Breaking Through
HIV and African Americans

by Charles Stephens

When my aunt died several years ago, we all believed it was cancer. This was not heard directly from her, but through a series of relatives. Whenever I would ask, “What kind of cancer did she have?” there would be a pause, a look of confusion, and an abrupt change of subject. No more information was provided – not a single detail more than was absolutely necessary. It was cancer, we were told, and the impression was that it should never be mentioned. No details of her treatment were given. The quality of her health care was never discussed.

In my family, illness was never specific. To discuss the intimate details of one’s suffering was taboo. And to discuss the intricate realities of one’s condition was rare. We had a kind of Christian sensibility of not burdening others with our problems. There was a virtue attached to suffering in silence.

Because we never really knew what was going on with each other, we could only guess or gossip. Sometimes we would use the truth like a weapon, in angry outbursts. As in a lot of families, myths and half-truths were more pervasive than facts. We developed notions about each other that later hardened into stories.

The one thing that families share, no matter their race, class, or culture, is that they hold secrets and hide their shame. Stigma fuels that secrecy and gives form, shape, and direction to the shame.

I would later discover that it was a hospital nurse who spoke the words my aunt could not bear to utter. Another aunt was with her until the very end. And as she left her room for the last time, this nurse followed her and stopped her in her tracks. “Your sister…” she said, “It wasn’t cancer. It was AIDS.”

continued on next page
A Complex Picture

AIDS among African Americans does not lend itself to a single explanation, narrative, or understanding. As we look at it deeply, we see a vast array of forces, largely social, that sustain the picture. As for the facts, the statistics reflect what many of us have witnessed in our own lives.

Black communities make up 14% of the U.S. population, but account for nearly half of the new HIV infections in this country and nearly half of people living with HIV. If we take a closer look, the picture becomes even more vivid. Black men who have sex with men (MSM) bear the heaviest burden. They account for more than half of new infections among all young MSM and experience more new infections than any other group (race/ethnicity, age, or sex).

Gender also provides perspective on how HIV acts along the lines of social marginalization. Though the number of new HIV infections among heterosexuals has dropped (due in part to a reduction in infections among black women), black women continue to be far more affected than women of other races. As a group, they account for nearly two-thirds of all new infections among women.

Cultural competence in health care settings is also very important. Stereotypes and assumptions made about African Americans, and African American women in particular, can influence how they are treated by clinical staff. This can prevent them from being more actively involved in their health care. The ability of black women with HIV to navigate health care settings is also affected by the other realities they face: isolation, isolation, isolation.
economic distress, family responsibilities, and the fear of losing social standing if their HIV status is discovered.

Injection drug users (IDUs) make up 8% of new HIV infections and 16% of people currently living with HIV. Once again, African Americans account for the greatest number of new infections in this group. The highest percentage of new infections in the transgender community is also among blacks, and in New York City, from 2005 to 2009, 90% of transgender people newly diagnosed with HIV were black or Latino. Being stigmatized and bearing the brunt of severe and pervasive structural violence increased the vulnerability of transgender women to HIV.

**Access to Health Care**

HIV does not affect every African American in the same way. But the picture of HIV among African Americans illustrates the importance of access to health care very clearly. Addressing the problems that create obstacles to health care and that lead to a reduction in health outcomes is crucial.

An examination of health care can shed some light on the issue. According to the Kaiser Family Foundation, 19% of African Americans in the U.S. are uninsured, or nearly one in five. Moreover, 31% of Latinos are uninsured, as are 17% of Asians/Pacific Islanders. The Affordable Care Act (also known as “Obamacare”) would significantly expand insurance coverage for people of color and reduce disparities in access. This is critical, since the majority of uninsured people of color have incomes in the range that would make them eligible for the ACA’s Medicaid expansion or for tax credits for coverage under the exchanges.

Medicaid expansion is a core element of the ACA. According to the Kaiser Family Foundation, 53% of uninsured blacks who will be eligible for the expanded program live in eight states: Florida, Georgia, Texas, North Carolina, Illinois, Louisiana, New York, and California. In these states, African Americans have a higher risk of being uninsured, which perpetuates the racial differences in health care access and health outcomes.

**Economic Distress**

Lack of financial resources can be a severe challenge when compounded by significant health issues like HIV. Economic distress can create a barrier to HIV prevention and treatment for African Americans due to housing instability, joblessness, lack of transportation, and food insecurity. It affects how choices are ranked and prioritized.

This is particularly true in HIV prevention, where decision-making is far from simple or rational. Sexual decisions aren’t made in the same way you choose a restaurant or movie. There are several forces that influence sexual decision-making, and economic realities are among the most powerful. This is also the case for adherence to treatment regimens. Economic insecurity hinders the ability to maintain the routines and rituals that make things like taking medication regularly possible. Stability helps ensure routine, and poverty destroys stability.

**Belief as Barrier**

The choices we make in life are governed by our values. In health care especially, values are often shaped by cultural influences like religion. Faith is one of the more dominant lenses that the African American viewpoint is shaped through.

But according to The New York Times, “More than half of all people without health insurance live in states that are not planning to expand Medicaid. People in those states who have incomes from the poverty level up to four times that amount ($11,490 to $45,960 a year for an individual) can get federal tax credits to subsidize the purchase of private health insurance. But many people below the poverty line will be unable to get tax credits, Medicaid or other help with health insurance.”

According to The New York Times, “More than half of all people without health insurance live in states that are not planning to expand Medicaid.”
American community uses to view itself. Morality creates order in the face of collective trauma; for a community often seen as less than human, it provides a way to assert the value and worth that has been denied.

I knew a person with HIV who told me that God told him to stop taking his meds. Such moments are hard to endure, and little in the training of even the most effective HIV treatment educator can prepare you for the moment when someone stubbornly and sincerely says he believes God has told him to stop HIV treatment. But I think it’s a mistake to condescend. The best response to faith isn’t always rational. In these instances, I’m not certain that people are unaware of the consequences of their beliefs. The choice they are making, for whatever reason, appears to be best for them at that moment.

