKNOWLEDGE AND WORK TO ELIMINATE STIGMA IN HEALTH CARE THAT CAN EXACERBATE OPLWH’S FEAR OF BEING REJECTED OR “OUTED.”**

Judgment-free listening is critical, but one [survey](#) of obstetrician-gynecologists revealed that one in four doctors had expressed disapproval of a client’s sexual practices during a medical history.

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▶ **PROMOTE MARKETING (SIGNAGE, HANDOUTS, ONLINE) THAT INDICATES THAT OPLWH AND SEXUAL MINORITIES AND GENDER DIVERSE PEOPLE ARE WELCOMED AND SERVED.**

▶ **INCLUDE STAFF (E.G., SCHEDULERS, RECEPTIONISTS, MEDICAL ASSISTANTS, OFFICE AND FACILITIES STAFF) IN CULTURAL COMPETENCY TRAINING.**

A new CME program, [Ending the HIV Epidemic Starts With a Conversation: An Education Toolkit](#), supports interprofessional teams in applying culturally sensitive approaches.

▶ **SEEK GUIDANCE ON POLICIES AND PRACTICES FROM OPLWH WHERE POSSIBLE.**

“In the medical field, folks don’t understand this, but there’s still a lot of stigma. A lot of us have gone to the doctor without telling anyone that we were positive because you are still dealing with the shame of it and you don’t know how you are going to be received,” says Venita Ray of the Positive Women’s Network-USA.

**Issue #4:**

**Help HIV and infectious disease specialists caring for OPLWH gain geriatrics expertise.**

*“A new medical awareness should be cultivated of treating HIV “throughout the life span,”” says the policy platform of the American Academy of HIV Medicine.*

▶ **EDUCATE HIV PROVIDERS ON PRINCIPLES OF GERIATRICS: GERIATRIC SYNDROMES, MULTIPLE CHRONIC CONDITIONS, GERIATRIC ASSESSMENT, MEDICATION MANAGEMENT, COGNITIVE IMPAIRMENT, ETC.**

A streamlined approach advanced by Maile Karris and Kristine Erlandson is “6 Ms” - Mind, Mobility, Medications, Multi-Complexity, and Matters Most, with the addition of Modifiable, for health-related lifestyle factors.

▶ **RAISE AWARENESS OF UNIQUE IMPACTS OF AGING WITH HIV.**

The Ryan White HIV/AIDS Program has released Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care: A Reference Guide for Aging with HIV.

▶ **INCREASE KNOWLEDGE OF HIV’S IMPACT ON NON-HIV-RELATED COMORBIDITIES AND THE POTENTIAL FOR POLYPHARMACY.**

▶ **FACILITATE REFERRALS AND CONSULTS BETWEEN GERIATRICIANS AND HIV SPECIALISTS.**

▶ **CREATE AND DISSEMINATE EDUCATIONAL RESOURCES AND PROFESSIONAL DEVELOPMENT OPPORTUNITIES TO BUILD CROSS-DISCIPLINARY EXPERTISE.**

▶ **ENCOURAGE RELATED CONTINUING MEDICAL EDUCATION (CME) CURRICULUM, MENTORING, ATTENDANCE AT CONFERENCES AND SPECIALIZED TRAININGS.**

▶ **ACKNOWLEDGE ALIENATION SOME OPLWH FEEL IN YOUTH-ORIENTED HIV CLINIC SETTINGS; SEEK GUIDANCE ON POLICIES AND PRACTICES FROM OPLWH.**

🚫 The AIDS Foundation of Chicago, which operates one of the nation’s largest Ryan White HIV case management systems, saw that most of its young managers felt ill-equipped to serve older clients. More than half said they had limited or no capacity to assess older clients’ knowledge of risk factors and prevention strategies and 44% had limited or no capacity to educate older adults about sexual health. In response, AFC developed an online training covering physical health, cognitive health, social support, cultural competence, and sexual health.



## Issue #5:

# Educate providers and staff in institutional long-term care settings.

*The prospect of being re-traumatized by stigma, rejection, or loss of autonomy and authentic identity in an institutional setting makes long-term care a highly charged subject. “For many older people living with HIV, they are so fearful that that would be the last place they would want to go,” says Paul Kawata, Executive Director of [NMAC](#) and a MAT summit participant.*

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### **BUILD BASELINE KNOWLEDGE OF HIV AMONG NURSING HOME AND OTHER LONG-TERM CARE FACILITIES’ STAFF AND PROVIDERS.**

“We have a couple of members who have intentionally been serving people living with HIV and see that as part of their mission, but there is also a lack of broader understanding that this is a group of people that needs support,” says Katie Smith Sloan, a MAT steering committee member and president and CEO of [LeadingAge](#), a national membership organization for nonprofit nursing homes and long-term care facilities.

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### **EXPAND TRAINING ON CULTURAL COMPETENCY FOR THE LONG-TERM CARE WORKFORCE TO AVOID “RE-CLOSETING” AND RE-TRAUMATIZING OPLWH.**

LeadingAge’s Sloan also sees promise in ongoing work across the industry to promote trauma-informed measures in long-term care and to provide cultural competence training to its workforce.


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### **GIVE PROVIDERS AND STAFF MORE EDUCATION ON MEDICATION ISSUES AND OTHER SPECIALIZED NEEDS.**

A [study](#) in the *Journal of the Association of Nurses in AIDS Care* concluded that HIV care in nursing homes “needs to evolve” after finding gaps in evidence-based care, including 20% of HIV patients who did not receive any antiretroviral therapy.

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### **INCREASE HEALTH CARE PROFESSIONALS’ KNOWLEDGE OF HIV’S IMPACT ON NON-HIV-RELATED COMORBIDITIES AND THE POTENTIAL FOR POLYPHARMACY (ADVERSE DRUG INTERACTIONS).**

 St. Mary’s Center in the Harlem neighborhood of New York City provides individualized skilled nursing in a homelike environment to people living with HIV/AIDS, as well as an Adult Day program, creative art therapy, social work services, and pastoral care. St. Mary’s also serves people with “medication adherence issues and those who are dually or triply diagnosed with HIV/ AIDS, substance abuse, and mental illness.”


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### **EXPLORE OPTIONS FOR AN HIV-RELATED PROGRAM ON THE [PACE](#) (ALL-INCLUSIVE CARE OF THE ELDERLY) MODEL.**

## Focus Area #2C: Mental and Behavioral Health Care

As many as half of older adults living with HIV suffer from depression – about five times more than the broader population. This has been found to correlate with other issues, including higher rates of vision and hearing loss, heart and respiratory problems, diabetes, and broken bones, perhaps because it suppresses the immune response.

Many HIV co-morbidities are made worse by substance use. HealthHIV.org’s State of Aging with HIV survey found that 25% of older people with HIV are in recovery for substance use, 50% use marijuana daily, 42% use tobacco daily, and 24% use alcohol daily.

Conversely, good mental health tends to track with self-care and medication adherence. “That’s what kept me alive for 13 years. Because I kept my mental health up,” says DeeDee Ngozi Chamblee, Executive Director and Founder of  La Gender, Inc.


