



AGING POSITIVELY:



Bringing HIV/AIDS into the Aging Services Mainstream

An Introduction for Funders



ACKNOWLEDGEMENTS



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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.

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.

EXECUTIVE SUMMARY



Aging and HIV/AIDS: A New Era of Convergence

For decades, aging and HIV/AIDS and their medical, governmental, community, and philanthropic structures and services were worlds apart. This made sense at first, when the majority of the first generation of people affected by HIV were young gay men, many of whom got their care in HIV-specific or infectious disease settings. The odds of living a long life with HIV/AIDS were small, and even survivors did not seek traditional aging services.

Those circumstances have now changed. Thanks to advances in treatment, the ability to live for decades with HIV has become a remarkable success story. Add to this the reality of older people who are acquiring the infection in their 50s or 60s, and HIV/AIDS must now be included as an aging issue. Of the 1.1 million people in the United States who are living with HIV/AIDS, half are 50 or older (50+). By 2030, it is anticipated that three out of four people who are living with HIV will be 50+.

This serendipity creates some unanticipated needs. While 50+ may seem young for aging services, many people living with HIV experience a cascade of other health challenges, including classic **geriatric syndromes**, even when their HIV is well-controlled, and need aging- and geriatrics-expert help at much younger-than-usual ages. This transition can be jarring and even traumatizing because HIV preparedness in mainstream primary, specialty, and geriatrics care settings is often woefully inadequate. Stigma and fear of being rejected or “outed” in unfamiliar care settings can drive people living with HIV into isolation and depression, dangerously sabotaging their ability to remain in care.

Good care also requires far more than medication. Social support and attention to the social determinants of health are critical and the ability to achieve a good quality of life, pursue personal goals, and engage with family, friends, and community requires a degree of security in housing, food, mobility, and social connection that seems unattainable for many.

As the profile of the epidemic has changed, new issues of diversity and social justice have also surfaced. The fastest growth in new infections is in the African American and Latinx communities, and women now account for a quarter of all people living with HIV. Bringing down barriers and finding ways to deliver the best possible care to these distinct communities will require research and sensitivity.

The whole-person outlook and community-based approach of aging services has the potential to bring comfort to this resilient but overlooked group of people. This report will raise the voices and examine the needs of older people living with HIV, while exploring opportunities for philanthropies to create meaningful impact in public and personal health and wellbeing.

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AGING AND HIV/AIDS



A Story No One Expected to Tell

Many stories have surprise endings, but the story of aging and HIV/AIDS has a surprise beginning. Early in the epidemic, when an AIDS diagnosis was a virtual death sentence, aging played no part whatsoever in the AIDS story. “We were all making preparations to die. No one considered aging,” recalls **Tez Anderson**, a long-term HIV survivor and founder of **Let’s Kick ASS**. [See: **I Am Positive About... Kicking ASS**]

That made perfect, if tragic, sense at the time. Since its first **mention** in the literature in 1981 (when it was so new it didn’t even have a name), Human Immunodeficiency Virus (HIV), the virus that causes AIDS (Acquired Immunodeficiency Syndrome), has infected more than 70 million people and **killed** about 32 million globally. More than 700,000 people have died in the United States -- almost twice the number of Americans who **died** in World War II.

I Am Positive About ... Kicking ASS

The phrase **AIDS Survivor Syndrome (ASS)** tells a difficult story about aging with HIV. **Tez Anderson** came up with it to explain the debilitating PTSD-like guilt, stress, rage, and isolation he felt after outliving most of his friends.



“I was told in 1986 that I would be dead in two years, so I kept making plans to die,” he recalls. His life effectively derailed, Anderson dropped out of college (“dead people don’t need college degrees”), lost his job (“dead men don’t need retirement accounts”), and withdrew.

Finally accepting the reality that he was indeed aging, in 2013 Anderson planned an event in San Francisco that touched a nerve. 250 people showed up. Now his organization, **Let’s Kick ASS**, hosts gatherings and a private Facebook group with 2,700 members, some of whom have never told their families their status. “Finally, they have people they can talk to.”

But the advent of powerful antiretroviral drugs in the mid-1990s provided hope and the storyline began to change. Today in the United States, about 1.1 million people are living with HIV or AIDS and half of them are 50 or older (50+), with a reasonable expectation of living even longer. Some are long-term survivors who have lived with the virus for decades; others acquired it in their 40s, 50s, or 60s. Their numbers are anticipated to rise: by 2030, as many as three out of four people living with HIV will be 50+.

To a meaningful degree, HIV/AIDS is becoming an older person's condition. The iconic red AIDS awareness ribbon is symbolically lengthening and taking on a touch of gray, and many older people living with HIV say they are not just surviving but thriving.



Members of the Elizabeth Taylor 50+ Network, based at the San Francisco AIDS Foundation, have a regular meeting at a local coffee shop.

Progress Leads to Possibility

Biomedical advances have transformed several acute, even fatal, diseases -- including HIV -- into chronic conditions, and today living with HIV is difficult but not deadly for people with access to care.

Managing an HIV viral load has become relatively straightforward and for many people, the medicine in the array of pills dubbed an “AIDS cocktail” can now be delivered in a single daily pill. With careful adherence, a person's viral load can reach an undetectable level, which also makes the virus untransmittable to others (hence the expression U=U.) [SEE: Medication: HAART, Pep, PrEP, and the taming of an epidemic]

This striking reversal of fortune has allowed many older people living with HIV to create purposeful and engaged lives for themselves and some to go even further, finding

ways to help others. “This is the most gratifying work I’ve ever done,” says **Vince Crisostomo**, a long-term HIV survivor and an organizer with the **San Francisco AIDS Foundation**. [See: [I am Positive About... Showing Someone Cares](#)]

But undetectable does not mean cured or trouble-free, and the epidemic continues. Many people living with HIV experience premature aging and by age 50 (or even **earlier**), have the health and functional status of a much older person. **Miriam Whitehead-Brice** of Baltimore was diagnosed at age 36; in the 20 years since, she's had sarcoidosis, shingles, depression, and 15 surgeries. “It was like all of a sudden, after HIV, all these issues came up,” she says.