Perhaps we rely too much on facts and talking points to guide these discussions. We rattle off statistics and scientific evidence, and while that might clarify things in the realm of the rational, it doesn’t offer much comfort in the realm of the emotional. In a world already uncertain due to their place in society and their health condition, people may hold onto faith in order to carry on. And though the consequences of their faith might be misguided, the need for it is not.

Faith offers clarity, order, peace, and, most critically, meaning. It connects us to the world and gives us the will to confront the mysteries of life and the ability to find joy even in the midst of suffering. This is what sermons are based on, gospel songs are written about, and the faith tradition of African Americans is rooted in. So to respond to the unshakable and stunning faith of black people, and the worldview that inspired it and the actions that stem from it, we must value the emotional, the irrational, the mysterious, and the unexplainable. It’s not enough for HIV advocates to provide facts; we must inspire meaning. The message shouldn’t just be tweaked, but repackaged. Certainly we must provide objective, scientific information. But perhaps there can be new ways to think about faith, to present AIDS not merely in the realm of science and public health, but also as part of a larger story.

**Conspiracies**

HIV conspiracy theories are another challenging ideological bump. “Big Pharma” is seen as profit driven and even responsible for the spread of HIV among African Americans. At other times the government is the culprit. Either way, suspicion creates a sense of distrust that hardens into a powerful paranoia. Such beliefs aren’t always rooted in ignorance, but perhaps in trauma.

Myth conquers fact because myth clarifies and comforts, while facts merely explain and can produce anxiety. The cold rational realities of life don’t always inspire action, which is why the leaders we choose are often those who inspire rather than reveal. People, particularly those in the grip of fear, don’t always want an explanation—they want comfort. Yes, you can explain that HIV was not created in a lab, or that there isn’t some huge government conspiracy, or that Magic Johnson has not been cured by some medicine being kept from us, and you will win some over with the power of truth. But for others—those who have an affinity for conspiracy-oriented explanations—truth is important but not always enough.

The response to conspiracy is not unlike that to faith. We must bring the facts with us, because our arsenal of scientific evidence is our most valuable tool. Facts may be inconvenient, but they are where we all eventually land. So we must also be prepared to speak to fear. People don’t always remember facts, but they often remember stories, and we must share those stories with them. Stories about the impact of HIV, how different communities have responded to it, how people have grappled with it, and how it has affected African American communities, are all extremely valuable.

**Stigma**

I’ve had three relatives die of AIDS, including my aunt—a two women and a male cousin who my family insisted was not gay, but rather a heroin user. Maybe the insistence upon his heterosexuality was because it was easier to have compassion for him as an IDU than as a gay man. I also continue to think about my aunt, who faced stigma fueled by
race, class, and gender, until the day she died. That reality inhibited, if not prevented, her ability to seek health care. Her example sheds light on what the statistics show. She offers a case study on what we are up against.

At a recent cultural competency training in the South, ACRIA educators experienced the reality of stigma and other barriers to care first-hand. In an exercise designed to help participants discuss barriers to health care, African American participants made the following statements:

• “We were taught that white people think they’re better.”
• “White people get better care.”
• “My family felt we couldn’t trust medical providers.”
• “We’ve been disrespected by providers.”
• “We have to work harder to get the information we need from them.”
• “In church, we constantly hear messages condemning homosexuals and sexually active unmarried women, so they don’t get care for fear of rejection by their churches.”
• “People don’t go to AIDS organizations or certain clinics because they don’t want to be seen walking into those places.”

As long as these beliefs and feelings remain widespread among African Americans, the goal of getting all people with HIV the care they need will be difficult, if not impossible, to attain.

The Path Forward
The ACA offers perhaps the best way forward in increasing access to health care for African Americans, particularly through the expansion of Medicaid to lower income individuals. Unfortunately, the Supreme Court ruled that state implementation of Medicaid expansion is optional. Even so, full implementation of the ACA remains the most critical and promising way forward.

We must also continue to fight stigma, particularly on the institutional level. Stigma is too often framed as an amorphous thing, and this makes it difficult to address in a tangible way. We should target institutions precisely and deliberately – churches, professional organizations, civic organizations, fraternities and sororities, social networks and affinity groups – and create anti-stigma messaging that is precise. Our messages must integrate the norms and cultural references of specific institutions and identify gatekeepers to be ambassadors for the messaging.

A crisis mindset is not sustainable. It moves people to action, but only temporarily. It’s a shot in the arm, an adrenaline rush. But it does not create the space emotionally or psychically to map out a plan, to imagine, to hope. We need to create new ways to frame HIV in African American communities. A message that acknowledges the very human desire not only to know, but also to feel, to reawaken not only the willingness to survive but also the passion to live. Most importantly, advocates, service providers, clinicians, and educators must be resilient as we work to ensure efficient systems, quality affordable health care, and culturally competent staff.

Charles Stephens is an Atlanta-based writer, activist, and co-Editor of the forthcoming anthology Black Gay Genius.
The recent reports from the CDC couldn’t be more clear. Gay men are acquiring HIV at rates far higher than other groups – the current numbers show that 63% of all new infections occur among gay or bisexual men, even though they make up less than 4% of people in the U.S. And the infection rate has increased since 2006, when the CDC estimated that gay men accounted for 53% of all new infections. We must take action to get this number down and to help those who are newly infected learn their status and get the care and treatment they need.

In 2003, after learning about my own HIV infection, I became mobilized to do more to help my peers combat the HIV epidemic. After securing a position in HIV prevention, I found myself wanting after hearing what messages were being sanctioned for dissemination to young gay men to help them make informed decisions about their intimate affairs. While immersed in trying to comprehend what my own diagnosis meant for me, I found myself having to simultaneously clarify public health information, which many found only partially helpful or confusing. The unfortunate result is that instead of using proven methods to keep themselves negative, many gay and bisexual men are using misinformed strategies that only serve to further divide gay men – increasing HIV-related stigma and identity-related social isolation. Sexual health for gay men is complex, especially given the fact that HIV is very easily transmitted through anal sex. To achieve an AIDS-free generation, our community’s health care messages must reflect the diversity of our lives and the ways in which we express our intimacy.