### Issue #1:

## Improve access to mental health (MH) and behavioral health (BH) care.

▶ **STRENGTHEN AWARENESS OF HIV/AGING ISSUES AMONG MH AND BH PROVIDERS.**

▶ **STREAMLINE REFERRALS BETWEEN MH, BH, AND MEDICAL SERVICES.**

▶ **TREAT BEHAVIORAL HEALTH PROBLEMS TO IMPROVE TREATMENT ADHERENCE AND CLINICAL OUTCOMES.**

 Ferguson Place, a residential treatment program run by PRC in San Francisco, was the first of its kind to address HIV/AIDS issues in people with co-occurring substance use and mental health issues.

### Issue #2:

## Expand work on HIV-specific concerns with cognitive decline, dementia, and Alzheimer’s Disease.

People living with HIV often experience cognitive decline at younger ages and there is growing evidence that HIV and aging may interact to adversely affect the brain and neurocognitive functions. Conditions include HIV encephalopathy and AIDS dementia complex, a serious consequence of HIV infection typically seen in advanced AIDS.

▶ **INCREASE SCREENING, TREATMENT, AND INTERVENTIONS FOR MILD FORMS OF COGNITIVE IMPAIRMENT COMMONLY SEEN IN OPLWH.**

▶ **INCREASE AWARENESS AND RESEARCH ON HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS.**

▶ **DEVELOP, INCREASE, AND SUPPORT THERAPEUTIC AND CAREGIVING OPTIONS.**


### **Issue #3:**

## ***Incorporate principles of trauma-informed care.***

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### **▶ RECOGNIZE THE HISTORY OF TRAUMA AMONG OPLWH.**

PTSD-like symptoms are so common among long-term HIV survivors that one organization took the name  [Let's Kick ASS](#), for AIDS Survivors Syndrome.

Trauma-informed care can take many forms. The art created in  [Bodyscapes](#) workshops (some of it seen in this report) explicitly draws on the power of creation to address trauma, believing that, “throughout this process of revealing our innermost stories, we transform ourselves from victims to interpreters of illness.”

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### **▶ HELP OPLWH REMAIN IN CARE BY RAISING PROVIDERS’ TRAUMA AWARENESS.**

Traumatized people who disproportionately negatively react to frustrations in the healthcare system may be construed as “difficult” and experience additional barriers to care, cautions Maile Karris, MD.

### **Issue #4:**

## ***Recognize and address the destructive power of stigma.***

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### **▶ EDUCATE PROVIDERS THAT MULTIPLE TYPES OF STIGMA EXIST THAT AFFECT OPLWH.**

These can include societal stigma (based on drug use, sexual orientation, gender identity, age, HIV status); internalized or self-stigma; provider or care setting stigma; intersectional stigma combining HIV and racial, ethnic, or other characteristics.

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### **▶ RECOGNIZE THAT FEAR OF REJECTION OR BEING “OUTED” IN NON-HIV SETTINGS DETERS MANY OPLWH FROM SEEKING CARE, JEOPARDIZING HEALTH.**

“Changing stigma is not a task for the faint of heart,” observes Stephen Karpiak of the National Resource Center on HIV and Aging at GMHC. One thing that can help is when the practitioners or staff members look like or share background or experience with those they serve.

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### **▶ SEEK GUIDANCE ON POLICIES AND PRACTICES (E.G., COMMUNICATIONS) FROM OPLWH WHERE POSSIBLE.**

### **Issue #5:**

## ***Prepare community-based support groups to assist OPLWH.***

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### **▶ OFFER EDUCATION, COACHING ON SERVING OPLWH TO COMMUNITY-BASED GROUPS.**

These can include Alcoholics Anonymous (AA), Al-Anon, NA (Narcotics Anonymous), long-term survivor groups, women helping women, and more.

▶ **HELP OPLWH CONNECT WITH GROUPS THAT ARE WELL PREPARED TO WELCOME PEOPLE LIVING WITH HIV.**

TPAN (Test Positive Aware Network), a long-established peer support group for people with HIV in Chicago, hosts Alcoholics Anonymous and Narcotics Anonymous meetings for people with (and without) HIV.

## **Focus Area #2D: Social/Psychosocial Support**

### **Issue #1**

## **Target social isolation.**

▶ **RECOGNIZE THE DESTRUCTIVE POWER OF SOCIAL ISOLATION AS A DRIVER OF POOR MENTAL AND PHYSICAL HEALTH IN OPLWH.**

A growing body of research has demonstrated that social isolation is actively dangerous, increasing the risk of premature death by up to 30% and exacerbating many health conditions.

▶ **PROMOTE SOCIAL OPPORTUNITIES, SUPPORT GROUPS, ACCESS TO ONLINE PEER SUPPORT.**

Buddy programs are some of the longest-established HIV support programs, including 🇺🇸 Philadelphia’s Action Wellness Buddy Program and the program at 🇺🇸 GMHC. Sometimes the “match” is intergenerational, allowing an older person an important chance to give back and support or mentor someone newly diagnosed.

Some in-person programs have gone online since COVID-19, while private Facebook groups have existed for years, including the 2,700-member 🇺🇸 HIV Long-Term Survivors League moderated by Tez Anderson. “There are people in this group that have never told anyone outside their family,” he says.

▶ **RECOGNIZE THAT SOME SUPPORT AND/OR FACILITATION MAY BE REQUIRED.**

The successful Village model of neighbors helping neighbors is being adapted to serve older people living with HIV in San Diego. 🇺🇸 2nd AC+: New Village Model - Leveraging Technology to Create Communities of Care Around Older People Living With HIV, led by Maile Karris, MD, uses an app to connect participants and is housed in the San Diego LGBT Center.

▶ **RECOGNIZE THE IMPORTANCE OF CAREGIVER SUPPORT.**

🇺🇸 Honoring Our Experience in San Francisco includes friends and “chosen family” in retreats in recognition of their trauma and need for support, regardless of health status.




## Issue #2:


# Address social determinants of health in programming.

Many people with HIV survive on low incomes and struggle with social determinants of health such as access to suitable housing, transportation, and nutrition.

### ▶ EMPHASIZE ECONOMIC INSECURITY AS A CRITICAL ISSUE FOR MANY OPLWH.

### ▶ INCLUDE PROGRAMS SUCH AS SUPPORTIVE HOUSING, SUBSIDIZED HOUSING, TRANSPORTATION, FOOD SECURITY, LEGAL COUNSELING, AND JOB TRAINING AND PLACEMENT AS PART OF A HOLISTIC APPROACH.

Food insecurity is so common that events run by the  Elizabeth Taylor 50+ Network in San Francisco always include food, says Vince Cristostomo. “Because rents are so high, people often skip one or even two meals in a day.”

At the  HIVE older adult program at APLA Health in LA, the prize for winning at weekly bingo is a free meal delivery from a popular restaurant.

### ▶ GET HIV AND AGING ISSUES ONTO THE AGENDA OF SOCIAL SERVICE PROVIDERS.

### ▶ EXPAND PATIENT EDUCATION AND ASSIST WITH PROGRAM NAVIGATION.

Involve social workers and community health workers, where available. Include insurance and benefits counseling.

APLA’s HIVE program also offer Life Skills Support in managing finances and Medicare.

### ▶ INCLUDE DISASTER PREPAREDNESS AND RESPONSE TO INCREASE PROGRAM RESILIENCY.

## Issue #3:

# Recognize diversity in identifying needs and designing programs.

### ▶ EXPLORE PROGRAM SEGMENTATION BY GROUP IDENTITY; LIVED EXPERIENCE; RACIAL, ETHNIC, AND SOCIOECONOMIC BACKGROUNDS; EXPERIENCE; GENDER; AND SEXUAL ORIENTATION.