It's unclear how much of this is **caused by** the side effects of powerful HIV medications versus the virus itself. Even when well-controlled, HIV lives on in the body, causing cells to age (known as cellular senescence) and placing the immune system on high alert at all times, which is believed to create chronic inflammation and drive the early onset of multiple co-morbidities — **additional diseases** such as cardiovascular disease, lung disease, neurocognitive disorders (including dementia and depression), liver disease (including hepatitis B and C), and cancer (lung, cervical, Hodgkin's lymphoma, and anal). In fact, people living with HIV who are in care are more likely to die of cancer than anything else.

Controlling these additional conditions is not accomplished with a single pill, so polypharmacy – the condition of taking many medications and facing possible contraindications – is often an unwanted consequence.

Physical and medical issues do not tell the whole story, either; in fact, almost the opposite is true. As **Stephen Karpiak**, senior director for research at the **ACRIA Center on HIV & Aging**, recently **wrote** in *Positively Aware* magazine, “For older adults with HIV, their care needs begin where the HIV Treatment Cascade ends.” Profound challenges such as stigma, social isolation, economic insecurity, guilt, and substance abuse are common and the need for social services is vast and frequently unmet.

Perhaps the most universal plea is for peer support from people who can truly understand. That’s why long-term survivor **Malcolm Reid** started the **Silver Lining Project** for mature African American same-gender-loving men in hard-hit Atlanta. “I recall going to a meeting and I noticed everyone is in their 20s. I was 57 years old at the time, and I was like, ‘OK, what are we doing for guys like me? Why aren’t we seeing them?’ Because they stay home and suffer in isolation.”

[See: [I Am Positive About... Supporting Each Other](#)]



I Am Positive About ... Supporting Each Other

Malcolm Reid feels blessed to have a loving husband of 22 years but wanted to help other mature men of color in Atlanta. So he founded the **Silver Lining Project**, now part of **THRIVE SS**, supported by **Gilead Sciences**.

SLP has social outings, support groups, and recently added the Silver Skills intervention. “We have modules on HIV and Aging, PTSD and Trauma, and Loss. That’s not just death and the loss of friends but many things you lose as you get older. Job, income, even your sexuality. You’re no longer the cute guy at the bar. We finish the series on a high note with Stigma. We want to give our folks the tools to understand and overcome the stigma and stigmatizing behaviors they encounter every day.”

The group tackles serious topics with flair and humor, like their signature medication reminder campaign: *I Thrive Because I Swallow*. “Obviously there is a sexual connotation but compliance is important, and it’s gone over pretty well,” Reid says.

[see [Getting Social](#)]



A Disproportionate Burden

To meet people's complex health and social needs, it is essential first to understand their stories.

HIV and aging pioneers include people who are newly diagnosed and long-term survivors; male, female, cisgender, and transgender; heterosexual, bisexual, and LGBTQ; members of all races and ethnicities; residents of cities, suburbs, and small towns and rural communities; and at various stages of awareness and disclosure of their HIV status.

The epidemiology also reveals the harsh disproportionality of the HIV/AIDS epidemic. For example,

- Among people 50+, African Americans **have** the highest rate of new infections, five times higher than that of whites.
- Older Hispanics have a **rate** of new infection more than double that of whites.
- The **impact** for minority gay men is mind-boggling: at current rates of transmission, half of black gay men and one quarter of Latino gay men are projected to become HIV+ in their lifetimes.
- Women (of all ages) are a frequently forgotten cohort even though they make up 25% of all new HIV diagnoses. More than half are women of color – a particularly **under-studied** group – and nearly 90% of infections in this group result from heterosexual contact.

These painful facts underscore the need to identify the disparities in care and support that affect people aging with HIV, as well as the need to continue working to reduce stigma, remove barriers, and identify effective ways to improving care and quality of life.

Medication: HAART, Pep, PrEP, and the Taming of an Epidemic

The story of aging with HIV/AIDS is intimately linked to the antiretroviral medications that have extended millions of lives. Today they are used in three main ways:

- **HAART:** People with HIV take medication known as HAART, or highly active **antiretroviral therapy**. Usually a combination of drugs, HAART reduces the viral load, increases the CD4 cell count to improve immune function, slows the development of opportunistic infections and AIDS, and, taken properly, can make the virus undetectable and untransmittable to others (U=U).
- **PeP:** People who suspect they have been exposed to HIV can try to prevent acquiring the infection by taking antiretroviral medications after the fact, called post-exposure prophylaxis or **PeP**. An emergency measure only, and only for people who are HIV negative.
- **PrEP:** **PrEP** stands for pre-exposure prophylaxis and allows people who are HIV negative but at risk of exposure to HIV to protect themselves with medication. Truvada (the brand name that producer Gilead Sciences has given to the compound emtricitabine-tenofovir) can **reduce** the chance of acquiring the infection by an estimated **99%**.

Prevention as cure?

PrEP is a key element of a broader **strategy** to stop the spread of HIV and ultimately eradicate the disease. Critics have **countered** that it may actually promote unsafe sex and increase the spread of other sexually transmitted diseases by undermining condom use and making people complacent.

The other major criticism of PrEP is its cost, which varies depending on insurance coverage but can be as high as \$2,000 per month retail. Gilead Sciences **announced** in May 2019 that it would donate 2.4 million bottles of Truvada for PrEP to needy patients.

Recommended Use and Access

In June 2019, the US Preventive Task Force (USPTF) gave PrEP an “A” rating and recommended that it be offered to people at high risk of infection. Under the Affordable Care Act, this rating **requires** private health insurers to cover the drug without cost sharing by 2021.