Evidence of how this plays out can be found on most online dating sites and apps. Amid the standard bare torso shots on sites like Adam4Adam or Manhunt, or apps like Grindr or Jack’d, visitors are almost immediately confronted with the advertiser’s definition of desirability. Phrases like “no fems, fats, blacks, or Asians” and “no one over 40” are so common that many of us, including site owners and administrators, have become desensitized to their divisive and negative existence in a space that should be welcoming to all in our community. Thus some members of our community are marked as socially or sexually undesirable and immediately isolated. Insensitive and harmful statements such as these need to be addressed and done away with. Many of these sites were created as safe spaces for men to connect with one another without the constraints of the heterosexually dominated culture in which we live.

DDF

Even more pervasive and potentially harmful is the acronym “DDF”, which stands for “drug and disease free,” as if the two are inextricably linked. Some profiles go further and list the date of their last negative HIV test. While this could educate gay men about the importance of regular screening, it instead gives many a false sense of security with potentially inaccurate information. In reality, it discourages the discussions between HIV-negative
and -positive gay men that could lead to more informed and protected sexual partnering. As a black gay man living with HIV, I wear many labels. But like everyone, I am not defined by any one of them. Unfortunately, our society often seeks to, and frequently succeeds in, separating us into categories that only distance and stigmatize us.

When it comes to older gay men, the messaging has already turned toxic. In fact, the CDC’s own risk reduction recommendations for young people include explicit instructions to avoid “sex with older partners who may be more likely to be infected.”

It is well established that stigma, whether from homophobia, racism, ageism, or HIV status, has a negative impact on our ability to slow the rate of new HIV infections, as well as the ability of those living with HIV to achieve positive health outcomes. How can we expect a person receiving messages that they are undesirable to feel empowered to negotiate sexual partnering? Or to question their medical providers when they feel invisible or feel they are already stigmatized by those providing their care? When someone is bombarded with images and messages that portray them as undesirable or “less than”, even the strongest willed among us may eventually internalize those feelings. This explains, at least in part, why communities of color and the LGBT community have higher rates of depression and substance abuse than the general population. And these can worsen over time as age adds another dimension of separation and isolation.

Finding sexual partners has become as quick and convenient as ordering take-out for dinner. And many of us treat it with the same detachment. We list our partner preferences with little regard for the feelings of those who may be reading our profiles, and discount those who do not match our list of qualifying criteria with barely a passing thought. It may be tempting – and easy – to write off these interactions as insignificant, but the frequency with which individuals who do not fit the “Abercrombie” ideal are cast aside can take a significant toll on that person’s self-concept. And placed within society’s consistent messages about the low value of people of color and LGBT individuals, the impact of these interactions can be that much more severe.

Ageism in Public Health Messages
It is troubling when society stigmatizes individuals and communities. But when our public health messaging does the same thing, we have a serious problem. There has been significant concern raised in the public health community about the burden of the HIV epidemic borne by black gay and bisexual men. Many experts fear that highlighting this community may backfire, further stigmatizing black gay men and driving them deeper into the closet. It could foster a sense of the inevitability of HIV infection among black gay men that may decrease protective efforts. In fact, a recent study published in the Journal of Acquired Immune Deficiency Syndromes again highlighted that HIV incidence among black gay men may be higher, in part, because of their limited sexual networks and the enhanced opportunity to become exposed to HIV that results from them. But when it comes to older gay men, the messaging has already turned toxic. In fact, the CDC’s own risk reduction recommendations for young people include explicit instructions to avoid “sex with older partners who may be more likely to be infected.”

While it is true that the likelihood that a partner may have HIV increases with age, it is also true that older Americans are considerably more likely to know their HIV status, be in care, continued on next page
and have an undetectable viral load. In fact, when compared with those between the ages of 25 and 34, people with HIV aged 45 to 54 are 24% more likely to know their status and more than twice as likely to be virally suppressed — significant factors in transmission risk.

With the growing knowledge of the role viral suppression plays in reducing HIV transmission, we have crossed the threshold where simple public health messages are sufficient for partner selection. Our community is better served by information that reflects the complexity of our lives and that doesn’t oversimplify sexual negotiation into tidy categories. But beyond the usefulness of the CDC’s questionable recommendation, the idea that any government-sponsored public health message would explicitly advise individuals to avoid sexual contact with a specific group is astonishing.

If it is acceptable to advise youth to avoid sexual contact with people above a certain age because HIV is more prevalent in that population, isn’t it then acceptable to advise them to avoid sexual contact with African Americans or Latinos in general? Both groups have higher HIV prevalence than their white, Asian, and Pacific Islander counterparts. What about recommending that women avoid having sex with bisexual men, because they are more likely to have HIV than heterosexual men? For that matter, we could simply suggest that women avoid sex with men altogether, since sex between two women carries the lowest risk of HIV transmission.

The problematic nature of the CDC recommendations should be clear to anyone. The disproportionate impact of HIV on minority and marginalized populations is already cited by bigots and homophobes to excuse and perpetuate discrimination. For proof, one need only turn to the official regulations regarding blood donations, which forbid gay and bisexual men from giving. It is evident every time a legislator argues against gay marriage or expanding any LGBT protections based on the so-called destructive and unhealthy nature of their “lifestyle”.

**Targeting the Message**

It is of course critical that we understand the nature of the U.S. HIV epidemic so that we know where best to target our prevention resources. The distribution of federal funding for HIV prevention has never adequately reflected the face of the epidemic. Improvements in surveillance, along with recommendations made in the National HIV/AIDS Strategy, have done much to change that. But with these improvements, it is imperative that we use even more caution when creating public health messaging so as not to further stigmatize those communities where HIV has already taken a heavy toll due to stigma and discrimination.