### ▶ BE AWARE THAT AGE-SPECIFIC GROUPS MAY BE PREFERRED.

Consider age at onset of infection and length of experience living with HIV (e.g., long-term survivors and people who acquired the infection late in life).

 **BE GUIDED BY OPLWH.**

It is worth noting that this strategy may have to overcome entrenched skepticism, particularly among older LGBTQ people. “A lot of these places and groups were never set up for us in the first place,” says NMAC’s Paul Kawata.

**Issue #4:**

**Lack of social support often includes a lack of caregivers.**

*Isolation, losing a generation of friends, never having children, and estrangement from family can leave people aging with HIV with few options when they need informal help. “These folks do not have caregivers. It’s that simple,” says Stephen Karpiak of GMAC. An important alternative is “families of choice” – friends who step up in times of need.*

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 **SUPPORT INFORMAL CAREGIVING PROGRAMS.**

 **PROMOTE ADVANCE CARE PLANNING FOR PEOPLE AGING WITH HIV, INCLUDING CREATING LIVING WILLS AND SELECTING HEALTH CARE DECISIONMAKERS.**

**Issue #5:**

**Support peer-led groups (or make skilled facilitation available).**

 *NMAC’s HIV 50+ Strong and Healthy program has made a series of very small grants for peer-led activities including a dog-walking group and a singles mixer. “I love the innovation that comes from that,” says Executive Director Paul Kawata. “The process forces you to reach out to other people, which ends your isolation.”*



*Ron Wiggin, Resurrection, 2017*

*Pastel on Fabriano paper, 15" x 22"*

# 3

## FOCUS AREA #3:

# THE WAY FORWARD

Policy-based advocacy offers the opportunity to create system-level improvements and seek stable long-term funding. Moving Ahead Together has benefited from several important policy initiatives. SAGE's [HIV & Aging Policy Action Coalition \(HAPAC\)](#) focuses on the needs of long-term survivors and LGBT older people living with HIV and the disproportionate impact on marginalized communities. AIDS United's [HIV and Aging: Older Adults Living and Thriving with HIV](#) policy platform, recently released, was informed by a year of listening sessions with diverse older adults living with HIV.



### LISTEN UP

For more first-person perspective on The Way Forward; Policy, Inspiration, and Replication Integrating and Improving Care and Services, please listen to excerpts from interviews with older people living with HIV/AIDS in this [video](#).

## Focus Area #3A: Policy

### Issue #1:

## Add aging issues to the Ending the HIV Epidemic (EHE) plan.

The federal [EHE initiative](#) focuses primarily on treatment, prevention, and directing funding to locations of high need in service of three goals: by 2020, 90% of people living with HIV will know their status; receive sustained antiretroviral therapy; and achieve viral suppression. [[CDC Infographic](#)]

### ▶ OPLWH SHOULD BE CONSIDERED AN EHE SPECIAL NEEDS POPULATION.

### ▶ EXPAND FOCUS TO INCLUDE PEOPLE LIVING WITH HIV, RATHER THAN FOCUSING ONLY ON PREVENTING NEW INFECTIONS.

Ensure that prevention-focused programming does not overlook ongoing needs of OPLWH, particularly long-term survivors.

### ▶ EXISTING FOCUS ON PREVENTION SHOULD ALSO EXPLICITLY INCLUDE OLDER PEOPLE'S RISK OF CONTRACTING HIV AND ACCESS TO TESTING.

### ▶ EXPLORE WAYS TO ALLOW OPLWH TO MAKE IMPORTANT CONTRIBUTIONS TO EHE PILOT PROGRAMS.

This can include serving as peer navigators and community volunteers.

### ▶ ADVOCATE FOR INCLUDING THE NEEDS AND CONCERNS OF OPLWH IN ALL FEDERAL, STATE, AND LOCAL PLANS AND INITIATIVES TO END THE HIV EPIDEMIC.



## Issue #2:

# Reconsider age specificity in program eligibility: Is anyone “too young” to receive aging services?

50 is considered the in-point for aging with HIV, and in communities of color, the lived experience of aging with HIV can begin even younger, but most relevant policies do not reflect this. Eligibility for aging services starts at age 65 (most Medicare beneficiaries) or age 60 (most Older Americans Act [OAA] services (with potential exceptions in OAA Title XI).

### ▶ **EXPLORE AND EXPAND ACCESS TO OAA PROGRAMS THAT DO NOT HAVE AGE RESTRICTIONS (SUCH AS SUPPORT FOR EARLY-ONSET DEMENTIA).**

A recent [survey](#) of Area Agencies on Aging (AAA) found more than half already serve people under 60 for specific needs.

### ▶ **RE-IMAGINE ELIGIBILITY FOR AGING SERVICES (E.G., NUTRITION PROGRAMS, BEHAVIORAL HEALTH) BASED ON NEED, FUNCTIONAL STATUS, OR RISK OF INSTITUTIONALIZATION, RATHER THAN AGE.**

### ▶ **TAKE ADVANTAGE OF LESS RIGID AGE RESTRICTIONS ON FUNDING FOR AGING RESEARCH, PARTICULARLY ON ISSUES OF LONGITUDINAL CHANGE OR DISEASE COURSE.**

## Issue #3:

# Explore opportunities within the Older Americans Act (OAA) and OAA reauthorization process.

### ▶ **PURSUE DESIGNATION OF OPLWH AS AN OAA “POPULATION OF GREATEST SOCIAL NEED.”**

Advocacy efforts during the 2020 reauthorization did not succeed; resistance from some aging groups focused on concerns that other disease groups would want similar access to already-scarce resources.

### ▶ **EXPLORE OTHER OAA FUNDING STREAMS, PROGRAMS FOR WHICH OPLWH ARE OR COULD BE ELIGIBLE.**

Existing OAA language on social isolation and COVID-19 may help unlock funding for OPLWH (many of whom also belong to other covered groups).

### ▶ **LEARN FROM, BUILD ON RELATED POLICY SUCCESSES AT THE STATE LEVEL.**

In 2019, Illinois [became](#) the first state to designate older adults living with HIV as a target population of “greatest social need.” California and Massachusetts have similarly designated LGBTQ older adults as communities of “greatest social need.”

## Issue #4:

# Prepare Medicare to serve a growing population of beneficiaries living with HIV.

Medicare is now the single largest source of federal financing for HIV care and treatment (although HIV spending represented just 2% of Medicare's total spending in 2016). A majority of Medicare beneficiaries with HIV are dually eligible for Medicare and Medicaid and receive low-income subsidies under Part D.

### ▶ **REQUIRE MEDICARE TO SUPPORT OPLWH WITH ENROLLMENT AND TRANSITION INTO THE PROGRAM.**

The American Academy of HIV Medicine [Policy Platform](#) states that, "Medicare providers must be prepared to assist with the care of patients from Ryan White clinics and other HIV care providers. Medicare providers may need further incentive to accept HIV patients. We must ensure that low/fixed income elderly don't lose access to care, medication, or case management services as they age and transition to Medicare programs."

An important resource: HRSA's TargetHIV.org [Medicare Coverage for People with HIV](#).