Access to PrEP has not been equitable, the USPTF noted in its **announcement**: “... although black/African American persons account for an estimated 44% of all new HIV infections in the United States, only 10.1% of those who initiated PrEP from 2012 to 2015 were black/African American. Similarly, black women, who are also disproportionately affected by HIV, were more than 4 times less likely to have initiated PrEP than white women. These barriers and disparities need to be addressed to achieve the full benefit of PrEP.” Overall, **less** than 10% of Americans who could benefit from PrEP have been prescribed it.

PrEP While Aging?

For older people, the evidence base for PrEP is still scanty, as the vast majority of participants in its clinical trials were under 50. Still, after noting possible bone density problems and the risk of toxicity to the kidneys, and warning of the need to monitor patients for drug interactions, two noted AIDS researchers, **Iacopo Franconi** and **Giovanni Guaraldi**, recently **concluded** that it may be worthwhile on a case by case basis, as “even in the absence of a dedicated PrEP study in elderly patients, there are no biological reasons for not believing this strategy may be one of the most effective medical prevention tools in people at high risk of HIV.”

SERVICES AND SUPPORTS



Aging into No Man's Land

Many people growing older with HIV/AIDS find themselves entering a sort of no man's land as their needs change. They may have received their HIV care from HIV clinics or infectious disease specialists, but over time may find these providers don't understand aging issues or know how to manage multiple non-HIV conditions. Older people may also "age out" of care settings that used to work for them, feeling out of step with programs that focus on the prevention needs of high-risk youth or stress only viral suppression.

"The issues that dominate HIV care today are cure and PrEP, and they ignore aging," says **Jules Levin**, the executive director of the **National AIDS Treatment Advocacy Project** who has [described](#) HIV and aging as "an unaddressed timebomb."

The bottom line is that older people still need good HIV care, but it needs to be good geriatric care as well, and the opportunity to find both in one place, or in combination, is still exceedingly rare. This guide will explore the needs and experiences of older people living with HIV, point to programs that already exist, and offer suggestions for bridging the gaps to help improve care and quality of life.

Integrating Services, Trying to Bridge Gaps, Avoiding Secondary Trauma

Despite the growing need, the HIV and aging services networks are often worlds apart. This may be due to a dearth of strong partnerships and a clash of organizational cultures.

"We've hit some walls with some of the aging organizations when we've tried to engage them," says **Roman Buenrostro**, director of special projects and planning at the **AIDS Foundation of Chicago (AFC)**, which operates the nation's largest HIV case management system funded by the Ryan White CARE Act. For example, he cites, "the organizations that focus on aging weren't as interested in talking about sex or sexually related issues," including counseling on safe sex practices, prevention, and HIV testing.

The unintended but unfortunate consequence can be a second wave of trauma for older people who had been stable in their care for years. **Sarah Hamilton** of **Funders Concerned About AIDS** has also seen the need. "People are seeking treatment for other conditions, like heart problems, and coming up against new stigma and discrimination that they haven't experienced for years when they go to places that haven't dealt with HIV positive people."

One reason may be lack of preparation to serve an HIV positive clientele, says **Tim Johnston**, who is senior director of national projects for **SAGE** and oversees **SAGECare**, SAGE's LGBTQ cultural competency training program for aging services providers. "It's brand new for a lot of them and baseline ignorance is a problem," he explains. "Many folks have wildly wrong ideas about how HIV is transmitted, like touching someone without gloves, or sharing a bathroom or eating utensils. A lot of misinformation." A new SAGECare education module coming out soon 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. (SAGE also offers a program in New York City called **SAGEPositive** for LGBTQ long-term survivors and older people living with, or at risk for, HIV.)

Conversely, HIV professionals, many of whom are serving an increasing number of older clients, are also realizing that they lack aging expertise. When the **AIDS Foundation of Chicago** surveyed its HIV case managers, 70% of them described training on HIV and aging as a high or very high priority. AFC has **developed** an online training that other organizations can also use to educate their social work and care management workforce.



I Am Positive About... Telling Our Story

As editor of **TPAN's Positively Aware** magazine, 30-year survivor **Jeff Berry** has the ear of his community and he's proud of the nonprofit magazine's independent edge.

That pride is balanced with caution, however, and Berry is mindful of the stigma and fear many of his readers live with because of being HIV positive. "We don't want to 'out' anyone, so we still mail the magazine in a plain wrapper."

Co-locating Services Can Help

Occasionally, HIV and aging awareness do come together in a single offering. In Chicago, **TPAN** (Test Positive Aware Network) recently launched a 50+ program called **Positively Aging**, supported by **Gilead Sciences**. One offering is a four-week program with individual counseling, group therapy sessions, and social and cultural outings. The first cohort just wrapped up, says TPAN Associate Director of Client Services **Ashley Martell**. “My takeaway was how grateful our clients were. They 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.”

One medical provider who has bridged the gap is geriatrician **Eugenia Siegler, MD**, who created the **Aging with HIV Program** at Weill Cornell Medicine’s Center for Special Studies in New York City with support from The **Fan Fox and Leslie R. Samuels Foundation**. “The HIV services network and the aging services network are completely siloed right now,” she observes, adding that the HIV network can be complicated to navigate and the aging services network was not designed either for people with HIV or for people in their 50s. Her program makes geriatrics consults available within the structure of an HIV clinic. She has also **surveyed** the few other integrated models in the US and internationally because, “we do not know how best to care for this population.”

Another powerful approach is leveraging the comfort level many patients feel when they are in a trusted HIV clinic by co-locating as many other services there as possible. One of the most celebrated examples is the **Golden Compass** program at UC San Francisco, on the Zuckerberg San Francisco General Hospital campus. Located in the established HIV/AIDS care clinic called Ward 86, Golden Compass launched in 2017 with **support** from the **AIDS Walk San Francisco**. The name refers to the four points of a compass to serve the medical and psychosocial needs of people 50+ living with HIV/AIDS: North, for Heart and Mind; East, for Bones and Strength; West, for Dental, Hearing, and Vision; and South, for Network and Navigation.