Prevention messaging should always strive to empower individuals to make healthy decisions for themselves and their partners. We should never perpetuate messages that label any group as possible carriers of disease, even unintentionally. There are many ways to reduce the number of new HIV infections in our community — from regular condom use to frequent HIV testing — and none of them include avoiding sexual contact with any particular group. Individuals of all races, ethnicities, and ages can have perfectly healthy and satisfying sex lives, regardless of their HIV status. The point of public health messaging should be to help the public understand this fact and teach them how to achieve it.

Kali Lindsay is Director of Legislative and Public Affairs for the National Minority AIDS Council.
Caring for the (Near) Majority

Addressing the Needs of Older Adults with HIV

by Liz Seidel

Thanks to the success of HIV treatment, and the fact that one in six new HIV infections occurs in older adults, people ages 50 and older will account for the majority of people with HIV in the U.S. by 2015. But they face many barriers to HIV testing and treatment.

HIV testing

Older adults are often absent from discussions around the testing and treatment of sexually transmitted infections, including HIV. The majority of older adults continue to have sex well into later life, but the myth that they are not sexually active persists. Ignoring the high rates of sexual activity among older adults can delay the care they need, and research suggests that doctors are not addressing these patients’ sexual health issues. The National Social Life Health and Aging Project (NSHAP) found that fewer than half of patients had talked to their doctors about sex after the age of 50. Many physicians do not think of their older patients as being sexually active or at risk for HIV. If they don’t discuss sex with patients, they are unlikely to offer them HIV testing, and the patients themselves may not feel comfortable asking. In addition, older adults are sometimes unaware of their risk for HIV. For many, HIV continues to be viewed as a gay disease or a young disease. Heterosexual older adults in particular may be unfamiliar with HIV risk factors.

Older lesbian, gay, bisexual, and transgender (LGBT) individuals also encounter barriers to HIV testing. Doctors often make assumptions, and some treat all their patients as if they are heterosexual. LGBT people who are unsure whether their provider is gay-friendly may be reluctant to talk about sex for fear of discrimination. A study of older LGBT clients at the Center on Halsted in Chicago found that only half had talked to their doctors about their sexual problems. In addition, discrimination can result in lower use of health care and other social services.

Failure to test for HIV has serious health effects for those who have HIV but are unaware of their status. Late testers are less likely to recover CD4 cells after starting medication and may progress faster to AIDS.

Doctors are not the only group responsible for the failure to test older adults for HIV. Current CDC guidelines do not recommend HIV testing for people over age 64. To reduce barriers to testing that result in late diagnoses, the CDC should update its guidelines to recommend HIV testing for all adults. More needs to be done to promote HIV testing for older adults, including targeting older adults themselves through social messaging campaigns. For example, these campaigns can let older adults with Medicare know that their coverage includes once-a-year HIV testing. Finally, doctors need to be trained to talk about sex with their patients regardless of their age, and to include HIV testing as a routine part of medical care.

Barriers to Care

People with HIV regularly encounter barriers when seeking care. These barriers can take many forms, including how others make them feel about the fact that they are positive, how the people with HIV themselves feel about the disease, and whether they have the tools and support they need to manage HIV. Newly diagnosed older adults, as well as older adults who have been positive for many years, may face additional barriers because of their age. HIV is still viewed as a young person’s disease, and older adults with HIV may encounter ageism and additional stigma.

Older adults with HIV also have to deal with aging-related illnesses and a declining immune system. It can be difficult to find a doctor who can address both HIV and aging issues. Generally, HIV doctors do not know a lot about aging, and geriatricians are not up to date on HIV management. ACRIA’s Research on Older Adults with HIV (ROAH) study found that older adults with HIV have an average of three times more comorbidities (other health problems) than...
Do As I Say, Not As I Do

by Marvin Freeman

In 2000, I was diagnosed with HIV and hep C. With the lifestyle I led, it didn’t surprise me. “Sex, drugs, and rock and roll” was it for me.

But my mindset was against taking any medications. It seemed to me that people I knew who took HIV meds went through many physical changes – I saw their bodies being disfigured, and many died. I would hear the war stories, and they were not good reports. I would see people in my support groups who weren’t doing too well.

I didn’t want to wake up the sleeping dog. I thought that if I just ignored it, HIV wouldn’t affect me. And I worried that the meds might trigger a “domino effect” that could mess up where I was at.

But they didn’t tell me that they weren’t taking their meds properly, and I didn’t investigate it any further because I was just so fearful of the HIV meds. Even though I was using street drugs, I was more afraid of the HIV drugs. I thought if I took them, things might show up two years down the line – like I might end up getting cancer from them. It was all fear-based. It was contempt prior to investigation.

Now, we all know HIV treatment is a big business, and that the drug companies don’t really care about us. It’s just big bucks. I felt they would put out these medications, not really wanting to find a cure, so they could get paid. I thought it was “bait and switch” – you didn’t know if you were getting a placebo or something, like the Tuskegee Syphilis Study. I thought, “Oh, c’mon, are you kidding me? I’m not doing that.” I had all these ideas that we were guinea pigs, and I wasn’t with that. I felt the corporations were going to take care of their own people and use us as guinea pigs – that the meds were designed for white men.

And I saw those drug company ads on TV all the time with so many freakin’ scary side effects: “This medication works but if you take it, your ass falls off!” You see an awful lot of that in the ads for HIV drugs, too. All those disclaimers so they can’t be sued – you’re damned if you do and damned if you don’t. You feel like if you take those meds, they may help you with one thing, but then you’ve got 5,000 more things you didn’t have on the table that now you have to deal with. It’s crazy. You see a magazine ad for an HIV drug with a nice-looking black guy and you think, “He looks good, but look at this stuff on the side of the page – are you kidding me?” That’s frightening, because you might be the 1% that gets that side effect.