### ▶ **UPDATE THE RYAN WHITE PROGRAM TO ENSURE BETTER INTEGRATION WITH MEDICARE (AND TO COORDINATE WHEN THAT IS ALLOWED) TO PREVENT OPLWH FROM "AGING OUT" OF TRUSTED SERVICES.**

### ▶ **INCREASE AWARENESS, DATA ON THE NEEDS OF OPLWH AS AN EMERGING MEDICARE POPULATION, INCLUDING MEDICATION COSTS AND CO-MORBIDITIES.**

### ▶ **MAINTAIN STATUS OF ANTIRETROVIRAL DRUGS AS A "PROTECTED CLASS" UNDER MEDICARE PART D.**

AIDS United [opposed](#) a 2018 proposed HHS rule to weaken this protection.

### ▶ **ENCOURAGE MEDICARE TO STANDARDIZE BENEFITS AND EXPAND FUNDING FOR HIV CASE MANAGEMENT SERVICES IN DIVERSE SETTINGS.**

### ▶ **ADD HIV-RELATED OUTCOMES AND DATA COLLECTION TO MEDICARE PERFORMANCE MEASURES, INCLUDING GENDER IDENTITY AND SEXUAL ORIENTATION.**

### ▶ **ADD HIV CARE QUALITY MEASURES TO NURSING HOME DATA COLLECTED AND REPORTED TO MEDICARE.**

### ▶ **EDUCATE OPLWH ABOUT THE WELCOME TO MEDICARE BENEFIT; HELP PROVIDERS MAXIMIZE ITS UTILITY.**

### ▶ **SEEK OPPORTUNITIES TO MAXIMIZE THE MEDICARE ANNUAL WELLNESS VISIT FOR OPLWH.**

► **PREPARE PEER SUPPORT PROGRAMS WITHIN THE AGING SERVICES NETWORK TO ASSIST OPLWH ENTERING MEDICARE.**

An excellent potential resource: [SHIP](#), the State Health Insurance Assistance Program.

**Issue #5:**

***Address Medicaid’s important role in serving OPLWH, and its multiple state-by-state challenges.***

► **STRENGTHEN COORDINATION BETWEEN MEDICARE AND MEDICAID TO IMPROVE CARE OF DUALY ELIGIBLE OPLWH.**

► **MAKE IT EASIER, AND PROVIDE HELP FOR BENEFICIARIES, TO TRANSITION INTO MEDICAID FROM OTHER PROGRAMS, INCLUDING PRIVATE INSURANCE.**

► **ENSURE THAT MEDICAID PROGRAMS THAT USE MANAGED CARE TO PROVIDE LONG-TERM SERVICES AND SUPPORTS (LTSS) ARE PREPARED FOR THE NEEDS OF OPLWH.**

► **ADD HIV-RELATED OUTCOMES TO MEDICAID PERFORMANCE MEASURES TO INCENTIVIZE GOOD CARE.**

► **SUPPORT MEDICAID EXPANSION AS A MEANS OF ADDRESSING SOCIAL DETERMINANTS OF HEALTH FOR OPLWH.**

States that reject Medicaid expansion offer fewer options for OPLWH in mental/behavioral health and important wraparound services (e.g., housing, transportation, case management).

OPLWH in non-expansion states are more likely to be have been un/underinsured and come to Medicare in worse health due to gaps in care, lack of viral suppression, disease progression, and untreated co-morbidities.

► **OPPOSE MEDICAID BLOCK GRANTS, CUTS, AND ELIGIBILITY CHANGES THAT WOULD REDUCE SERVICES.**

**Issue #6:**

***Strengthen protections under Social Security Disability (SSI).***

*Recent changes to SSI’s HIV disability rules and claims review standards have led to some OPLWH being cut off. Particularly among long-term survivors, people who went on SSI when young then transition to traditional Social Security when older may lose up to 75% of income due to limited work history.*

- ▶ **SUPPORT LEGAL SERVICES PROVIDING REVIEW, APPEALS, AND ADVOCACY GROUPS WORKING ON THIS ISSUE.**

One such organization is the  [Center for HIV Law and Policy](#).

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- ▶ **PROVIDE SUPPORT FOR JOB READINESS, RE-TRAINING, AND PLACEMENT SERVICES FOR PEOPLE WHO ARE RULED ABLE TO WORK AND WHOSE SSI IS WITHDRAWN.**

### **Issue #7:**

## **Leverage role of regulators to integrate and strengthen systems.**

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- ▶ **ENCOURAGE ACCREDITING BODIES (E.G., HRSA) TO INCLUDE NON-HIV SPECIFIC OUTCOMES SUCH AS ADVANCE CARE PLANNING AND COMPLETION OF MEDICARE WELLNESS EXAMS IN HIV QUALITY MEASURES.**

### **Issue #8:**

## **Recognize, address the need for options in long-term services and supports (LTSS).**

*Many nursing homes and assisted living facilities are unprepared to accommodate OPLWH and fears of being “outed” or “re-closeted” are common among OPLWH.*

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- ▶ **ADD HIV AND LGBTQ EDUCATION TO THE INDUSTRY’S EXISTING CULTURAL COMPETENCE TRAINING, WORKFORCE DEVELOPMENT, AND TRAUMA-INFORMED CARE. INCLUDE MEDICAL PERSONNEL AND VOLUNTEERS.**
- 

- ▶ **RAISE PROVIDER AND STAFF AWARENESS AND PREPAREDNESS ON CHALLENGES THAT SOME OPLWH LIVE WITH, SUCH AS SUBSTANCE USE.**
- 

- ▶ **PURSUE STATE-BASED APPROACHES TO DISCRIMINATION PROTECTIONS FOR OPLWH IN LONG-TERM CARE SETTINGS, BUILDING ON RECENTLY PASSED ILLINOIS MODEL.**
- 

- ▶ **EXPAND ALTERNATIVES TO NURSING HOME PLACEMENT FOR OPLWH, INCLUDING AGING IN COMMUNITY, IN-HOME CARE, LOW-INCOME HOUSING, AND SUPPORTIVE HOUSING.**
- 

- ▶ **ADVOCATE FOR EXPANSION OF HOUSING AND HOUSING ASSISTANCE UNDER THE HOUSING OPPORTUNITIES FOR PERSONS WITH AIDS PROGRAM (HOPWA).**
-



- ▶ **RECOGNIZE THAT ECONOMIC INSECURITY AND LACK OF SAVINGS PUT MANY LTSS OPTIONS OUT OF REACH FOR SOME OPLWH.**

- ▶ **EXPLORE OPTIONS FOR AN HIV-RELATED PROGRAM WITHIN THE PACE (ALL-INCLUSIVE CARE OF THE ELDERLY) MODEL.**

**Issue #9:**

**Address discrimination, legal status of OPLWH, and criminalization concerns.**

- ▶ **END CRIMINALIZATION OF HIV EXPOSURE OR ADDITIONAL PENALTIES FOR COMMITTING OTHER CRIMES WHILE HIV POSITIVE.**

Such statutes are currently on the books in 37 states (as of 2020, according to the [CDC](#)), and should be removed.

🌀 The HIV Is Not a Crime [initiative](#), co-sponsored by the Elizabeth Taylor AIDS Foundation, Gilead Sciences, The Counter Narrative Project, Positive Women’s Network, The Sero Project, Transgender Law Center, and the US People Living with HIV Caucus, launched a public education campaign in spring 2020 that included an online town hall.

