JANUARY 2010
HIV & AGING POLICY WHITE PAPER

Contrary to popular images, HIV/AIDS is rapidly becoming an *older persons'* disease:

- The number of adults age 50 and older with HIV/AIDS rose from 65,655 cases in 2001 to 104,206 cases in 2004 – an increase of 59% in only three years.[1]

- Between 10%[2] and 19%[3] of those newly diagnosed with HIV infection are 50 years or older.

- The percent of people with AIDS over the age of 50 is now more than twice that of people under age 24.[4]

- Currently, about 29% of all people with AIDS in the United States are 50 or older.[5] In some cities, as many as 37% of people living with AIDS are 50+.[6]

- By 2015, *half* of persons living with HIV in New York City will be age 50 and older.[7]

- At least half of those living with HIV are lesbian, gay, bisexual, or transgender (LGBT), with the gay male and transgender communities hardest-hit by this disease.[8] Men who have sex with men is the only risk group in the U.S. in which new HIV infections are increasing.[9]

- In New York City, nearly twice as many people over the age of 50 receive an AIDS diagnosis at the same time they first test positive as do those under 50 (42% to 23%), a fact that reflects how much later many older adults are tested, compared to younger adults.[10]

Even these data may be underestimates; as we'll explain in this paper, there is good reason to believe that the ratio of known-to-unknown HIV infection rates is higher among older people than it is among younger people.

Because the "face" of HIV is aging so rapidly, because a significant proportion of people with HIV remain LGBT, and because the rate of HIV infection among transwomen is so high, SAGE has produced this White Paper outlining some of the key concerns we have identified, and recommendations for policy and advocacy.

HIV testing

The Gay Men's Health Crisis (GMHC) reports that "approximately half of all new HIV infections are caused by people who are unaware of their HIV status and who have been infected themselves for less than two years."[11]

This means that controlling the spread of HIV is in part dependent on people learning that they carry the retrovirus. That can only be accomplished through routine testing.

It is also vital for people living with HIV be diagnosed as early as possible. The AIDS Community Research Initiative of America (ACRIA) reports, "Studies have found that untreated, older HIV-positive individuals are twice as likely to die than their younger, untreated counterparts."[12] The mortality difference is thought to be due to the natural decrease in immune function with age.[13] Yet within three months of being on highly-active anti-retroviral treatment (HAART), older people have similar rates of undetectable viral loads and no significant differences in survival rates compared to younger patients.[14]

Despite these compelling reasons older people should be tested for HIV, they are much less likely than younger persons to get those tests. Indeed, it is impossible to even find out how many older people have been tested; all reports we found do not bother reporting on the HIV testing rates of anyone over age 64.

Even older men who have sex with men – the original, most publicized risk group – very often fail to get tested. A study of gay men in five U.S. cities found that half of those tested were unaware of their HIV status.[15] Overall, one in four men participating in the study was infected.[16] Black gay men were twice as likely to be infected with HIV as men of other races, with more than two-thirds of them unaware they had HIV.[17] Studies of transgender women show they often have HIV rates even higher than those of gay men, yet they are also undertested: a recent meta-analysis found that while 11.8% of transgender women reported being HIV+, studies in which participants were actually tested found a positive rate of 27.7%.[18]

Some – including (until recently) the Centers of Disease Control and Prevention (CDC) itself – have argued that the rate of undetected HIV in people age 50 and older is relatively small. This is clearly *not* the case: A 1992 study at Harlem Hospital in New York City found that of the 371 adults who died there that year and who had no previous diagnosis of HIV infection, 9.9% were found to be HIV positive, with those 60 years of age and older having a prevalence rate of 5.2%.[19]

Here we will discuss the major barriers to increasing the number of persons aged 50 and older who are tested for HIV.

Older people don't think they are at risk of HIV.

The chief barrier to older people learning they are infected with HIV is the belief that they are not at risk. Some older people believe they know how HIV is spread, and that they engage in no risky behaviors. For instance, in the 2000 CDC Behavior Risk Factor Surveillance System, 81% of those aged 55-64 said they had no risk for getting HIV, and only 15.1% said they had a "low" risk.[20]

Older adults may also have little knowledge about HIV. A 1998 study by Zablotsky found that 47% of women older than 50 were "totally uninformed" about HIV, compared to 14% of the younger adults.[21] In a Florida study, more than 60% of older respondents had minimal knowledge of behaviors associated with risk for HIV exposure.[22]

Reflecting their myths (or lack of knowledge) about how HIV is spread, older people "have made fewer behavioral accommodations to avoid risk": they are 1/6 as likely to use condoms as people in their 20s, for example.[23]

Certain populations under the LGBT umbrella are very prone to underestimating their HIV risk. The CDC still starts its lesbian fact sheet, "To date, there are no confirmed cases of female-to-female sexual transmission of HIV in the United States database," despite ample anecdotal reports of such transmission.[24] Yet 7,381 HIV+ women have officially admitted to having sex with women, and more than 60% of the 246,461 cases of HIV+ women are missing information on whether they had sex with women; clearly, lesbians are not immune.[25] A meta-analysis of HIV and transgender people found that 71.6% believed they were not at risk for getting HIV/AIDS, despite that population having a seropositive rate higher than that of most populations of men who have sex with men.[26]

Doctors don't think older people are at risk of HIV.