It also seemed to me that the clinics in our neighborhoods weren’t getting the best medications or the best information. They were getting the hand-me-downs or the leftovers. So I went into Manhattan, to the “Caucasian” hospital, because I felt they were getting stuff fresh off the truck. My doctor there knew I was still using street drugs, but she knew it was important to keep me in care. She didn’t judge me – I was very fortunate to have her when I was using. That helped me make the decision to finally start meds. Her compassion and understanding – that was rare and special.

When I eventually did get medications, I knew you could sell them. Guys would hang around the pharmacies where they knew people were picking up their HIV meds. You would show them your meds, they would tell you the going rate, and you would get your money. Once you had the connection, it was easy. But when I did that with drugs from my neighborhood pharmacy, the dealer would say, “This is old, so I can’t give you full price for it.” That reinforced what I believed about the poor care we were getting in the ‘hood.

Actually, many doctors know that people sell their meds. But they want to keep them in care, and if they refuse to give them prescriptions, they’ll just go somewhere else and lie about it. So they hope that one day, like me, their
patients will do what they want them to do. At least the patients are still in care. And if too many people leave, what’s going to happen to the clinic? They could shut down.

My health remained good for ten years. The information I read said, “If you don’t take the meds, this bad stuff is going to happen.” But nothing happened! That reinforced my fear-based decisions. I didn’t want to wake up the sleeping dog. I thought that if I just ignored it, HIV wouldn’t affect me. And I worried that the meds might trigger a “domino effect” that could mess up where I was at. Today I know that’s not the case, but back then you couldn’t tell me that. So I never knew what my CD4 count was. I still don’t – I can’t play that numbers game. Every time I got my labs, my doc would say, “You’re doing good, but if it falls below a certain number, you need to start.” And that was all I wanted to know.

In 2010, I got clean and sober and got work as an adherence educator, an HIV test counselor, and a group prevention facilitator. For two years I did HIV testing for many people, and I told those who tested positive to go on the meds. I preached adherence.

But I wasn’t practicing what I preached, and I felt so hypocritical. I knew the facts, I went to the workshops, I had the information, I saw the stats, and I would teach all that. I saw the success others were having and I saw their bravery. It became very taxing at times. Sometimes while leading a workshop, I would try to avoid questions –

---

I knew I was not doing what I was saying. I knew what I was teaching was true for others, but that fear factor just wouldn’t let me cross over that barrier.

---

I would just give generic answers like, “Make sure you’re seeing your primary care doc.” And that was it. But I was evasive, because I knew I was not doing what I was saying. I knew what I was teaching was true for others, but that fear factor just wouldn’t let me cross over that barrier.

Then my health started to fail. I could no longer keep up the facade. I began to listen and embrace the advice I was giving. I could no longer look the other way. To my surprise, my fears were not validated. I didn’t get sick, and my body didn’t fall apart! To the contrary, I feel so much better. I can truly say that adherence works. I’m happy to report that I’ve been undetectable for two years. And I’m still with the same doctor I’ve had for ten years.

Today, I can personally advocate that the meds work. We need more people like me who can say, “I was in the exact same place you are.” That will have more of an impact than all the statistics. Real-life testimony that is tangible, touchable, and reachable will work. We have to hope that people will believe the testimonies of those who are taking the meds and living.
In 2000, a full decade before predicted, Latinos became the largest minority group in the U.S.—over 13% of the population. They include people of Mexican descent (66%), Central and South Americans (15%), Puerto Ricans (9%), Cubans (4%), and other Latinos (6%). Additionally, non-Spanish-speaking immigrants from Latin America include the Mixtec-Zapotec Indians from Mexico, Mayan Indians who speak Mayan, Paraguayans who speak Guarani, Ecuadoreans, Peruvians, and Bolivians who speak Quechua or Aymara, and Brazilians who speak Portuguese.

According to Kaiser Permanente, the historical, social, economic, and political differences between these groups often affect their health care experiences. Providers must avoid the stereotype of “the Latino patient” and base their treatment approach on specific medical needs and cultural background.

**Shared values**

Even though no one “Latino culture” exists in the U.S., many values of people from these countries overlap. Shared cultural values include the following:

- **Familismo** refers to the significance of family, the primary unit within Latino culture. It includes attachment to the family, strong feelings of familial loyalty, and the obligation to support the family emotionally and materially. Traditionally, Latino families believe that personal issues, including health, should be handled within the family and that health care decisions should be made with family involvement.

- **Collectivism** – close, nurturing, and supportive interpersonal relationships are valued in most Latino cultures over individualism, which is
more prominent in U.S. culture. Latinos tend to think of the collective well-being over individual needs.

- **Simpatia** is the desire to maintain harmony, politeness, and respect in relationships. It can be applied to relationships within and outside the family, including doctor-patient relationships.

- **Personalismo** highlights Latinos’ desire for intimate, personal relationships and individualized attention. It is important in health care settings.

- **Folk Medicine** uses folk healers (curanderos, santeros) and natural or herbal remedies, and may attribute symptoms to nonphysical causes, including as “caballerismo”). But it can also lead to aggression, the subordination of women, and idolization of their reproductive and nurturing capacities, along with rejection of homosexuality.

- **Marianismo** – the traditional Latina mother and wife is expected to be submissive and take orders from her husband. She feels she should stand behind him whatever he decides, even if she disagrees.

- **Language** is the primary means by which a culture transmits beliefs, values, and norms. For many Latinos in the U.S., language inhibits access to services and is a barrier to knowledge about medical conditions, especially for those who do not speak any English.

- **Machismo** reflects the male dominant role and is deeply entrenched in Latino culture. On the positive side, it promotes a man’s dedication to his family’s honor and welfare (also known as “caballerismo”). But it can also lead to aggression, the subordination of women, and idolization of their reproductive and nurturing capacities, along with rejection of homosexuality.