The Associate Director of the Golden Compass is **Meredith Greene, MD**, who brings a unique perspective as one of very few physicians who have completed fellowships in both geriatrics and HIV medicine. “I think aging providers may not always be aware that there is still so much stigma surrounding HIV,” she says. “Many in aging and geriatrics view HIV as a chronic illness but don’t realize the stigma that patients can feel and how much they do feel safe in trusted clinics. If services are offered outside that setting, providers really have to make an effort to help people feel welcome and not stigmatized.”

Patrice Henry (second from right in back row) with members of Older Women Embracing Life (OWEL), where she serves on the Board.



I Am Positive About... Making Meaning by Helping Others

When **Patrice Henry** was diagnosed with AIDS in 1995, she was told she had two months to live. “The first thing that came to mind was, how was I going to tell my mother that I have AIDS?” Her next thought was, “Why me?” The doctor treating her said, “Why not you? But maybe God wants to use you.”

Her health improved and she accepted a job offer to become Senior Community Program Coordinator and Lead **Patient Navigator** for **Johns Hopkins Medicine’s Moore Clinic (now known as the John G. Bartlett Specialty Practice)**, where she has worked for 20 years counseling patients who receive a diagnosis of HIV. “I say a prayer walking through the hallway for God to equip me to help these individuals,” she says.

Stigma is still the biggest challenge. “I’ve had people take two or three steps away from me when they hear I work in HIV. We need to get there with no shame about HIV,” she says. “I believe that this is what I am meant to do.”

Finding Common Ground

An important resource for both practices is [The HIV and Aging Consensus Project: Recommended Treatment Strategies for Clinicians Managing Older Patients with HIV](#). Developed with funding that included multiple [grants](#) from [Archstone Foundation](#), the resource is regularly updated and is now [housed](#) at what the [American Academy of HIV Medicine](#) describes as “the go-to site for HIV and aging” – [HIV-age.org](#). As the original work group [put](#) it, “In this era of caring for older adults with HIV, these two medical disciplines are finding they have much to learn from each other.”

Two important areas of common ground Dr. Greene sees between geriatrics and HIV care are a focus on the wellbeing of the whole person, rather than a disease-centric approach, and attention to the social determinants of health.

Housing is a good example. Many HIV positive people have spent years on disability and may have incomes below the poverty line. Some live in expensive urban centers like San Francisco and New York where rents climb relentlessly. Housing counseling can be useful. In addition, people living with HIV who are homeless or unstably housed have health disparities; in response, UCSF’s Ward 86 offers care through its [POP-UP clinic](#) – which stands for **Positive Health Onsite Program for Unstably Housed People**.

“I am a strong believer that if you can’t understand and address the social factors, you’re not going to be able to fully address the medical issues,” says Dr. Greene.



I Am Positive About ... Reaching Out Through My Faith Community

Former HIV nurse and health care administrator **Chris Lacharite** (seen on the left) started the [Long-Term HIV Survivors Network](#) as an outreach program at Metropolitan Community Church of the Palm Beaches. The MCC denomination has a focus on social justice and was started by a gay Baptist minister.

As a survivor, Lacharite understands the comfort members find in each other’s company. “We try to get people out of isolation and offer activities that promote resilience and self-care,” he says. Grants allow him to organize casual dinners twice a month, pool parties, yoga, and game nights. Recently the group marched in the Pride Parade. “A lot of my guys had tears in their eyes. It was very healing.”



Embarrassment and Preconceived Ideas Are Dangerous: “Age is Not a Condom”

Prevention, early detection, and staying in care are three crucial ways older adults can protect themselves from the ravages of HIV/AIDS, but bashfulness and wrong assumptions often stand in the way.

Research shows that about 40% of older people are still sexually active, and the majority of HIV infections are sexually transmitted. Even so, older people are **less likely** to bring up safe sex practices or to be asked about their sexual health by a health care provider, and less likely talk to sexual partners about their status, use a condom, take PrEP for prevention, or get tested for HIV. Even the US Preventive Services Task Force (USPSTF) **recommendation** for HIV testing ends at age 65.

“Doctors underestimate the sex lives of older adults. We still have sex!” says **Miriam Whitehead-Brice**, a member of **Older Women Embracing Life (OWEL)**. “I speak to groups and ask, ‘Is anyone asking their grandma if she’s using a condom?’ They laugh and say, ‘She’s just baking cookies.’ But I tell them, ‘She just wants you to hurry up and get out of the house because Mr. Bill is coming over!’” [\[See: I Am Positive About... Reaching the Next Generation\]](#)

Another false assumption some older people make is that they are no longer at risk because of their age. “Sexually transmitted diseases are running rampant in senior apartment buildings, nursing homes, and assisted living, partly because women who don’t have the fear of pregnancy any longer feel they can be as wild as they want,” says **Melanie Reese**, executive director of **OWEL**. “It’s OK to be wild but you have to be wild and safe.” [\[See I Am Positive About... Being Heard\]](#)

These social barriers have serious medical consequences, in part because being diagnosed late means the infection is more likely to have progressed toward AIDS and the likelihood of passing the virus to others is higher.

The research and advocacy organization **ACRIA** has tackled this mindset through a memorable social media and advertising and education **campaign** using the slogan “Age is Not a Condom.” [\[See Getting Social\]](#)

Breaking Down Barriers: Stigma Comes in Many Forms

Perhaps the most commonly cited barrier to getting optimal care and support is stigma, which takes many forms and causes pain and fear for individuals, often driving them underground, delaying testing, or sabotaging their motivation and ability to stay in care.