Products of our society, physicians typically buy into prevalent myths that older people don't have sex. One research paper concluded, "physicians are more likely than not to hold stereotypes about older adults and sex."[27] For example, the physicians these researchers interviewed thought about sexual health with

younger people, but did not “give any type of prevention advice” to older adults.[28] Another researcher noted that “sexual histories are routinely absent in assessing older adults.”[29]

Yet older adults do continue having sex: 53% of those 65-74 and 26% of people 75-85 years of age reported to the 2007 National Social Life, Health and Aging Project that they remained sexually active.[30] Still, even in this Viagra era, only 38% of the men and 22% of the women reported having discussed sex with their physician since they turned 50.[31] A study of Chicago gay men compared those over and under age 60 and found the two groups had a similar frequency of sexual contacts.[32] Forty-four percent of the older cohort reported multiple partners, virtually matching the 45% of multiple partners found in the 30 to 39 age group.[33]

Although studies have shown that between 13% and 41% of HIV+ people age 50+ were infected by sharing intravenous needles, physicians are unlikely to ask about or counsel their older patients about this risk factor: nearly every article reviewed for this paper talked about sexual transmission among older people, but most said nothing about intravenous drug use.[34]

Finally, both elders and their physicians may assume symptoms of infection with HIV are symptoms of other common illnesses, aging related or not.[35] The symptoms of acute HIV infection (generally occurring within 2-4 weeks of infection) include: decreased appetite, fever, fatigue, rash, headache, swollen lymph glands, sore throat, malaise, muscle stiffness or aching, and ulcers of the mouth and esophagus.[36]

Accessing HIV tests through doctors is particularly problematic for transgender people, who frequently avoid health care providers due to cost, past problems, and fear of encountering prejudice when they disrobe and their gender status is revealed. A meta-analysis of transgender research found that 49.9% of transgender people did not have health insurance, and nearly a third had been refused medical care because of their gender identity.[37] Past negative experiences with health care providers is also common for other LGBT populations, and may result in those patients not revealing their same-sex risk factors to their doctors or avoiding obtaining care altogether.

Routine testing of older people has not been recommended.

Beliefs about who should be tested for HIV have evolved as understanding of the epidemic has grown. Most recently, (in September 2006), “the Centers for Disease Control and Prevention (CDC) published revised guidelines recommending that all individuals between 13 and 64 years of age be screened for HIV regardless of recognized risk factors.”[38] While this recommendation

covered those 50 to 64, it is notable for who it does *not* cover: anyone 65 and older.

Less noticed than the age 64 cut-off for universal screening is a secondary recommendation. In a statement issued on the first National HIV/AIDS and Aging Awareness Day (September 18, 2009), the National Institutes of Health noted that the CDC also recommends HIV testing at least annually "for adults aged 64 and over who have risk factors for HIV infection, such as injection drug use."[39] While this recommendation provides for the testing of people age 65 and up, it must be remembered that physicians do not always ask older people about their risk factors. Moreover, 10-25% of people testing positive for HIV in a Veterans Administration study had no identified high-risk behaviors.[40]

More evidence of the need to rethink how older people and HIV testing should be approached comes from the Centers for Medicare and Medicaid Services (CMS). In a September 9, 2009 "Proposed Decision Memo," CMS noted that a "recent cost-effectiveness analysis found that screening patients up to age 75 years met conventional cost-effectiveness thresholds if screening was done with streamlined counseling, patients were sexually active, and the prevalence of HIV in the population was greater than 0.1%."[41]

HIV testing should always be under informed consent.

Currently, in most states, patients must give explicit permission to have an HIV test. Since many medical professionals do not think of older people as being at risk for HIV, this option may not be offered as regularly to people 65 and over, which probably results in fewer older people being tested. In addition, some elders may erroneously believe they're being tested for HIV when the doctor orders "standard" blood tests. Informed consent means making people fully informed about what an HIV test is, what a positive result means, and discussing the availability of anonymous testing. The CDC itself recommends the practice of opt-out screening, in which patients are told they will be tested (usually along with other standard blood tests) unless they decline to be tested.[42] SAGE and its partner agencies, ACRIA and GMHC, believe in an opt-in approach, both for the practice of informed consent, and for the larger concern: ensuring that HIV tests are routinely offered by medical providers so that older adults understand that HIV is a risk at any age.

Criminalization laws may discourage testing.

No one condones someone who knowingly infects someone else with HIV. From 1990 to 2000, the Ryan White CARE Act, which channels federal funds to states for AIDS treatment and care, required every state to certify that its criminal laws were "adequate to prosecute any HIV infected individual" who knowingly exposes someone to HIV.[43] All 50 states retain a criminal statute that could be used for

this purpose, although the approaches vary widely.[44] A large, international coalition of HIV/AIDS groups have signed on to a document opposing criminalization.[45] They cite two prevention-related reasons for this opposition: "Applying criminal law to HIV transmission could discourage people from getting tested and finding out their HIV status, as lack of knowledge of one's status could be the best defense in a criminal lawsuit. Indeed, in jurisdictions with HIV-specific criminal laws, HIV testing counselors are often obliged to caution people that getting an HIV test will expose them to criminal liability if they find out they are HIV-positive and continue having sex." They also note that criminalization may result in "[c]reating distrust in relationships between HIV-positive people and their health care providers: People may fear that information regarding their HIV status may be used against them in the criminal justice system. This impedes the provision of quality treatment and care and could also negatively impact the enrollment of HIV-positive people into much-needed research studies."[46]

Testing policy recommendations

SAGE recommends…

…that agencies and programs at all government levels begin urging all sexually active and/or intravenous drug-using people to be tested, regardless of age.

…that physicians and other health care professionals routinely discuss and recommend testing to all adult clients, regardless of age.