For example, during a recent workshop in New York City, one Latina who had been infected by her ex-husband said she could never again be in an intimate relationship, since once she disclosed her HIV status, “no one would want to be with me.” A gay man in the group told her, “You just have to be honest and it will be fine. No one will fault you. You have nothing to be ashamed of. Your husband brought this into your house – you’re not like me, who lived a lifestyle looking for trouble.” He repeatedly referred to his homosexuality as “mi problema” (my problem).

---

**Stigma**

Among Latinos, both HIV and the behaviors associated with it are highly stigmatized. Latino gay men often carry enormous shame, a sense of isolation and loneliness, and the belief that they hurt their families by being gay. Latinos with HIV refer to HIV as “nuestra condición”, (our condition) and themselves as “pacientes como nosotros” (patients like us), instead of using the term “VIH” (HIV) or “pacientes que son positivos” (patients who are positive).

Disclosure

For Latinos with HIV, the decision to disclose is shrouded in feelings of fear, shame, and anticipated rejection, and is greatly influenced by familismo and simpatia. Familismo can offer people comfort and support, but can also be a source of great conflict, since simpatia means keeping family members free of shame and the burden of an HIV diagnosis. Withholding information about one’s HIV status often leads to isolation, in direct conflict with the concept of familismo.

In many Spanish-speaking groups that I’ve led, disclosure was a prominent theme, focusing on family members, peers, and intimate partners. Some continued on next page
members had disclosed to everyone in their lives, while others vowed to keep their HIV status secret. One woman in her mid-40s had not disclosed to anyone except her health care provider and her grown daughter, who lived in South America. She expressed terror that her brother would discover her secret and would respond by throwing her out and forcing her mother to disown her. Since her mother was her only social support, the thought of losing her was devastating. Despite the closeness of their relationship, she dreaded the idea of burdening her with the pain of such information.

**Safer Sex**

Many Latino men feel the need to prove their masculinity, and so may seek multiple partners and take risks. Machismo gives them the power to decide sexual and contraceptive behavior. Many times, Latinas, in accordance with marianismo, are often unable to demand that condoms are used. Research has found that, although many married Latinas saw themselves at risk for HIV because their husbands had multiple sexual partners, most had not used condoms, citing partner resistance as their primary reason.

In one HIV workshop in the Bronx, an HIV-positive heterosexual male said he was petrified of putting anyone at risk, especially after one of his children was born with HIV. That being said, he held strong feelings against the use of condoms, claiming they were “unnatural and no woman would want me to use one.” Several women in the group said they had never used a condom before. One explained the idea had never crossed her mind, especially with her husband.

**Adherence**

Belief in folk medicine is common among Latinos and is often used in addition to prescribed treatments. But the two models can conflict. In a group in Queens, one female talked about her longstanding difficulty adhering to her HIV meds. This baffled and frustrated her providers, since she maintained they had saved her life. The problem was that each morning she would take a mix of vitamins, juices, and herbal teas. But her HIV regimen called for taking the medications with food each morning. She said, “I can’t take my medication because I’m just too full after taking all my vitamins.” Her case manager helped her develop a schedule in which her HIV meds were a priority, but she could also take her herbal remedies.

**Patient-Provider Relationship**

Many times, Latino patients and caregivers seek a friendly and warm approach to care. Simpatia guides Latinos’ desire to maintain patient-provider relationships that are rooted in respect and politeness. Often, this results in the feeling that they cannot ask questions or cast doubt on a health care provider’s opinions.

In a group in Brooklyn, a Latino man with HIV told of going to his doctor with cold symptoms. The doctor recommended he go to the local pharmacy and just buy an over-the-counter cold remedy. But

---

**Some facilities have bilingual staff and interpreters, but without appropriate training on interpretation techniques and medical terminology, miscommunication can lead to medical errors.**

at the pharmacy, he was frustrated that his doctor had not written down exactly which medicine to buy. “There are so many different medicines. How am I supposed to know which will interact with my other meds? He just should have told me what I needed.” He left the store without any medicine. Not wanting to question his doctor’s orders or seem disrespectful, he never discussed it with his doctor.

**Language**

A limited ability to speak English can prevent Latinos from seeking care to the same degree that a lack of health insurance can. In addition, English-speaking Latinos seek more preventive services than those who do not speak English. The lack of Latino health care providers may keep away Latinos who prefer to have providers who speak their language and share their culture. Some facilities have bilingual staff and interpreters, but without appropriate training on interpretation techniques and medical terminology, miscommunication can lead to medical errors. Family members, especially children, and untrained staff should not be used as interpreters when relaying sensitive medical information such as HIV test results. Regional Spanish translation is necessary to accommodate for differences in terminology.

The reading level of materials for Latinos must also be checked for each target audience. Latinos face enormous educational barriers and many have literacy problems. Without attention to literacy level in both Spanish and English, HIV materials will be of little or no use to a large percentage of Latinos.

Networking with Spanish-language radio and television stations has been an effective way of communicating import-
This may explain why Latinos are likely to learn their HIV status later in the disease process than whites.

The lack of culturally appropriate health care, little targeted HIV education, economic difficulties, fear of deportation, and a perceived low HIV risk combine to leave Latinos at high risk of HIV. Although the time between untreated HIV infection to an AIDS diagnosis is generally agreed to be 10 to 12 years, 65% of Latinos are diagnosed with AIDS within one year of their HIV diagnosis, meaning they have been unknowingly living with HIV for many years. They also have lower CD4 cell counts and higher viral loads when first tested for HIV.

Since HIV has long been associated with gay men and injection drug users, health care providers are less likely to recommend HIV testing to married Latinas, who make up an increasing share of women with AIDS. One way to encourage HIV testing among Latinos is to frame it as a prevention method that will benefit not only the patient but the entire family. Slogans such as “Protege tu familia: Hazte la prueba” or “Protect your family: Get tested” can be strong motivators for Latinos who do not identify with groups they feel are at risk for HIV.