People who are living with HIV can tell horror stories about overtly discriminatory treatment by health care providers and even family members. **Patrice Henry** recalls a story a client told her about a family Thanksgiving. “She got there, and her aunt told her that she would have to go to Rite Aid and buy her own paper plates because she would not let her eat off the family china.” [\[See: I Am Positive About... Making Meaning by Helping Others\]](#)

Older people may face what is termed “double stigma” from a **combination** of anti-HIV feeling and ageism. They may also experience “self-stigma,” driven by internal feelings of guilt, shame, and self-loathing.

The emerging concept of “intersectional stigma” is the research focus of **Thurka Sangaramoorthy**, a cultural and medical anthropologist at the University of Maryland **examining** the experience of underserved populations living with HIV.

“People don’t experience HIV stigma on its own; there are lots of other things going on,” she explains. “How they feel about themselves, how they’ll be treated, based on who they are, what they look like, what color their skin is, whether they are men or women.”

As Annette, 56, a participant in Sangaramoorthy’s research program **told** her, “I had stigma before I was diagnosed. Just being Black is a problem. Being a Black woman with HIV, that’s another.”

For other marginalized groups, like transgender people, stigma increases their already high levels of risk, explains **Tim Johnston** of **SAGE**. “Trans folks may fear discrimination or mistreatment when accessing care. Some also turn to sex work or underground economies to survive, and they are victims of sexual assault at higher rates.”

Intravenous drug users also face stigma and isolation. HIV infections from injection drug use had begun to drop but that progress is now **at risk** because of the national opioid epidemic. Funders like the **Comer Family Foundation** are trying to **address** both problems by supporting support safe injection sites and “clean needle” syringe exchange programs.

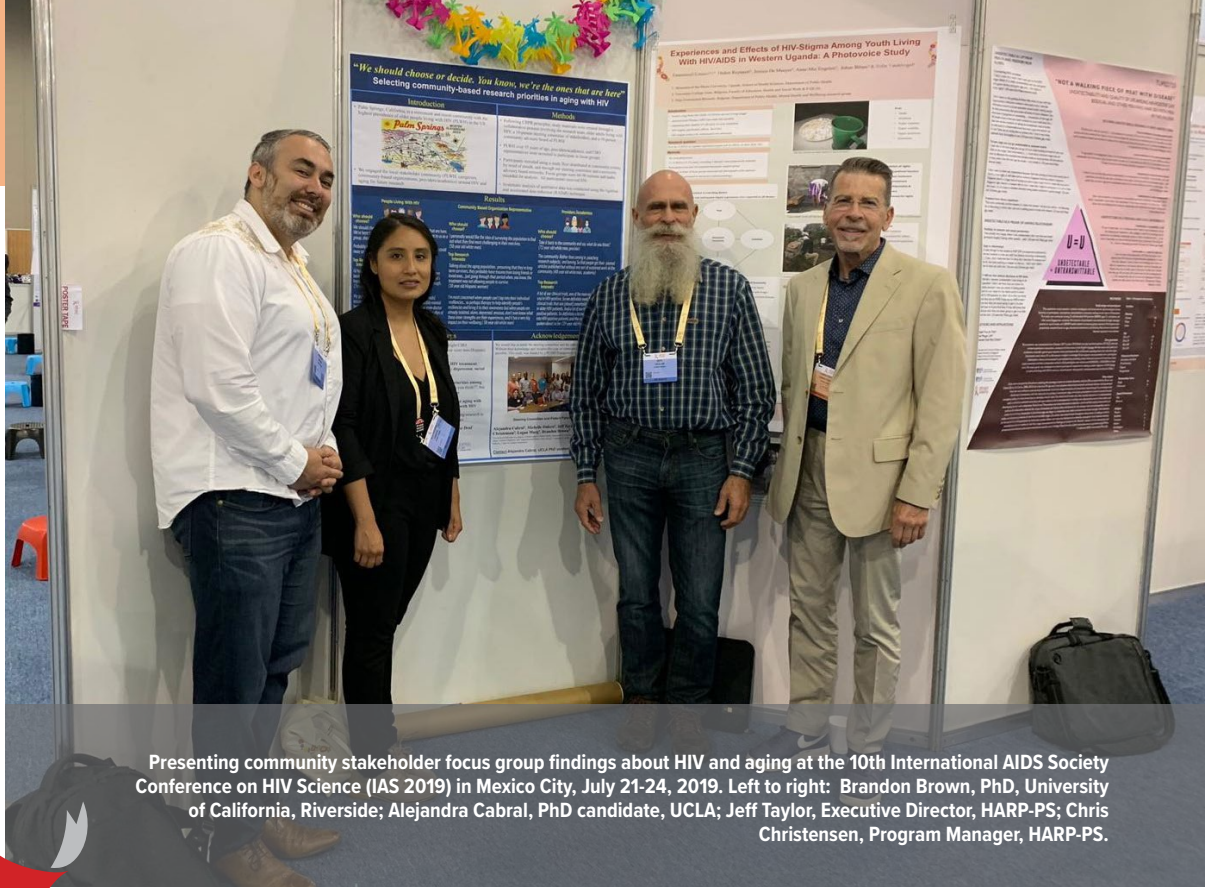
Improving Services by Listening

Developing better care and services for diverse subpopulations of people living with HIV means listening and learning from their experiences. In some cases, this has included creating community-based research programs.

Palm Springs, California is home to one of the largest concentrations of gay male long-term survivors of HIV, and to the **HIV & Aging Research Project – Palm Springs (HARP-PS)**, spearheaded by survivor **Jeff Taylor** (who jokingly calls Palm Springs “God’s LGBTQ waiting room.”) With a **grant** from **PCORI** and additional support from **Desert Community Foundation** and the pharmaceutical industry, this project helps identify research priorities for community stakeholders (older people living with HIV, clinicians, service providers, caregivers and family, and academic researchers) with input gathered through focus groups and workshops. The top three issues it identified were isolation and depression; aging co-morbidities and the inflammation that causes them; and neurocognitive problems. “We’ve got to study HIV positive people as they get older and this is one place we have a concentration of people,” Taylor says.