…that health care providers be trained in LGBT cultural competency issues, and that issues of bias and discrimination be addressed through training, policy, and law.

…that routine HIV testing of older people be expanded and that an HIV test be included in routine blood work with informed consent.

…that further research and consultation be done to identify and mitigate the possibility that criminalization laws are discouraging people from finding out their HIV status.

HIV prevention

Ironically, the medical success of shifting HIV/AIDS from a fatal disease to a chronic but livable one means that HIV+ people thereby have more years in which they can potentially pass the retrovirus onto others. Preventing further transmission of the disease therefore takes on even more importance.

No one knows enough.

Unfortunately, even HIV experts may need to know more about the intersection between HIV and older people. The first CDC-led National HIV/AIDS and Aging Awareness Day was only in 2009, and in its announcement of the day, the National Institutes of Health rededicated itself to "research aimed at preventing HIV infection in older adults and improving the health and quality of life of those who are affected."[47] As previously noted, many physicians do not think older people need to know about safer sex practices or how to safely use injection drugs. Physicians may also not know that older people may be *physically* more at risk because of aging-related thinning of vaginal and anal membranes.[48]

Patients may not tell physicians critical information.

2008 research by the New York City Department of Health and Mental Hygiene found that men who disclose their homosexuality or bisexuality to their physicians were almost twice as likely as those who don't to be tested for HIV (63% vs. 36%).[49] Unfortunately, more than a third (39%) of New York City gay or bisexual men do not disclose their sexual orientation to their doctors.[50] Worse, the racial groups with the highest rates of HIV – HIV/AIDS rates among older people are 12 times higher for African-Americans and 5 times higher for Hispanics compared to whites[51] – are even less likely to be out: 60% of New York City Black and 48% of Hispanic gay/bisexual men remain closeted in their physicians' offices.[52]

Public education materials don't address older adults.

In 2003, researchers specializing in aging asked all states' public health departments to send them "copies of all educational materials related to HIV/AIDS education such as pamphlets or brochures that are distributed to the public." A follow-up request was more specific: "any educational materials on HIV/AIDS which are specifically tailored to adults 50 years of age and older." Although all 50 states responded, only 15 had materials specifically intended for an older adult audience.[53] Worse, of the nine states where half of the United States' population 65+ lives (California, Florida, New York, Texas, Pennsylvania, Illinois, Ohio, Michigan, and New Jersey), only Florida and Illinois had materials aimed at older adults.[54]

Even HIV and LGBT organizations have sponsored few efforts to educate older LGBT persons about HIV. Two of the few exceptions are AIDS is Ageless: HIV Over 50 by the AIDS Project Hartford, available at http://www.med.unc.edu/aging/elderhiv/screen3.htm, and ACRIA and SAGE's publication *Older and Wiser: Many Faces of HIV*, available through ACRIA.

Stigma makes prevention harder.

HIV stigma is pervasive, with the latest study showing that more than one quarter of Americans report negative feelings toward HIV-positive persons.[55] Stigma lies at the root of many of the problems faced by older HIV+ adults, and we'll discuss it more later on. Stigma may inhibit prevention, as older adults may choose not to disclose their HIV status even with sex partners. While 57% of the older adults in the Research on Older Adults with HIV (ROAH) study did disclose to all their sexual partners, 16% disclosed to no sexual partners. The reasons why they did not disclose to others ranged from "I don't want to worry them" to "The person might kill me."[56] Older men consistently report feeling more stigma than older women, and African-Americans feel more of it than whites.[57]

Stigma has many sources, including federal policy. For 20 years the U.S. "banned HIV-positive non-citizens from entering the United States, and banned those already living here from attaining most types of legal status."[58] Although the Obama Administration has rescinded these bans, their long existence has contributed to a sense that HIV+ people are dangerous.

Homophobia, transphobia, and ageism all make HIV prevention and treatment more difficult. A study of gay men over 40 found that some had given up on insisting on safer sex because they were afraid to make demands on younger partners who had agreed to have sex with them, or because they found the idea of growing older Gay unpleasant. One man said, "I'm not looking forward to retirement. I won't have much to live on. I'll be alone… So, why not end it early, and have fun while you're doing it?"[59] A study of 272 transgender people age 50 and up found that only a third practiced safer sex consistently. Many reported that because it was hard for transgender people to find partners or because they wanted to be validated sexually in their preferred gender role, they did not insist on safer sex.[60]

Substance use complicates prevention efforts.

Both alcohol and illicit substance use affects people's ability or willingness to use safer sex practices. The ROAH study found that among HIV+ older persons, "[u]nprotected anal or vaginal sex occurred more frequently when alcohol or illicit drugs were used with sex (40%) than when no substance was used (27%)."[61] The number of partners also is affected by substance use: abusers are "more likely to have multiple sexual partners which increases the risk for both being infected and infecting others with HIV."[62] Thirty-seven percent of the ROAH respondents continued to use illicit substances, and 38% continued to use alcohol.[63] On the other hand, 54% reported that they are in recovery programs or interventions.[64]

In general, substance abuse rates are higher among LGBT populations than the general public. This is particularly true of substance use: one meta-review concluded that the "incidence of substance abuse [is] in the range of 28-35% in LGBT samples and 10-12% in the general population."[65] It is believed these elevated rates are largely due to the "social stress" created by constant exposure to homophobia, biphobia, and transphobia. One study suggesting such a link looked at African-American and Latino men age 50 and older who have sex with other men and found that "most" used drugs in conjunction with sex. "Many were secretive about their sexual encounters, had unprotected sex, were also sexually active with women, and reported high levels of stigma about homosexuality."[66]

Tobacco use is now nearly universally seen as a threat to the health of several critical organs and body systems. Fifty-seven percent of the ROAH respondents smoke, compared to a 24% rate for New York State overall.[67]

Needle exchange programs are inadequate.