- ▶ **END DISCRIMINATORY PRACTICES THAT EXCLUDE PEOPLE LIVING WITH HIV FROM PURCHASING LIFE AND DISABILITY INSURANCE.**

The [Equal Insurance HIV Act of California](#), passed in September 2020, requires that a person’s HIV-positive status be treated like any other chronic condition and will no longer allow insurers to refuse life and disability income insurance applications based solely on a positive HIV test.



*Raoul Thomas,  
3 Heads Are Better Than 1,  
2018*

*Pastel on Fabriano paper,  
11” x 15”*

## Focus Area #3B: Inspiration and Replication

### Issue #1

## Ensure broad-based exploration and learning and a strength-based approach.

*Both HIV care and geriatrics are more-than-usually patient-centered care systems and HIV has a strong history of patient engagement in care and advocacy.*

- ▶ **BUILD ON A TRADITION OF ENGAGED PATIENTS AND SELF-ADVOCACY TO IMPROVE CARE OF OPLWH.**
- ▶ **MAXIMIZE THE UNREALIZED POTENTIAL FOR BETTER COORDINATION IN BOTH SECTORS.**
- ▶ **IDENTIFY AND PURSUE COMMON GROUND BETWEEN HIV AND AGING SECTORS FOR FUTURE WORK.**

### Issue #2:

## Seek to turn the relative newness of aging with HIV into an asset.

*The absence of long program histories or a robust evidence base can present a challenge, particularly when funding (such as Title III-D or Older Americans Act funds) is restricted to evidence-based programs, and when working with philanthropy, where metrics-based evaluation is often prioritized. In a field of high need and very limited services, embracing any way to grow is a priority.*

*As Jewish Healthcare Foundation executive Nancy Zionts reflected during the MAT summit, “Right now it’s a program here, a program there – we have to get past an N of 1.”*

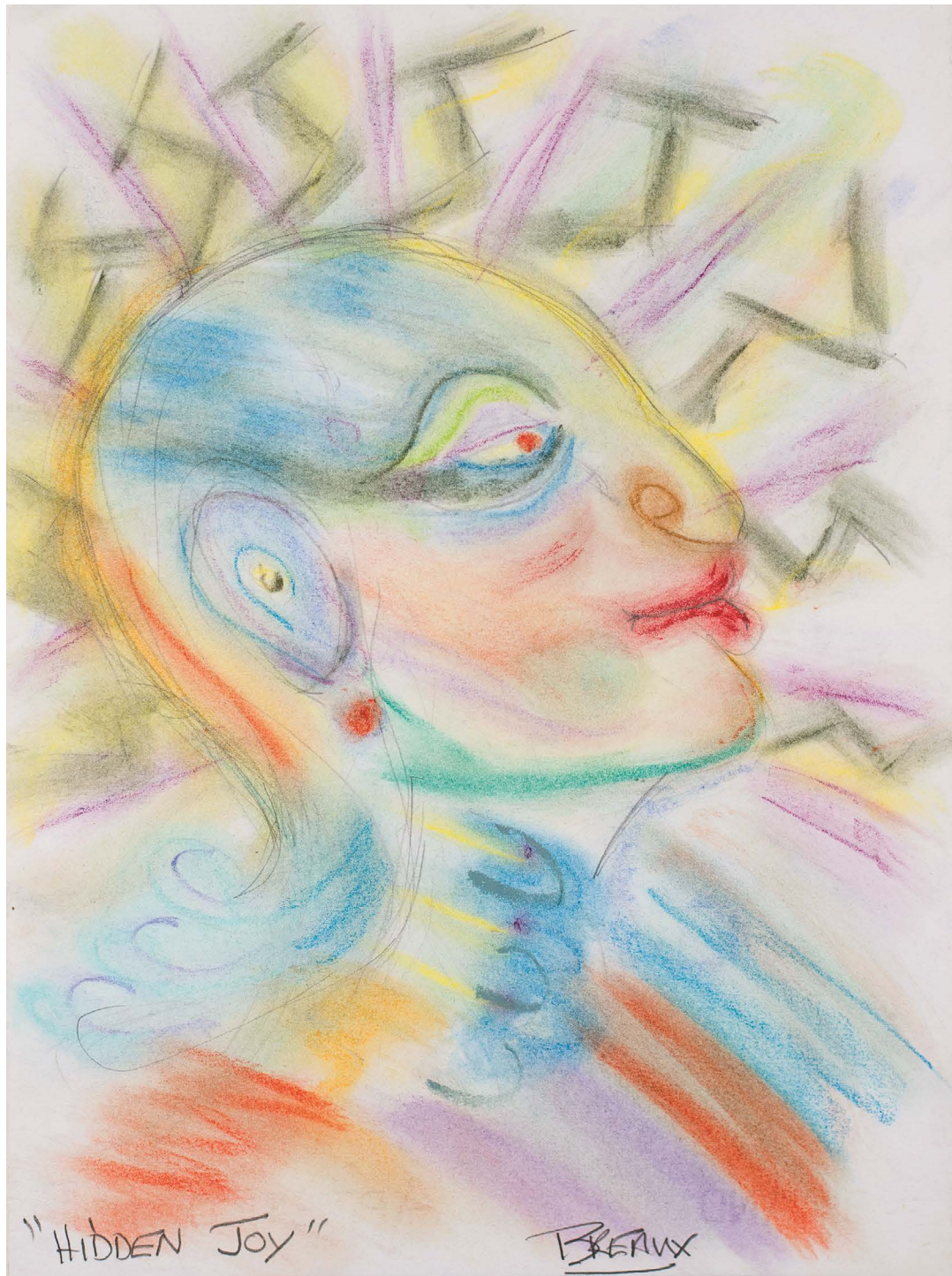
- ▶ **ACKNOWLEDGE THE NEWNESS OF THE FIELD AND RELATIVE LACK OF PROGRAM EXAMPLES, WHILE WORKING TO ADDRESS THAT; MAKE THIS AN ADVANTAGE BY CULTIVATING DISCOVERY AND INNOVATION.**
- ▶ **USE EXAMPLE OF FLEXIBILITY AND REDUCED FUNDING RESTRICTIONS IN MANY COVID-19-RELATED PROGRAMS TO SHOW THAT IMPORTANT WORK IS NOT EXCLUSIVELY EVIDENCE-BASED.**

**Issue #3:**

**Listen and learn from the resilience,  
courage, and authentic voices of OPLWH.**

*The Denver Principles are hallmarks of the HIV movement that have driven progress and should continue. In the words of long-term survivor and Director of Special Projects at the AIDS Foundation of Chicago, Román Buenrostro, "In many respects, I feel I am here now to create the system of services that, at some point, I will be needing."*

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Harry Breaux, *Hidden Joy*, 2017 / Pastel on Fabriano paper, 15" x 22"

[\*\*Back to TOC\*\*](#)



# APPENDIX A:

## The Moving Ahead Together Framework

(condensed) (PDF)