Thurka Sangaramoorthy, PhD, is a cultural anthropologist with expertise in medical anthropology and epidemiology.



Presenting community stakeholder focus group findings about HIV and aging at the 10th International AIDS Society Conference on HIV Science (IAS 2019) in Mexico City, July 21-24, 2019. Left to right: Brandon Brown, PhD, University of California, Riverside; Alejandra Cabral, PhD candidate, UCLA; Jeff Taylor, Executive Director, HARP-PS; Chris Christensen, Program Manager, HARP-PS.



In Baltimore, the members of **OWEL** have collaborated on research with the **Johns Hopkins School of Nursing** through the **CHECC-uP Project (Community-Based Cervical Cancer Prevention and Education Among Women Living With HIV)**, an intervention study led by Dr. Hae-Ra Han to promote cervical cancer screening in women living with HIV. OWEL's contribution was recently **honored** with the **Henrietta Lacks Memorial Award**.



I Am Positive About... Reaching the Next Generation

Miriam Whitehead-Brice is an advocate, an **OWEL** member, a minister, a grandmother of four, and a 19-year HIV survivor. When she found out she was HIV positive three years into her marriage, her husband stood by her.

Now she is also the author of *My Grandma is HIV Positive*. "I talk to my grandchildren. I tell them, children aren't the only thing that comes from unprotected sex. Children leave the nest, but HIV is not leaving the nest."



“Social Support Keeps You in Care”

Ensuring that support services respect the comfort level of various populations living with HIV may hold the key to improving services. Many advocates believe that designing services and supports specifically targeted to their needs may be more successful than generalized services. “Even if [long-term HIV survivors] are comfortable in the broader senior community, nobody can understand what they went through and what affects them. The best thing is to be around people who understand,” says **Jeff Taylor**.

Older people living with HIV may also prefer support programs where they can be among their own age, rather than trying to fit in with a younger generation at meetings and events. “I started our group because I think social support is huge,” says **Malcolm Reid**, program manager of the **Silver Lining Project** in Atlanta, where the membership is composed of older same-gender-loving men of color. “Social support keeps you in care.”

Gender and familial differences may be instructive as well. The life experience of gay male long-term survivors may be quite different from that of African American grandmothers, who, as Thurka Sangaramoorthy’s **research** has discovered, are much more likely to be working, sometimes as primary breadwinners and caregivers with responsibility for multigenerational households. Resilience, coping strategies, and needs may look quite different as a result.

The role of race cannot be minimized in HIV/AIDS care any more than in other sectors and HIV support groups tend to self-segregate by race as well. “I will go to the white organizations’ meetings, and I am often the only black person in the room,” says **Malcolm Reid**. “It’s getting better but especially in the South, there is still a lot of racism. But more than that, there is the need for communal language and understanding.”

In New York City, geriatrician **Eugenia Siegler** also sees the need to be attentive to people’s preferences in the area of HIV/AIDS clinical care and urges funders to take this seriously in their grantmaking. “This is an area that is so new. The populations, the necessary clinician skills, and access to services, are all so different. Part of the support has to be a careful exploration of what the local environment is and what the patients want.”



Funding Complex Care: Medicare, Medicaid, and the Ryan White CARE Act

Even with highly effective medications available, people living with HIV/AIDS have complex and involved health and social needs. Here are some fast facts on federal and state funding mechanisms:

- About one out of four people living with HIV is covered by Medicare. Most are dually eligible for Medicaid.
- HIV/AIDS care represented about 2% of all Medicare spending, or \$10 billion, in 2016.
- The number of Medicare beneficiaries living with HIV has tripled since the 1990s but still only represents less than 1% of the Medicare population.
- Average Medicare per capita spending is about four times higher for HIV+ beneficiaries (about \$45,000 per year) than for HIV-negative beneficiaries.
- Much of the difference is in Part D drug spending. Medicare beneficiaries living with HIV average \$11,600 per year, compared to \$1,800 per year for those who are HIV-negative (in 2014).
- Many people living with HIV receive extra help through the [Ryan White HIV/AIDS Program](#). Administered by [HRSA](#), (the Health Resources and Services Administration), “Ryan White” is the largest federal program focused specifically on providing HIV care to low-income people living with HIV who are uninsured or underserved. Through grants to cities/counties, states, and local community-based organizations, the program provides a comprehensive system of HIV primary medical care, essential support services, and medications.

Source: [Kaiser Family Foundation](#)

AN OPPORTUNITY FOR PHILANTHROPY



Mapping the Philanthropic Landscape

While global HIV/AIDS philanthropic funding has remained relatively flat for the past decade, the field experienced a five percent decline in overall funding between 2016 and 2017, bringing its total of \$638 million, the lowest on record in three years.

The two largest HIV funders in the US are also the two largest HIV funders in the world; together they accounted for more than half of the world's HIV/AIDS philanthropic funding. They are **The Bill and Melinda Gates Foundation**, which dispersed more than \$241 million worldwide in 2017 (almost none of which was in the US), and **Gilead Sciences**, which dispersed more than \$155 million worldwide.

About two thirds of philanthropic dollars for HIV/AIDS go to support international (non-US) and global work.

HIV/AIDS-focused grantmaking within the US represents a very small fraction of overall domestic foundation and corporate giving – only about 62 cents of every 100 dollars. In 2017, HIV/AIDS-related grants disbursed to the US totaled \$186 million. **Funders Concerned About AIDS (FCAA)** has opined that, “funding remains remarkably inadequate both in the US and internationally.”

Domestically, Gilead Sciences was the funder investing by far the largest amount in the US (\$125 million in 2017), more than six times more than next foundation on the list, **ViiV Healthcare**.