While thirty-eight states have syringe exchange programs to reduce the number of new HIV infections caused by the use of shared needles, the federal government has refused to support such programs for 21 years.[68] The syringe exchange programs not only have been proven to reduce HIV transmission rates, but they also frequently connect users to additional materials and services, such as alcohol pads, condoms, and referrals to substance abuse treatment programs.[69] Studies have also shown that injection drug users who access syringe exchange programs are less likely to use local emergency rooms and more likely to enter detoxification programs.[70]

Very little attention has been paid to transgender individuals' use of syringes to inject hormones and/or silicone, and to what degree such users share needles, although a meta-analysis of transgender studies found that 24.7% of transgender women injected silicone, and 27% used syringes for hormone delivery; similar data for transgender men is not available.[71] It is important to note that standard needle cleaning procedures won't work for either silicone or hormones, since both are oil-based, a fact known to few transgender individuals, their physicians, or HIV education specialists.[72] Few needle exchange programs carry needles in the gauges used for hormones or silicone.[73]

Jail and prison policies need revision.

The ROAH study surveyed 1,000 New York City residents who were both HIV-positive and 50 or older. Nearly half (49%) of the men and more than a third (37%) of the women had at some point been incarcerated.[74] A meta-analysis of studies of transgender people found that 32.8% had been incarcerated.[75] Although there is no evidence that these individuals contracted HIV while in prison, it is known that LGBT prisoners are far more likely to be sexually

assaulted in prison than are non-LGBT prisoners. "One study found that one-quarter of the women sexually abused in several Midwest correctional facilities were either lesbian or bisexual – a higher proportion than their representation in the correctional population."[76] Another study found that 59% of California transgender prisoners had been sexually victimized, compared to 4% of the general prison population.[77]

Prevention policy recommendations

SAGE recommends…

…that agencies and programs at all levels of government serving adults age 50+ begin disseminating information about and discussing HIV risk behaviors and emphasizing that age does not protect someone from being infected with HIV.

…that physicians and other health care professionals be trained in the actual sexual and drug use practices of older adults, encouraged to take sexual histories and talk to their older patients about sex, and taught how older patients can most effectively be counseled to reduce their risk of exposure to HIV.

…that physicians and other health care providers be trained in lesbian, gay, bisexual, and/or transgender cultural competency and in addressing HIV stigma in order to encourage more patients to share all relevant information with their providers.

…that all creators of HIV education materials be encouraged to include illustrations of older adults in those materials, and that educational efforts, including social media efforts, be specifically designed for and directed at older adults.

…deeper funding for and promotion of substance abuse recovery programs, including federal funding for needle exchange programs. These programs must be comprehensive and holistic, including being able to address co-occurring mental health disorders, and geared to the specific needs of older adults.

…adoption of the recommendations of the National Prison Rape Elimination Commission, particularly as they concern the protection of lesbian, gay, bisexual and/or transgender prisoners.

…that HIV prevention education and care in jails and prisons be increased, with a continuation of this care available after release.

Health concerns

The medical management of older people with HIV is very complex. Data is just now emerging that will better define how optimal care can be delivered to this aging population.[78] In this section, we'll talk about some of the major medical issues.

Older adults are diagnosed late.

Because both older people and physicians don't think of older people being at risk of HIV, and because some symptoms of HIV infection are similar to symptoms of other common medical conditions affecting older people, older people are more likely to be diagnosed with HIV during a hospitalization and at a later stage of the disease.[79] Since early treatment of HIV is more effective, survival rates in older people with a new diagnosis of HIV infection are shorter than they are in younger people.[80]

Older HIV+ people have many co-morbid conditions.

In general, older people are far more likely to have chronic health conditions than are younger people. The ROAH study found that 91.4% of HIV+ people age 50+ had at least one other major health condition, and 77% had two or more.[81] The most common co-morbidities were depression (52%), arthritis (31%), hepatitis (31%), neuropathy (30%), and hypertension (27%).[82] The National Institutes of Health (NIH) notes that, "[o]lder adults with long-term or new HIV infection experience complex interactions among HIV, antiretroviral therapy, age-related changes to the body, and, often, treatment for illness association with aging….It is imperative we in the research community decipher the medical implications of aging with HIV and continue developing more sophisticated treatment approaches…."[83] What already seems apparent is that "HIV infection accelerates the development of frailty, a condition of the elderly that makes people more vulnerable to illness, injury and death."[84] HIV also can lead to neurocognitive problems and a decrease in bone density, both of which overlap with common aging-related conditions such as dementia and osteoporosis.[85] NIH approvingly listed ongoing research efforts "studying the interaction between HIV and aging in areas as diverse as diseases of the liver, kidney, brain, heart and lung; cancer; bone density; physical activity; mental health; balance; hearing; response to retroviral therapy; immune function; [and] adherence to medical care."[86]

In addition, a model needs to be adapted that focuses on the management of multiple co-morbid conditions in older adults with HIV. Today the recommended primary care physician for a person with HIV is the HIV specialist. That model is no longer applicable as HIV takes its place as one among many chronic health conditions which affect aging older adults.[87]

Drug interactions are largely unknown.