### Focus Area #1: COMPLEXITIES AND CHALLENGES

<b>Issue #1: The epidemic has changed over time.</b>	<ul style="list-style-type: none"><li>• The survival rate is much improved.</li><li>• Demographics have changed.</li><li>• The age profile has changed dramatically.</li><li>• Geographic distribution has shifted.</li></ul>
<b>Issue #2: Certain groups bear a disproportionate burden.</b>	<ul style="list-style-type: none"><li>• Racial disparities are high.</li><li>• Black women face disproportionately high rates of infection.</li><li>• Transgender older women face high risk of infection, stigma, and isolation.</li><li>• Targeted HIV services for older women are rare.</li><li>• Older people are more likely to have late-stage HIV at time of diagnosis.</li><li>• Older people and their medical providers underestimate their risk.</li></ul>
<b>Issue #3: Stigma perpetuates discrimination and creates obstacles to care and support.</b>	<ul style="list-style-type: none"><li>• Multiple forms of stigma apply.</li><li>• HIV stigma is reinforced by lack of community and provider understanding.</li><li>• Misperceptions about HIV infection abound.</li><li>• Social and racial justice concerns are common.</li><li>• Discomfort in accessing aging services remains an issue for older people living with HIV.</li></ul>
<b>Issue #4: Location matters; most services are local.</b>	<ul style="list-style-type: none"><li>• Small towns and rural places may have different needs and resources than urban centers.</li><li>• Communities' ability to obtain public funding or partially self-fund varies significantly.</li><li>• Virtual support groups and professional services delivered by telehealth can expand options but OPLWH's access and capacity to use technology varies.</li></ul>
<b>Issue #5: One size does not fit all in program design.</b>	<ul style="list-style-type: none"><li>• Diversity among OPLWH may require extra creativity in creating services.</li><li>• Differences matter; but scarce resources can make customizing or expanding services challenging.</li><li>• Experience matters; long-term survivors' needs differ from those of older people newly diagnosed.</li><li>• Even successful programs may not be easily replicated.</li></ul>
<b>Issue #6: Underestimating the challenge and overestimating progress.</b>	<ul style="list-style-type: none"><li>• "A manageable chronic disease"</li><li>• Less public focus.</li><li>• Multiple co-morbidities and accentuated aging are part of the experience.</li><li>• Recruiting new HIV providers is getting harder and older specialists are starting to retire.</li><li>• Overtaken by COVID-19?</li></ul>

## **Focus Area #2: INTEGRATING AND IMPROVING CARE AND SERVICES**

### **Focus Area #2A: CORE PRINCIPLES**

<p><b><i>Issue #1: Health equity principles should inform HIV and aging programs and care.</i></b></p>	<ul style="list-style-type: none"> <li>• Acknowledge the health disparities, racial and social inequities, stigma, marginalization, and discrimination that many OPLWH experience.</li> <li>• Leverage the social determinants of health.</li> <li>• Bring a social and racial justice lens to HIV and aging programming and advocacy.</li> <li>• Employ a values-based approach to build intergenerational, intersectional, and multi-sector appeal.</li> </ul>
<p><b><i>Issue #2: Promote person-centered care by connecting HIV, aging, and social care providers.</i></b></p>	<ul style="list-style-type: none"> <li>• Offer or co-locate complementary services where possible.</li> <li>• Establish systems to increase communication, expertise sharing, and referrals between HIV, geriatric/primary care (PC) providers, and social services.</li> <li>• Learn from one-stop-shop integration used in many Ryan White programs.</li> <li>• Leverage the trust that OPLWH feel with providers and settings in their “comfort zones” when adding, integrating new services.</li> </ul>

### **Focus Area #2B: MEDICAL CARE**

<p><b><i>Issue #1: Help primary care providers and geriatricians build their knowledge of HIV issues.</i></b></p>	<ul style="list-style-type: none"> <li>• “Could it be HIV?”</li> <li>• Create and disseminate educational resources and professional development opportunities to help geriatrics and PC providers build HIV expertise.</li> <li>• Increase health care professionals’ knowledge of the potential for polypharmacy in patients living with HIV and other conditions.</li> <li>• Encourage HIV-related Continuing Medical Education (CME) curriculum, mentoring, attendance at conferences and specialized trainings.</li> </ul>
<p><b><i>Issue #2: Include sexual health in primary and specialty care for older adults.</i></b></p>	<ul style="list-style-type: none"> <li>• Encourage and support regular taking of sexual history from older adults.</li> <li>• Encourage, support, and provide appropriate training for providers on “difficult conversations” about older adult sexuality and HIV, potential risk factors, HIV testing, knowing HIV status, and prevention options.</li> <li>• Promote geriatric and PC provider and staff awareness of PrEP and PEP medication and U=U.</li> </ul>
<p><b><i>Issue #3: Build primary care providers’ and geriatricians’ cultural competency on HIV issues.</i></b></p>	<ul style="list-style-type: none"> <li>• Acknowledge and work to eliminate stigma in health care that can exacerbate OPLWH’s fear of being rejected or “outed.”</li> <li>• Promote marketing (signage, handouts, online) that indicates that OPLWH and sexual minorities and gender diverse people are welcomed and served.</li> <li>• Include staff (e.g., schedulers, receptionists, medical assistants, office and facilities staff) in cultural competency training.</li> <li>• Seek guidance on policies and practices from OPLWH where possible.</li> </ul>



## Focus Area #2C: MENTAL AND BEHAVIORAL HEALTH CARE

<p><b>Issue #1: Improve access to mental health (MH) and behavioral health (BH) care.</b></p>	<ul style="list-style-type: none"> <li>• Strengthen awareness of HIV/aging issues among MH and BH providers.</li> <li>• Streamline referrals between MH, BH, and medical services.</li> <li>• Treat behavioral health problems to improve treatment adherence and clinical outcomes.</li> </ul>
<p><b>Issue #2: Expand work on HIV-specific concerns with cognitive decline, dementia, and Alzheimer’s Disease.</b></p>	<ul style="list-style-type: none"> <li>• Increase screening, treatment, and interventions for mild forms of cognitive impairment commonly seen in OPLWH.</li> <li>• Increase awareness and research on HIV-associated neurocognitive disorders.</li> <li>• Develop, increase, and support therapeutic and caregiving options.</li> </ul>
<p><b>Issue #3: Incorporate principles of trauma-informed care.</b></p>	<ul style="list-style-type: none"> <li>• Recognize the history of trauma among OPLWH.</li> <li>• Help OPLWH remain in care by raising providers’ trauma awareness.</li> </ul>
<p><b>Issue #4: Recognize and address the destructive power of stigma.</b></p>	<ul style="list-style-type: none"> <li>• Educate providers that multiple types of stigma exist that affect OPLWH.</li> <li>• Recognize that fear of rejection or being “outed” in non-HIV settings deters many OPLWH from seeking care, jeopardizing health.</li> <li>• Seek guidance on policies and practices (e.g., communications) from OPLWH.</li> </ul>
<p><b>Issue #5: Prepare community-based support groups to assist OPLWH.</b></p>	<ul style="list-style-type: none"> <li>• Offer education, coaching on serving OPLWH to community-based groups.</li> <li>• Help OPLWH connect with groups that are well prepared to welcome people living with HIV.</li> </ul>

## Focus Area #2D: SOCIAL/PSYCHOSOCIAL SUPPORT

<p><b>Issue #1: Target social isolation.</b></p>	<ul style="list-style-type: none"> <li>• Recognize the destructive power of social isolation as a driver of poor mental and physical health in OPLWH.</li> <li>• Promote social opportunities, support groups, access to online peer support.</li> <li>• Recognize that some support and/or facilitation may be required.</li> <li>• Recognize the importance of caregiver support.</li> </ul>
<p><b>Issue #2: Address social determinants of health in programming.</b></p>	<ul style="list-style-type: none"> <li>• Emphasize economic insecurity as a critical issue for many OPLWH.</li> <li>• Include programs such as supportive housing, subsidized housing, transportation, food security, legal counseling, and job training and placement as part of a holistic approach.</li> <li>• Get HIV and aging issues onto the agenda of social service providers.</li> <li>• Expand patient education and assist with program navigation.</li> <li>• Include disaster preparedness and response to increase program resiliency.</li> </ul>