Very Limited Focus on Aging

FCAA has also done a rare and valuable [study](#) revealing that global HIV/AIDS grantmaking targeted to older people totaled just over \$3 million in 2017. Funding for HIV in the US represented only \$1.6 million of that total. This very small number means that aging-related work receives less than one percent of all US-based HIV-related philanthropy, even though 50% of all people living with HIV are 50 or older.

There are, however, exciting new funding initiatives that have begun to change some of these trends. One particularly noteworthy new program is the **Gilead HIV Age Positively initiative**, which made \$17.6 million in grants to US-based organizations in 2019, drastically increasing the total grant funding for HIV/AIDS and aging. Another is **The Southern HIV Impact Fund**. **Formed** in late 2017 by **Gilead Sciences, Ford Foundation, Elton John AIDS Foundation, ViiV Healthcare, and Johnson & Johnson**, the Fund, which is not aging-specific, made an initial investment of \$2.65 million in support of 37 organizations in nine Southern states. Funders Concerned About AIDS convened the collaborative and **AIDS United** is managing the fund.

While FCAA has expressed concern about the overall drop in giving, executive director **John Barnes** underscores the importance of the mission and urges a bigger tent with new partnerships. “Private philanthropy dollars comprise only 2% of global resources for HIV and AIDS but that is an absolutely essential component,” he said. “We must engage those who address closely inter-related issues, including health equity, racism, homophobia, poverty, and reproductive health and justice. These not only intersect with, but often fuel the HIV/AIDS epidemic.”

Image via www.ETAF.org.



I Am Positive About ... Showing Someone Cares

Simply having somewhere to go can make a difference, says **Vince Crisostomo**, who leads the **Elizabeth Taylor 50+ Network** at the **San Francisco AIDS Foundation**. Popular programs include gatherings at coffee shops and screenings. There’s also an intergenerational program called **BridgeMen** that provides community service. “I cast a wide net because you never know what’s going to resonate,” he says.

The program receives funding from The **Elizabeth Taylor AIDS Foundation (ETAF)**. The actress, who also co-founded **The Foundation for AIDS Research (amfAR)** in 1985, established ETAF in 1991 to provide direct care, love, and moral support to the most vulnerable patients. “We appreciate the fact that the individuals in the program love Elizabeth Taylor and see her as someone who cares about them,” says executive director **Cathy Brown**.

Funding Recommendations

Improving care and quality of life for people aging with HIV/AIDS offers a huge range of opportunities, many of them suitable for small or community foundations. Here are a few ideas and starting points.

Support Wraparound Care

Housing: “Housing is healthcare” is a frequent refrain. Organizations such as [HousingWorks](#) help people living with HIV avoid homelessness by providing dedicated housing and supportive housing services. Other suggestions include improving conditions in SRO’s and board-and-care homes and making shelters more welcoming to people living with HIV.

Food security: Memphis-based [Friends for Life](#) is the Mid-South’s oldest and largest AIDS Service Organization. With [support](#) from [Plough Foundation](#), through a grant with [Listen for Good](#), they have provided congregate meals, a food pantry, and nutritional counseling for people living with HIV.

Subsidizing food served at support groups and other events is also valuable, says **Vince Crisostomo** of the [San Francisco AIDS Foundation](#). “Because rents are so high, people often skip one or even two meals, so all our activities have a food component.”

Legal: Many people diagnosed with HIV never bothered with legal documents and financial plans that assumed a longer life, and need help with advance care planning documents, living wills, regular wills, leases, and contracts. Eviction defense is also sought after.

Income replacement and job training: Many long-term survivors have been on SSI disability for decades but recent changes in renewal standards have left many scrambling. Others are aging out of private disability policies and facing impoverishment in their later years. [The Reunion Project](#) recently [partnered](#) with the [National Working Positive Coalition](#) to offer job fairs to people living with HIV who need to work again.

Mobility: Whether housebound by disabilities or unable to afford a car or transit fares, many older people living with HIV have limited mobility. Transportation services, mobile outreach vehicles that can visit people at home, and MetroCards, vouchers, and subsidies for transportation to support groups are all needed.

Promote Outreach and Education

Health fairs: Events that are not explicitly about HIV/AIDS present excellent opportunities for outreach, says **Dorcas Baker**, Regional Coordinator for the [MidAtlantic AIDS Education and Training Center, RP](#) and co-founder of [Older Women Embracing Life \(OWEL\)](#). She created [Testing for Turkeys](#), an annual mini health fair and Thanksgiving turkey giveaway event that offers confidential HIV and Hepatitis C screenings, linkage to care and other health information, and voter registration. “Sometimes we get people who already know they are positive but have been out of care. This gives us a good opportunity to re-engage them in care,” she says.



Encourage Positive Voices: Nothing reduces stigma like putting a human face on an issue. Local advocates need support to find speaking, media, and professional development opportunities, such as a speakers bureau. “One of the things I really like in the HIV world is that most conferences have people living with HIV in attendance and able to ask questions. I don’t see that as much in aging conferences or trainings,” says **Meredith Greene** of the **Golden Compass** in San Francisco.

Bridge Gaps in Medical Care

Leverage Continuing Medical Education: One way to increase HIV expertise among geriatricians and primary care providers, and to share geriatrics principles with HIV providers, is through tailored CME. One good source is the **Provider Education Center** of the **American Academy of HIV Medicine**.

Look to Nursing: Nursing funders would agree with long-term survivor **Melanie Reese**: “Please support nurse-led HIV care! Nurses have the knowledge but more important, they let it seep through into their heart space. They are compassionate, supportive, empathetic, and serve the whole being, not just a particular area of the body.” **The Association of Nurses in AIDS Care** is a good place to start.