Families USA reported that older people were given an average of 28.5 prescriptions per year in 2000, and estimated that number would grow to 38.5 in 2010.[88] We know very little about how all these drugs interact with antiretrovirals and other drugs used to treat HIV and AIDS-related infections. We do know something about statins (used to lower "bad" cholesterol levels): Many drugs used for HIV "are broken down by the body in ways affected by statins and vice versa. This means that some drugs may increase statins to toxic levels, resulting in increased adverse effects from the statins, particularly the breakdown of muscle tissue."[89] An additional problem is that many drug trials screen out patients with co-morbidities; this practice virtually guarantees that older persons are not included in trials and that we subsequently miss out on learning both how those experimental drugs affect aging bodies, and how drugs interact.

Depression is epidemic.

The most common comorbidity in the ROAH study was depression. Fifty-two (52%) of respondents were depressed, a rate almost 13 times higher than that of the general New York City population.[90] We are singling out this comorbidity not just because it was so prevalent, but also because depression is linked to many additional problems: ""Older HIV-positive adults who are depressed are more likely to have financial problems, have fewer people to turn to for support, lack critical HIV-related information, live alone, have thoughts of suicide, and experience greater levels of stigma related to HIV and aging as compared to older adults who are not depressed."[91] Depression in HIV+ adults is associated with decreases in CD4 cell count, declines in several lymphocytes, a faster progression to AIDS and a higher risk of mortality.[92] Of particular importance is the fact that depression is the most consistently reported factor negatively affecting medical treatment adherence, including adherence to HIV-related drug regimes.[93]

Depression in older adults often goes undiagnosed and untreated. One reason for that is that many people, including physicians and older people themselves, believe that it's impossible to be old *without* being depressed.[94] Another reason it may go undiagnosed is the popular myth that all depressed people act sad. Instead, the indications of depression may include agitation and irritability, or even "vague complaints of aches and pains or gastrointestinal upset."[95] Complicating the picture still further, many medications commonly used by older people, including "steroids, anticancer drugs, tranquilizers, anti-anxiety agents, and drugs to treat Parkinson's disease, hypertension, heart disease, rheumatoid arthritis, and pain," may worsen depression.[96]

Depression is an especially severe problem for LGBT people. In one study, gay and bisexual men reported a depression rate of 31%, compared to 10.2% for

heterosexual men.[97] Bisexual men and women consistently report higher rates of depression than heterosexuals; in some studies, their rates are comparable to lesbians and gay men, whereas in other studies, their rates are higher.[98] Studies of transgender people report depression rates in the 50-60% range.[99]

Standards of care don't exist.

Many "Standards of Care" guidelines help guide physicians' treatment of people with HIV: a Pfizer resource for health care professionals links to 14.[100] Several of these are designed for specific populations or conditions, including the treatment of children, adolescents, and pregnant women. In sharp contrast, however, there are no guidelines for how to manage an older person with both HIV and other comorbidities. This gap is being addressed by a partnership between the AIDS Community Research Initiative of America, the American Academy of HIV Medicine, and the American Geriatrics Society, aimed at developing new guidelines for the treatment and management of HIV in older patients.[101]

Health policy recommendations

SAGE recommends…

…increased government and private funding to develop and disseminate a Standards of Care specific to older persons with HIV, addressing both physical and mental health components of care.

…that physicians and other health care professionals begin considering HIV infection as a possible diagnosis for all adults regardless of age.

…that older adults be included as identifiable groups at every stage of the HIV medical and pharmacological research process.

…increased federal funding for basic research into the particular medical and mental health needs and experiences of older adults living with HIV, including:

- *Research into the interactions between HIV and common diseases and chronic conditions of older adults;*
- *Research into the interactions between medications treating HIV and those treating common diseases and conditions of older adults;*
- *Research aimed at holistically and simultaneously treating depression and other mental health conditions that are exacerbated with an HIV diagnosis, including substance abuse and sexual risk-taking.*

…continued public education depression awareness campaigns, making sure to include the message that depression in later life is not "normal."

Social support

The importance of social support to individuals' physical, mental, and emotional health has been known since at least 1976, when the president of the American Psychosomatic Society, Dr. Sidney Cobb, gave his presidential address, "Social Support as a Moderator of Life Stress." Nearly 3000 researchers have since cited this seminal work.

Older people with HIV may be isolated.

When it comes to older adults with HIV – indeed, for anyone with health problems – having adequate social support is critical. Dr. Cobb described social support as "information leading the subject to believe that he is cared for and loved…esteemed and valued…[or] belongs to a network of communication and mutual obligation."[102] People who are retired and/or have impairments that limit their ability to socialize outside the home may have difficulty finding people who can provide these life-sustaining connections. Several studies have shown that to be the case for older people with HIV. In three separate studies, HIV researcher Charles Emlet, Ph.D., found that HIV-positive people age 50+ had a one in two chance of living alone; the ROAH study found that 70% of that population in New York City lived alone, compared to 32% of all NYC residents over the age of 65.[103] Two-thirds (69%) of the HIV-positive older New Yorkers had a close friend with whom they shared confidences, but 42% said that the emotional support they had received in the past year had been inadequate to meet their needs.[104] "Levels of loneliness have been shown to be negatively related to self-rated health and life satisfaction and positively correlated with depression in older adults," the ROAH researchers noted, going on to say that the HIV+ older adults had an average loneliness score (53 on a scale of 20 to 80) far higher than the average score (32) of a sample from the general population of people age 65 and older.[105] Another study found that whereas 27% of people with HIV aged 20-39 were considered to be "socially isolated," the rate was 41% for those 50 and older.[106]