<p><b>Issue #3: Recognize diversity in identifying needs and designing programs.</b></p>	<ul style="list-style-type: none"> <li>• Explore program segmentation by group identity; lived experience; racial, ethnic, and socioeconomic backgrounds; experience; gender; and sexual orientation.</li> <li>• Be aware that age-specific groups may be preferred.</li> <li>• Be guided by OPLWH.</li> </ul>
<p><b>Issue #4: Lack of social support often includes a lack of caregivers.</b></p>	<ul style="list-style-type: none"> <li>• Support informal caregiving programs.</li> <li>• Promote Advance Care Planning for people aging with HIV, including creating living wills and selecting health care decisionmakers.</li> </ul>
<p><b>Issue #5: Support peer-led groups (or make skilled facilitation available).</b></p>	

### **Focus Area #3: THE WAY FORWARD**

#### **Focus Area #3A: POLICY**

<p><b>Issue #1: Add aging issues to the Ending the HIV Epidemic (EHE) plan.</b></p>	<ul style="list-style-type: none"> <li>• OPLWH should be considered an EHE special needs population.</li> <li>• Expand focus to include people living with HIV, rather than focusing only on preventing new infections.</li> <li>• Existing focus on prevention should also explicitly include older people’s risk of contracting HIV and access to testing.</li> <li>• Explore ways to allow OPLWH to make important contributions to EHE pilot programs.</li> <li>• Advocate for including the needs and concerns of OPLWH in all federal, state, and local plans and initiatives to end the HIV epidemic.</li> </ul>
<p><b>Issue #2: Reconsider age specificity in program eligibility: Is anyone “too young” to receive aging services?</b></p>	<ul style="list-style-type: none"> <li>• Explore and expand access to OAA programs that do not have age-restrictions (such as support for early-onset dementia).</li> <li>• Re-imagine eligibility for aging services (e.g., nutrition programs, behavioral health) based on need, functional status, or risk of institutionalization, rather than age.</li> <li>• Take advantage of less rigid age restrictions on funding for aging research, particularly on issues of longitudinal change or disease course.</li> </ul>
<p><b>Issue #3: Explore opportunities within the Older Americans Act (OAA) and OAA reauthorization process.</b></p>	<ul style="list-style-type: none"> <li>• Pursue designation of OPLWH as an OAA “population of greatest social need.”</li> <li>• Explore other OAA funding streams, programs for which OPLWH are or could be eligible.</li> <li>• Learn from, build on related policy successes at the state level.</li> </ul>

<p><b><i>Issue #4: Prepare Medicare to serve a growing population of beneficiaries living with HIV.</i></b></p>	<ul style="list-style-type: none"> <li>• Require Medicare to support OPLWH with enrollment and transition into the program.</li> <li>• Update the Ryan White program to ensure better integration with Medicare (and to coordinate when that is allowed) to prevent OPLWH from “aging out” of trusted services.</li> <li>• Increase Medicare’s awareness and data on the needs of OPLWH as an emerging Medicare population, including medication costs and co-morbidities.</li> <li>• Maintain status of antiretroviral drugs as a “protected class” under Medicare Part D.</li> <li>• Encourage Medicare to standardize benefits and expand funding for HIV case management services in diverse settings.</li> <li>• Add HIV-related outcomes and data collection to Medicare performance measures, including gender identity and sexual orientation.</li> <li>• Add HIV care quality measures to nursing home data collected and reported to Medicare.</li> <li>• Educate OPLWH about the Welcome to Medicare benefit; help providers maximize its utility.</li> <li>• Seek opportunities to maximize the Medicare Annual Wellness Visit for OPLWH.</li> <li>• Prepare peer support programs within the aging services network to assist OPLWH entering Medicare.</li> </ul>
<p><b><i>Issue #5: Address Medicaid’s important role in serving OPLWH and its multiple state-by-state challenges.</i></b></p>	<ul style="list-style-type: none"> <li>• Strengthen coordination between Medicare and Medicaid to improve care of dually eligible OPLWH.</li> <li>• Make it easier, and provide help for beneficiaries, to transition into Medicaid from other programs, including private insurance.</li> <li>• Ensure that Medicaid programs that use managed care to provide long-term services and supports (LTSS) are prepared for the needs of OPLWH.</li> <li>• Add HIV-related outcomes to Medicaid performance measures to incentivize good care.</li> <li>• Support Medicaid expansion as a means of addressing social determinants of health for OPLWH.</li> <li>• Oppose Medicaid block grants, cuts, and eligibility changes that would reduce services.</li> </ul>
<p><b><i>Issue #6: Strengthen protections under Social Security Disability (SSI).</i></b></p>	<ul style="list-style-type: none"> <li>• Support legal services providing for review, appeals and advocacy groups.</li> <li>• Provide support for job readiness, re-training, and placement services for people who are ruled able to work and whose SSI is withdrawn.</li> </ul>
<p><b><i>Issue #7: Leverage role of regulators to integrate and strengthen systems.</i></b></p>	<ul style="list-style-type: none"> <li>• Encourage accrediting bodies (e.g., HRSA) to include non-HIV specific outcomes such as advance care planning and completion of Medicare Wellness exams in HIV quality measures.</li> </ul>

<p><b><i>Issue #8: Recognize, address the need for options in long-term services and supports (LTSS).</i></b></p>	<ul style="list-style-type: none"> <li>• Add HIV and LGBTQ education to the industry’s existing cultural competence training, workforce development, and trauma-informed care. Include medical personnel and volunteers.</li> <li>• Raise provider and staff awareness and preparedness on challenges that some OPLWH live with, such as substance use.</li> <li>• Pursue state-based approaches to discrimination protections for OPLWH in long-term care settings, building on recently passed Illinois model.</li> <li>• Expand alternatives to nursing home placement for OPLWH, including aging in community, in-home care, low-income housing, and supportive housing.</li> <li>• Advocate for expansion of housing and housing assistance under the Housing Opportunities for Persons with AIDS Program (HOPWA).</li> <li>• Recognize that economic insecurity and lack of savings put many LTSS options out of reach for some OPLWH.</li> <li>• Explore options for an HIV-related program on the PACE (All-Inclusive Care of the Elderly) model.</li> </ul>
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<p><b><i>Issue #9: Address legal discrimination and criminalization concerns.</i></b></p>	<ul style="list-style-type: none"> <li>• End criminalization of HIV exposure or additional penalties for committing other crimes while HIV positive.</li> <li>• End discriminatory practices that exclude people living with HIV from purchasing life and disability insurance.</li> </ul>
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**Focus Area #3B: INSPIRATION AND REPLICATION**

<p><b><i>Issue #1: Ensure broad-based exploration and learning and a strength-based approach.</i></b></p>	<ul style="list-style-type: none"> <li>• Build on a tradition of engaged patients and self-advocacy to improve care of OPLWH.</li> <li>• Maximize the unrealized potential for better coordination in both sectors.</li> <li>• Identify and pursue common ground between HIV and aging sectors for future work.</li> </ul>
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<p><b><i>Issue #2: Seek to turn the relative newness of aging with HIV into an asset.</i></b></p>	<ul style="list-style-type: none"> <li>• Acknowledge the newness of the field and relative lack of program examples, while working to address that; make this an advantage by cultivating discovery and innovation.</li> <li>• Use example of flexibility and reduced funding restrictions in many COVID-19-related programs to show that important work is not exclusively evidence-based.</li> </ul>
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<p><b><i>Issue #3: Listen and learn from the resilience, courage, and authentic voices of OPLWH.</i></b></p>	
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# **APPENDIX B:**