**Conclusion**

To communicate with patients from different cultures, providers must be able to respond to their cultural expectations. So, in addition to collecting information on a patient’s health problems, every provider should ask about a patient’s cultural background. In *The Latino Patient*, Nilda Chong proposes using the GREET model when working with Latinos:

- **G** eneration
- **R** easons for Immigrating
- **E** xtended or Nuclear Family
- **E** thnic Behavior
- **T** ime in the U.S.

This model provides an opportunity to collect cultural information while demonstrating interest in the lives of their Latino patients, establishing confianza (trust).

Health care providers should remember that Latinos are diverse. They must not stereotype but rather treat each Latino patient as unique, with the respect each deserves. The process of becoming culturally competent is a continual learning process, and each interaction is an opportunity for learning.

According to the National Minority AIDS Education and Training Center, providers can offer culturally sensitive care to Latinos with HIV if they:

1. Have a good understanding of their own cultural beliefs and values.
2. Understand the nuances of different Latino communities.
3. Know the sociopolitical influences and barriers to care that various Latino communities face.
4. Develop the skills and knowledge needed to work with diverse groups of Latinos.

Providers must remain mindful of the many factors that contribute to HIV risk among Latinos and the impact that cultural and gender expectations have. The HIV epidemic among Latinos presents important challenges to community leaders, patients, health care providers, policymakers, researchers, and public health officials. A holistic approach to address HIV is extremely important if we are to reduce HIV and treatment differences among Latinos, and improve health care and health status for all.

---

*Luis Scaccabarrozzi is Director of HIV Health Literacy Programs at ACRIA.*
Back in 1986, my friends found me unconscious in my bedroom. They brought me to the ER, and a few days later I was told that I had AIDS. Because I didn’t have insurance or speak fluent English, they told me to go to Cook County Hospital for follow-up care. But it was a hassle – I had to take a train and a bus, and then wait in long lines. Sometimes I spent the whole day just getting blood tests and meds. And there weren’t really any Spanish-speaking doctors there. They were mostly Filipino or from India and spoke very little Spanish. I appreciated their attempt to communicate, but they didn’t understand cultural things. They would tell me not to eat too much salt with my tacos – but I was Mexican, not Puerto Rican, so I rarely ate tacos. When I felt better, I stopped taking my meds and I stopped going to the doctor.

A couple of years later, I ended up back in the same ER. By that time, I had learned more English, for my work. I don’t think that my spoken English was the best, but I understood almost 100% of what people said to me. Luckily, a friend told me about a clinic for gay men near me. I couldn’t believe I had been sent so many miles away when there was a clinic within walking distance! I’ve had many friends who were also sent all the way across town to Cook County just because their English wasn’t perfect. Travelling for so long is just as much a barrier to care as language is.

The doctor at the gay clinic was very meticulous and asked many questions about my medications and exactly how I took them. So I told him that I crushed them up, poured them into a hot bath, and soaked in them every day for a couple of weeks before I started taking them orally, so they would work better.

He got very angry and even began to yell at me. He sent me to a psychiatrist and a learning specialist. The psychiatrist didn’t find anything wrong. But every time I went back to see this doctor, he always seemed angry with me and didn’t spend much time explaining anything – just ordering blood tests and giving me my prescriptions for the next three months. And he would ask the same question every time, very slowly: “[Aarre...youuu...taking yourrrrr...me – di – caaaaaaa – tions?” I’d always say yes, because I was.

Maybe he thought that I didn’t understand him, or maybe he just thought I was stupid. Actually, it was harder to understand him when he spoke like that, and I had to really pay attention. It was funny but I found myself also responding very slowly. And whenever I would have to change doctors, the new doctor would also speak to me very sloowly.

Years later, a Spanish-speaking case manager began to work at the clinic, and he asked me about any learning disabilities or developmental difficulties I might have. He also asked about my educational level. I asked why he was asking all these questions, and he mentioned that the medical notes from every doctor at the clinic stated the same thing: “suspected mild mental retardation”, “suspected psychiatric disorders”, “suspected learning disabilities”, etc. All this had begun with my first doctor and been copied throughout my medical history with each new doctor.

But no one had ever asked me why I soaked in the tub with my meds. It’s what we always did back home – my grandmother and mother did the same thing. They said the body would absorb the medications better if you soaked in them first. I have many friends who practice Santeria, and when they take herbs, they soak in them first. My family had done this back when we couldn’t afford meds. We would get a few herbs together and would either soak in them or have them as teas. I’ve always done that and it’s always given me great results. I’ve never had side effects from my HIV meds, and I believe it’s because I soak in them first. My friends complained of vomiting, nausea, lack of appetite, etc., but I never had any of that.
But instead of asking me why I soaked with my meds, that first doctor just said I was into what he called “witch medicine” – as he referred to Santeria. He even made fun of me by asking me if I cut chickens’ heads off in religious ceremonies. I told him I was Catholic and that we didn’t do that in the church. And that was that.

He said I was into “witch medicine” – as he referred to Santeria. He even asked me if I cut chickens’ heads off in religious ceremonies.

It wasn’t until that new case manager came and asked about my beliefs and my customs that the medical notes changed. In fact, he made sure that when I changed medications again, I had enough to start taking them orally and to soak in. He suggested I try not to wait as long before I started taking them orally, because the doctors wanted to see how well they were working as soon as possible. So I began soaking in them for only a week, and by the second week I was taking them orally. My case manager spoke to my new doctors and they never put anything related to mental retardation into my medical history.

I think my culture has been a barrier to my care. I’ve had friends who began new treatments sooner than me and did better. It angers me that I might have been denied new treatments because the doctors thought they would be wasting them on someone who wasn’t taking them properly. Once I told that first doctor that I soaked in my medications, he just categorized me as mentally retarded and never bothered to listen to the rest of my story. I think many Puerto Ricans in my age group soak in their meds, and a doctor should know this and not be so judgmental about cultural beliefs. I know I will never stop soaking in new meds because it works for me.