Being older and lesbian, gay, or bisexual is a risk factor for isolation both for those with HIV and those without. The ROAH study found that 80% of HIV+ people who were LGBT lived alone, compared to 67% of the heterosexuals.[107] Family contact also varied by sexual orientation: 53% of heterosexuals had frequent face-to-face contact with siblings, compared to 33% of the LGBT respondents, for example.[108] A national study with 416 LGB participants aged 60-91 found that 65% lived alone.[109] The same percentage was found in a sample of lesbian and gay elders in New York City,[110] and a Los Angeles study found that 75% of older lesbians and gay men lived alone.[111] This compares to the national figure of 30% of older people living alone.[112]

Older gay men may be particularly vulnerable to isolation. More than 274,000 U.S.-residing men who have sex with men have died of AIDS, decimating many gay male friendship circles.[113] One man in his 50s told researchers, "I always thought these men that I was friends with would be around for me when I was older. I'm the only one of my friends that hasn't died…[T]here were ten of us…."[114]

Older people with HIV may lack practical assistance.

Another aspect of social support is having someone to rely on in an emergency or when one needs practical help. Twenty-five percent (25%) of the New York HIV+ older adults got such assistance from paid helpers like home health aides, and 15% were assisted by volunteers.[115] Twenty-nine percent (29%) said that in the past year, they had needed more assistance with daily living tasks than they had received, and 44% had no one at all or someone "only occasionally" who could assist when needed.[116] Lacking the informal caregivers who provide an estimated $300 billion a year in donated home and nursing care to U.S. residents who need such care, these HIV+ elders will turn to the formal care system, which is already economically challenged.[117]

Here, again, being LGBT is by itself a risk factor. A recent national study of lesbians and gay men over 40 found that 20% said they had no one to rely on.[118] This was the same percentage SAGE found in its survey of gay and lesbian New York City elders.[119] These figures are as much as ten times higher than the number of heterosexual elders who report they have no one to rely on in an emergency.[120]

Stigma again plays a role.

Stigma plays a role in limiting the social network of older people who have HIV. Emlet describes people living "lives of what I am calling protective silence," noting that that silence "can create social isolation and alienation from others."[121] Two-fifths of the New York sample reported that they had people in their lives they would like to tell about their HIV status, but hadn't.[122]

There are cracks between formal support systems.

Theoretically, at least those HIV+ people who are 60 and older should have access to *two* comprehensive, publicly-funded support networks: the AIDS service organizations (ASOs), largely funded by the federal Ryan White Care Act, and the aging services network, funded through the federal Older Americans Act. In practice, however, ASOs "have primarily served younger persons, [so] the needs of older adults have remained relatively invisible in that system…." On the aging network side, since "HIV is not a disease typically associated with aging, social workers employed in the aging network may feel unfamiliar and

uncomfortable with issues related to sexuality and HIV among older people."[123] Therefore, "[d]espite the availability of [aging and ASO] programs throughout the United States at the local level, coordination between these systems have developed only in a relatively small number of geographic areas. Personnel from these systems do not typically communicate or attempt to coordinate services. Additionally, each service sector is characterized by philosophical or knowledge barriers that may prevent comprehensive and sensitive care to older adults living with HIV/AIDS."[124] Other researchers ask, "Can those who have directed care initiatives for the HIV population embrace the known and tested paradigms which are intrinsic to achieving successful aging? Can the medical model evolve into one that is more responsive to those aging with HIV?"[125]

In addition, even though many strides have been made in the past years, we still have not completed developing a comprehensive and sensitive suite of services and supports to enable all older adults to age in their own preferred communities. More work must be done to support aging at home and in community.

There has also been a gap between mainstream aging systems and services developed within and for the LGBT community, as documented in the recent Administration on Aging (AoA) request for proposals for an LGBT Aging Resource Center. AoA set three goals for the new Center, including: "educate mainstream aging services organizations about the existence and special needs of LGBT elders," and "sensitize LGBT organizations about the existence and special needs of older adults."[126] Progressive as this new development is, it too neglects to mention HIV as a critical problem facing LGBT older adults.

Social support policy recommendations

SAGE recommends…

…that both AIDS service organizations and the aging services network recognize, integrate, and provide additional support and encouragement to friends, family, and other people involved with older adults with HIV.

…that additional funding go to home health and other services to support older adults' desire to remain in their homes and communities, and that these services be encouraged to identify and conduct outreach to older adults with HIV.

…that policy changes and official statements explicitly and implicitly promote the worth and dignity of people with HIV, regardless of age.

…that both AIDS service organizations and aging services network personnel be cross-trained in aging and HIV, and that they be encouraged to coordinate on federal, state, and local levels to provide a seamless and appropriate suite of supports to older people living with HIV.

Financial concerns

Finances are a huge concern to people living with AIDS. A large majority of the ROAH study participants were not working: 54% were on disability, 7% were retired, and 20% said they were unemployed.[127] Since the current average SSDI check is just over $1,000 per month, even older people whose income is supplemented by SSI may barely be able to make ends meet. More than half (53%) of ROAH study participants reported they had “just enough to get by,” and 23% said they “do not have enough to make ends meet.”[128]

Drug costs can be extremely high.