## **Key Resources**

[HIV.gov](#) – information from across the Federal government on HIV/AIDS

[HIV/AIDS Epidemic in the United States: The Basics \(Fact Sheet – Kaiser Family Foundation\)](#)

[HIV and Aging Toolkit](#) from the AIDS Education and Training Center Program (AETC)

The American Academy of HIV Medicine [Provider Education Center](#)

American Academy of HIV Medicine [Policy Platform](#)

[National Resource Center on HIV & Aging \(Gay Men’s Health Crisis/GMHC\)](#)

[National Resource Center on LGBT Aging](#)

[HIV/AIDS: Your Rights and Resources](#) from SAGE (Advocacy and Services for LGBT Elders)

[About the Ryan White HIV/AIDS Program \(HRSA.gov\)](#)

[TargetHIV.org](#) - Tools for HRSA’s Ryan White HIV/AIDS Program

[TargetHIV – Aging-related Resources](#)

[TargetHIV Technical Assistance Directory and Best Practices Compilation](#)

[Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care](#)

[Optimizing HIV Care for People Aging with HIV: Putting Together the Best Health Care Team](#)

[TargetHIV: Medicare Coverage for People with HIV](#)

[The Basics of Medicare for Ryan White HIV/AIDS Program Clients \(PDF\)](#)

[The Ryan White Program: The Basics \(from the Kaiser Family Foundation\) \(2020\)](#)

[Medicare and HIV \(Kaiser Family Foundation\)](#)

[Housing Opportunities for People with HIV Program \(HOPWA\) \(HIV.gov\)](#)

[Philanthropic Support to Address HIV/AIDS in 2018 \(Fundors Concerned About AIDS FCAA\)](#)

[“You’re Awfully Old to Have \*This\* Disease”: Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS \(\*The Gerontologist\*\)](#)

[ROAH: HIV & Aging in San Francisco: Findings from the Research on Older Adults with HIV 2.0 \(2018\)](#)

10th International Workshop on HIV & Aging (2019) – [Enduring Materials](#)

[Transitioning from Medicaid Disability Coverage to Long-Term Medicare Coverage: The Case of People Living with HIV/AIDS in California](#)



# **APPENDIX C:**

## **Key Participants**

### ***Members of the Moving Ahead Together Steering Committee***

John Barnes, Executive Director, Funders Concerned About AIDS  
Mark Brennan-Ing, Senior Research Scientist, Brookdale Center for Healthy Aging, Hunter College, the City University of New York  
Román Buenrostro, Director of Special Projects and Planning, AIDS Foundation of Chicago  
Vince Crisostomo, Director of Aging Services, San Francisco AIDS Foundation  
Margaret Franckhauser, Director of Aging Services, JSI Research and Training Institute  
Karen Fredriksen Goldsen, Principal Investigator of the National Health, Aging and Sexuality/Gender Study, University of Washington  
Peter Kaldes, President and CEO, American Society on Aging  
Maile Young Karris, MD, Owen Clinic Research Director; Associate Director, San Diego Center for AIDS Research Clinical Investigations Core, University of California San Diego  
Sandy Markwood, CEO, National Association of Area Agencies on Aging (n4a)  
Jesse Milan, Jr., President and CEO, AIDS United  
Colin Pekruhn, Program Director, Grantmakers In Health  
Anna Sangster, Program Manager, International Federation on Aging  
Katie Smith Sloan, President & CEO, LeadingAge  
Aaron Tax, Director of Advocacy, SAGE  
Nancy Zionts, COO and Chief Program Officer, Jewish Healthcare Foundation  
John Feather, CEO, Grantmakers In Aging

### ***Moving Ahead Together Summit Participants (additional to the Steering Committee members listed above)***

Kelli Abbott, Public Health Analyst; HAB HIV and Aging Workgroup Project Manager, Health Resources & Services Administration (HRSA) HIV/AIDS Bureau  
Emily Baransy (STAFF), Director of Operations & Program Development, GIA  
John Beilenson (STAFF), President, SCP (Strategic Communications & Planning)  
Scott Bertani, Director of Advocacy, HealthHIV  
Kevin Bradley, Associate Director of Online Learning, LeadingAge  
Cathy Brown, Executive Director, Elizabeth Taylor AIDS Foundation  
Laura Cheever, Associate Administrator, HRSA HIV/AIDS Bureau  
Raniyah Copeland, President and CEO, Black AIDS Institute  
Alice Daniels (STAFF), Administrator & Program Assistant, GIA  
Charles Emler, Professor, Co-Investigator, Aging with Pride: National Health, Aging, and Sexuality/Gender Study, University of Washington  
Kristine Erlandson, MD, Associate Professor, Medicine-Infectious Disease, University of Colorado Anschutz Medical Campus  
Vicki Gottlich, Director, Center for Policy and Evaluation, Administration for Community Living  
Tanya Grandison, Public Health Analyst and Project Officer, HRSA HIV/AIDS Bureau  
Meredith Greene, MD, Assistant Professor of Medicine and Associate Director, Golden Compass Program at Ward 86, University of California San Francisco  
Brian Hujdich, Executive Director, HealthHIV  
Sandy James, Legal Services Specialist, Office of Elder Justice and Adult Protective Services,

U.S. Department of Health and Human Services  
Karyne Jones, President and Chief Executive Officer, National Caucus and Center on Black Aging, Inc.  
Paul Kawata, Executive Director, NMAC (National Minority AIDS Council)  
Stephen Karpiak, Senior Director for Research at Gay Men’s Health Crisis, Director of the National Resource Center on HIV and Aging  
Elliot Kennedy, Director, Office of Policy Analysis and Development, U.S. Department of Health and Human Services  
Julie Lifshay, Director of Housing, Aging, & Retention in Care, San Francisco AIDS Foundation  
Marlene Matosky, Branch Chief of the Clinical and Quality Branch; HAB HIV and Aging Workgroup Senior Sponsor, HRSA HIV/AIDS Bureau  
Sam McClure, Director, LGBT Health Resource Center, Chase Braxton Health Care  
Ronald “Chris” Redwood, Nurse Consultant; Clinical and Quality Branch; HAB HIV and Aging Workgroup Co-Chair, HRSA HIV/AIDS Bureau  
Michael Ruppel, Executive Director, AIDS Institute  
Karyn Skultety, Executive Director, Openhouse  
Elizabeth Sobczyk, Director of Strategic Alliances, Gerontological Society of America  
Elliott Sparkman Walker (STAFF), Senior Communications Consultant, SCP  
Barry Waller, Assistant Commissioner, Texas Department of Aging and Disability Services

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Moisés Agosto-Rosario, Director of Treatment, NMAC  
Tez Anderson, Founder/Executive Director, Let's Kick ASS  
Harry Breaux, Activist, Long-term Survivor  
Gregg Cassin, Honoring Our Experience  
DeeDee Ngozi Chamblee, Executive Director and Founder of La Gender, Inc.  
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### ***Photo credits***

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