Dementia Care: Many long-term HAART patients show signs of neurocognitive disorders, including dementia. This area clearly requires further exploration as the first generation of long-term survivors enters late old age. **Bader Philanthropies** has **funded** the **AIDS Resource Center of Wisconsin** to develop a best-practice screening approach to identifying early warning signs of dementia for HIV patients.

Syringe Exchange: The linkage between the opioid epidemic and HIV transmission through shared needles is getting more **attention**. Funders interested in supporting harm reduction through syringe exchange programs can consult a **startup guide** from the **Comer Family Foundation**. “We do needle exchange in every single state, focusing on this gap where the federal government cannot fund,” says director **Mary Pounder**.

Deepen Social Support

Support Positive Singles: Opportunities for social interaction can be hard to come by. A recent round of grants from **NMAC’s HIV 50+ Strong and Healthy** program has supported local programs like a dog-walking group as well as singles mixers for people who are living with HIV.

Caregiver Support: Many caregivers go through the same trauma as the people they love. Dedicated support services and groups are needed.

Encourage Self-Management: The well-regarded Chronic Disease Self-Management Program (CDSMP) has been adapted for people living with HIV in a version called **Positive Self-Management Program**.

Help People Make Their Stories Count: Oral history projects, storytelling, and interview-based research can help inform the development of new interventions, says medical anthropologist **Thurka Sangaramoorthy**. “NIH funding is entirely vaccine and medically based and there are lots of us trying to do prolonged engaged community-driven work that is not fundable there.”



Melanie Reese (left), executive director of Older Women Embracing Life (OWEL) with board member Patrice Henry (right.)

I Am Positive About... Being Heard

Melanie Reese brings her banking background and two decades as an HIV survivor to her role as executive director of **OWEL (Older Women Embracing Life, pronounced Oh-well)**, in Baltimore.

Her viral load is undetectable but Reese has still had some bad experiences in the health care system, like the dental clinic where technicians, “dressed up in black space suits and didn’t want to get near my mouth.” She was horrified but knew what to do: “When I get angry, I get active.”

Reese serves on advisory boards, goes on Capitol Hill visits, and speaks frequently and frankly to community groups about HIV: “If you’re engaged in any kind of intimate sexual behavior, you’re at risk.”

Reese thinks big. OWEL’s next goal: working with a coalition of other advocates and organizations to remodel part of a Baltimore senior center into a multi-faceted HIV clinic modeled on San Francisco’s Golden Compass.

“OWEL was ahead of its time, we are extremely relevant, and we need funding to do the work that we do.”

THE END OF AIDS?



In a situation as multi-faceted as the HIV/AIDS epidemic, competing goals may be unavoidable. In February 2019, the Trump administration unveiled *Ending the HIV Epidemic: A Plan for America*, which emphasizes prevention and seeks to reduce new HIV infections in the United States by 90 percent by 2030. While few disagree outright, many advocates for older people living with HIV believe a broader focus is needed and the phrase “the end of AIDS” rubs some long-term survivors the wrong way. Others question how ending the epidemic will be possible without a closer focus on the stigma, discrimination, access problems, and social determinants of health that keep up to *half* of people living with HIV out of continuous care.

“Our goal as a society is to end the epidemic, and our second goal is to help anyone infected to live a long, fruitful, happy, productive life. Sometimes goal number two, which is just as important as goal number one, is lost along the way,” says Weill Cornell’s **Eugenia Siegler**.

Powerful medications do not present a “magic bullet” equal to this task. “The drugs have given a newfound life to a lot of people so AIDS isn’t a death sentence, but they don’t really get at the underlying issues that cause people not to have good health.” says anthropologist **Thurka Sangaramoorthy**.

Plenty of work remains to be done. More medical research is needed to understand the results of living for decades with the virus and on the powerful HIV drug protocol. Issues such as increased rates of diabetes, heart disease, liver and kidney damage, cognitive decline (including dementia), and bone weakening are likely to remain critical issues for survivors for decades to come. More attention is needed to create the interventions that will work best for subpopulations. The aging services and HIV services world need to find the best ways to work together.

“People aging with HIV are some of the most vulnerable, stigmatized, and systematically excluded people in our society. This issue should feel relevant to many different kinds of funders,” says **John Feather**, CEO of **Grantmakers In Aging**. “Whether you work on social determinants of health, or clinical research, or mental health and social services, or social justice issues, we need to work together to be ensure that people entering late life with HIV have access to care and services to meet their complex needs.”

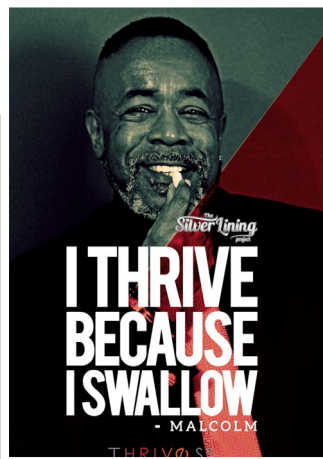
Simply by surviving, older people living with HIV have demonstrated levels of resiliency and engagement that are remarkable. Many are giving back through advocacy, education, and mutual support despite their own formidable challenges. As we work together to seek solutions, they are our best guides.

GETTING SOCIAL

Some of the most effective organizations working to reduce stigma and increase education and awareness have turned to memorable social media campaigns.



Examples of ACRIA's "Age is Not a Condom" campaign, 2016 and 2014.



The Silver Lining Project launched this campaign to support the serious topic of medication adherence in a light-hearted spirit.

NHCOA NatlHispanicCouncilAging @NHCOA

One in every five older adults living with HIV is Hispanic/Latino. It is estimated that 84,874 Hispanic seniors were living with HIV by the end of 2014. bit.ly/2svf9Rw #DoingIt #LetsStopHIVTogether



10:01 AM - Feb 15, 2018 - Sprout Social

National Hispanic Council on Aging has conducted #LetsStopHIVTogether outreach with a testing and prevention message since 2012.



THANK YOU



Visit us at GIAging.org

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