For the more than 100,000 HIV-positive people receiving Medicare, the young Part D (prescription drugs) benefit is helpful – to a point.[129] That point varies from person to person, depending on their income. This problem, widely called the “donut hole,” occurs when drug expenses rise to a certain (variable) level, at which point the beneficiary has to cover all additional drug costs until a second level is reached. When this second threshold is reached, Medicare Part D kicks in again, paying 95% of all subsequent prescription costs until the end of that calendar year.[130]

HIV-positive people face a unique problem with the Medicare Part “donut hole”: it does not coordinate with the other major prescription-drug assistance program for people living with HIV, the AIDS Drug Assistance Program (ADAP). ADAP, federally funded through the Ryan White HIV/AIDS Treatment Modernization Act of 2006, pays for prescriptions (and health care services), but only when the costs cannot be paid by another program. ADAP therefore can help pay Medicare Part D premiums, deductibles and co-pays, and can kick in when cumulative drug costs push someone into the “donut hole.” The problem is that ADAP covers fewer drugs than Medicare Part D does, meaning many HIV-positive people in the “donut hole” will still have out-of-pocket drug costs. More significantly, the drugs paid for by ADAP are *not* counted by Medicare Part D, so many HIV-positive people never move out of the “donut hole” and again become eligible for the more comprehensive Part D benefits.[131]

Housing for people living with HIV is inadequate.

It’s hard to find a more succinct description of the importance of stable housing to people living with HIV than the “Whereas…” clauses in House Concurrent Resolution 137, introduced in the U.S. Congress on June 2, 2009, by Rep. Jerrold Nadler. H.Con.Res. 137 expresses “the sense of Congress that the lack of adequate housing must be addressed as a barrier to effective HIV prevention, treatment, and care, and that the United States should make a commitment to providing adequate funding for developing housing as a response to the AIDS

pandemic." The evidence the Congressional co-sponsors cite include the following:

"[G]rowing empirical evidence shows that the socioeconomic circumstances of individuals and groups and structural factors such as housing status are of equal importance, or even greater importance, to health status than medical care and personal health behaviors;

"[T]he link between poverty and disparities in HIV risk and health outcomes is well established, and new research findings demonstrate the direct relationship between inadequate housing and greater risk of HIV infection, poor health outcomes, and early death;

"[R]ates of HIV infection are 3 to 16 times higher among persons who are homeless or unstably housed, 70 percent of all persons living with HIV/AIDS report a lifetime experience of homelessness or housing instability, and the HIV/AIDS death rate is 7 to 9 times higher for homeless adults than for the general population;

"[P]oor living conditions, including overcrowding and homelessness, undermine safety, privacy, and efforts to promote self-respect, human dignity, and responsible sexual behavior; [and]

"[H]omeless and unstably housed persons are 2 to 6 times more likely to use hard drugs, share needles, or exchange sex for money and housing than similar persons with stable housing, as the lack of stable housing directly impacts the ability of people living in poverty to reduce HIV risk behaviors."[132]

Homelessness is yet another problem that especially affects transgender people. A meta-analysis found that nearly 13% of transgender people reported being homeless.[133]

It is important to note that while there is a federal Housing Opportunities for Persons with AIDS (HOPWA) program and several federal housing programs for elders, we have not found evidence of a comprehensive effort to train HOPWA staff about aging issues, to train elder housing workers on HIV issues, or to form a HOPWA/elder housing effort to jointly examine and address the needs of older persons with HIV.

The picture is even more complicated for people with HIV who are also LGBT. In October 2009, the Obama Administration's U.S. Housing and Urban Development Secretary Shaun Donovan addressed the issue. Saying, "the evidence is clear that some are denied the opportunity to make housing choices in our nation based on who they are and that must end," the Secretary commissioned the first-ever national study of housing discrimination against

LGBT people and announced proposed rules aimed at banning discrimination in federally-funded housing programs.[134]

Employment discrimination exacerbates financial insecurity and risky behaviors.

Although discrimination against people with HIV is outlawed under the Americans with Disabilities Act, cases of discrimination continue to happen.[135] Employment discrimination against LGBT people has still not been outlawed on the national level, and in many states and localities, it is still perfectly legal to fire someone on the basis of their sexual orientation or gender identity. The Williams Institute recently released an overview of pay studies that found that gay men earn 10 – 27% less than their heterosexual counterparts.[136] In a society where access to health insurance and pensions are frequently tied to employment, employment discrimination has double and triple effects that can reverberate for a lifetime.

Employment discrimination is particularly rampant against transgender people, especially if they are also a racial minority. As a result, sex work is common among transgender people: a review of 29 studies found that the percentage of transgender women engaging in sex work ranged from 24 to 75%, with a mean of 41.5%.[137] A San Francisco study of transgender men found that 31% had engaged in sex work.[138] Although most people imagine younger sex workers, FORGE reported on a 55-year-old transgender woman who preferred prostitution to being "stuck with fellow employees 8 hours a day, 40 days a week. That much harassment is bad for one's mental health."[139]

Employment discrimination may also result in enough stress to exacerbate such problems as substance abuse and mental illness. When employment discrimination leads to engaging in sex work, HIV repercussions multiply. To name just one, sex workers are often offered more money if they engage in unsafe sexual behaviors, giving them a compelling financial reason to risk acquiring the HIV virus.

Financial concerns policy recommendations

SAGE recommends…

…that prescriptions paid through AIDS Drugs Assistance Programs be counted as Medicare Part D "true-out-of-pocket-costs" that may enable older people with HIV to move past the "donut hole" and become eligible for Medicare Part D catastrophic coverage.

…that renewed efforts be made to ensure all older people with HIV are stably housed in settings where their health and mental health needs are supported.

…that federal legislation be passed outlawing discrimination in employment, housing, and services based on sexual orientation or gender identity.

Intersecting issues: HIV and LGBT

There is discrimination and barriers to access.

As addressed earlier, the stigma of HIV is a major barrier to addressing the root of problems faced by HIV+ older adults. The LGBT older adults served by SAGE's programs face multiple levels of discrimination and stigma that intersect with their capacity to access needed services.

During its three decades of serving LGBT older adults, SAGE has documented numerous barriers LGBT older adults face in systems that were designed for heterosexual and non-transgender elders. These barriers include:

- Invisibility;
- Lack of cultural competency training for aging services providers and allied professionals;
- Prejudice; and
- Discriminatory policies and practices.

Antigay bias and HIV stigma could be keeping older men from disclosing their sexual risk factors. According to 2008 data collected from the New York City Department of Health and Mental Health, 50% of men over the age of 50 did not indicate a documented source of transmission, over twice as many as those who identified as MSM (men who have sex with men). It is likely many of these "unknowns" are men who have sex with men, but who do not want to admit that risk factor due to their own or others' homophobia.

A 2008 New York City Department of Health and Mental Health study looked at MSM of all ages. It found that 39% do not disclose their sexual orientation to their doctors. Black, Latino, and Asian MSM are much more likely than white MSM not to disclose homosexual behavior to health care providers.[140] In general, doctors tend not to ask older patients about their sexual practices -- this is common for older patients of all sexualities and genders. This silence keeps doctors from assessing their patients' risk factors, and can lead to serious health problems.[141]

The dual-invisibility of being LGBT and HIV positive also presents challenges to older LGBT people when accessing benefits and entitlements. For example, many aging services providers never even consider that some of their clients are undoubtedly lesbian, gay, bisexual or transgender. Even those who do suspect they have LGBT clients often do not know how to provide services in effective and culturally competent ways. For example, very few aging services providers have had any training on how to diffuse and counter homophobic or transphobic

comments some aging service clients may direct at other clients, and little to no attention has been paid to addressing aging professionals' biases. Most blatantly, some laws and policies actively discriminate against LGBT older adults, denying them benefits and protections – like being able to live together in congregate housing and nursing homes, or having community property protected when one partner qualifies for Medicaid long-term care coverage – that other older adults take for granted.

At the same time, many states and localities (but not the federal government) have passed laws forbidding discrimination on the basis of sexual orientation (and sometimes gender identity or expression) in public accommodations.[142] Yet even where LGBT consumers and clients are theoretically protected, enforcement of the laws – particularly when it comes to services for older adults such as senior centers, senior housing, and nursing homes – is often overlooked. Indeed, the administrators of many aging programs do not even realize they are covered by such laws.

It is difficult to quantify how many LGBT older adults are accessing (or refusing to access) mainstream services when agencies do not ask relevant demographic questions, and there is little financial support for research to quantify and analyze the endemic problems faced by LGBT older adults in the service arena. Just as we find it nearly impossible to obtain information on HIV infection and transmission rates in older adults, there is no federally-funded research and data collection on LGBT older adults, effectively obscuring the many unmet needs and vulnerabilities of LGBT older adults.

The U.S.'s HIV and aging systems need to be coordinated.

As the population with HIV continues to age, more and more people are going to be eligible for both aging and HIV service systems. Neither system has been comprehensively cross-trained on the intersection of aging and HIV, and there are no large-scale efforts to coordinate the systems so that older people with HIV are sensitively, adequately, and seamlessly served. Research into the intersection of aging health issues and HIV is in a rudimentary stage, leaving patients and their physicians in the position of being "guinea pigs" as they combine treatments for HIV and the typical comorbidities associated with aging without the guidance of previous research. Stigma is a pervasive problem, contributing to the spread of HIV and to the isolation and, therefore, vulnerability of people living with HIV. Neither older adults nor their physicians adequately understand that many older adults are engaging in risky sexual and drug use behaviors, and that both should be making concrete changes: older adults in how they engage in sexual behavior and drug use, and physicians in how they advise and treat their older adult patients.

Recognize and utilize the strengths of HIV-positive older adults.

While this paper has focused on the vulnerabilities of older persons who are HIV-positive, it would be a mistake and unfortunate to dismiss the considerable strengths and resources that characterize HIV-positive older adults. The ROAH study found that participants scored high on scales of autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance.[143] These strengths can and should be tapped to help build a system that adequately and humanely addresses the myriad of issues facing what will soon be the majority among those with HIV: adults aged 50 and older.

Intersecting issues policy recommendations

SAGE recommends…

…renewed commitment to the development of a comprehensive, national AIDS strategy by the White House Office of National AIDS Policy.

…revision of administrative regulations for the Older Americans Act to add lesbian, gay, bisexual and transgender persons to the list of vulnerable populations which get particular emphasis or attention in the allocation of federal funds.

…inclusion of older adults in Ryan White Care Health Services Planning Councils and persons with HIV in state and local area agency on aging advisory councils.

…revision of administrative regulations for the Older Americans Act to stipulate that state agencies receiving funding for data collection must collect data on LGBT populations.

…enforcement of existing sexual orientation and gender identity/expression laws banning discrimination in public accommodations used especially by older adults.

…passage of a federal and additional state and local sexual orientation and gender identity/expression non-discrimination laws to guarantee LGBT older adults' equal access to services.

….new policies, modified case reporting systems, and training to give long-term care ombudsmen the tools they need to document, address, and resolve complaints of discrimination on the basis of HIV status, sexual orientation and/or gender identity/expression.

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