They should have listened better, instead of sending me off to psychiatrists and learning disability counselors. Having a translator or someone who understood my culture also would have helped. Imagine being categorized as mentally retarded because of your beliefs or language limitations! Now I understand why the doctors spoke to me so slowly. It wasn’t my language – they just thought I was stupid. I felt like I was being spoken to like a child, as if I was dumb and didn’t understand much of anything.

Now, if I think my culture or beliefs might have an impact on my services, I speak up, to educate service providers. I have to let them know that I know how to take medications so I’m not given fewer treatment options. And I educate friends who have just tested positive about their own rights.

But when I have to see a specialist who doesn’t speak Spanish, I find it annoying if they speak to me so sllowwly. I want to say to them, “Just because I don’t speak English perfectly and have an accent, it doesn’t mean I’m dumb.” I see the same issues with others who don’t speak English well – they continue to be given fewer options or are sent to faraway places that make it hard to access services. Now, when I hear about an injustice like this I make sure I speak up.
A Hidden Crisis: HIV in the Two-Spirit Community

by Harlan Pruden, Tim Nuttle, and Shannon Finucane

The growing epidemic of HIV among Native Americans and Alaskan Natives (NA/AN) is reason for concern. Roughly 5.2 million people in the U.S. identified as NA/AN in the 2010 U.S. census. While the Native community in the U.S. accounts for less than 1% of reported HIV cases, they have the third highest rate of HIV infection, after African Americans and Latinos. They also have the shortest life expectancy after an AIDS diagnosis of any race or ethnicity.

As indigenous people, once we are gone, we are gone. Take for example the Onondaga Nation in upstate New York. There are only 2,000 Onondaga left in the world, with 700 living on their traditional land. In 2008, they had three new HIV cases. Some may say “That’s only three people”, but that is over nine times the rate of HIV infection in the overall U.S. population. When considered in the scale of the Native population, HIV is taking an enormous toll.

According to the CDC, men who have sex with men (MSM) and MSM/IDU (intravenous drug users) accounted for 62% of all new diagnoses of HIV among Native Americans. Though useful for tracking behaviors that lead to increased risk, these labels don’t help us understand why people of different identities engage in risky behavior or tell us how to treat people with HIV in a culturally sensitive and supportive way.

Two-Spirit Identity

There were once about 400 distinct indigenous Nations in North America. Of that number, 170 have documented multiple-gender traditions. At the Third Annual International Gay and Lesbian Native Gathering in 1990, activists created the term “Two-Spirit” to encompass these multiple traditions. They wanted a term that “reflected the combination of masculinity and femininity which was attributed to males in a feminine role and females in a masculine role” in many indigenous cultures. Our male-embodied Two-Spirit people (what the CDC call MSM) bear the brunt of the HIV crisis.

The Two-Spirit tradition is primarily a matter of gender, not sexual orientation. Within traditional Native communities, women farmed, gathered food, and cooked, while men hunted. Although there was division of labor along gender lines, there was no hierarchy based on gender – a community could not survive without both of the equal halves of a whole. The Native commitment to gender equality opened the door for multiple genders, without the idea that a man was taking on a lesser gender by placing himself in a women’s role, or vice versa.

The Native commitment to gender equality opened the door for multiple genders, without the idea that a man was taking on a lesser gender by placing himself in a women’s role, or vice versa.

Traditional Roles of Two-Spirit People

People of Two-Spirit gender functioned as craftsperson, shamans, medicine-givers, mediators, and social workers. In many Native communities, men’s and women’s styles of speech were distinct – sometimes even different dialects were spoken. Two-Spirit people knew how to speak in both the men’s and women’s ways. Many nations had a division of labor, women gathered and men hunted. As a result, there were men’s camps and women’s camps. Women were not allowed in the men’s camp and vice versa. Since it was believed that Two-Spirit people had both men’s and women’s spir-
its, they were the only ones allowed to go between the two camps. They brokered marriages, mediated divorces, settled arguments, and fostered open lines of communication between the sexes.

Two-Spirit people challenged the rigid views of colonizers and missionaries – not just of a binary gender system, but their entire binary system of “this or that”. The Two-Spirit’s mere existence threatened the colonizers’ core beliefs, and the backlash was violent. Captain Vasco Nunez de Balboa, a Spanish conquistador, unleashed violent dogs on the male-bodied Two-Spirit people from what is now Panama. Word of this brutal treatment spread quickly from Nation to Nation. Many Nations decided to take actions to protect their Two-Spirit people. Some Nations hid them by asking them to replace their dress, a mixture of men and women’s clothing, with the attire of their biological sex. After years of colonization, some of those Nations converted to Western religions that did not accept their community structures and forgot, or even denied, ever having a tradition that celebrated Two-Spirit people.

Colonization and Challenges to HIV Prevention
HIV prevention among NA/AN is filled with challenges. The historical trauma suffered by Native peoples has led to increased rates of alcoholism and drug abuse, which contribute to partner violence and make HIV prevention difficult. The stigma now associated with sexuality and gender in Native communities, along with the close-knit nature of these communities, can make it difficult to confidentially discuss and confront HIV.

In 2011 the CDC released the National Intimate Partner and Sexual Violence Survey. One of the most staggering findings was that nearly half of the men who identified as Native reported rape, physical violence, or stalking by an intimate partner. HIV and other sexually transmitted infections (STIs) are more likely to be transmitted during sexual violence because of physical trauma. Intimate partner violence also causes power inequality in relationships, making it difficult to negotiate condom use. This staggering amount of intimate partner violence is fueling the HIV epidemic among Native communities.

Alcoholism leads people to engage in risky sex and can lead to intravenous drug use. These are the most common HIV transmission modes among Native people, who have the highest rates of drug use among all racial groups. In 2011, intravenous drug use accounted for 37% of HIV transmissions among Native women and 11% among men. This is almost double that of other races. Another factor fueling the spread of HIV in Native communities is the high rates of STIs, since they increase the risk of HIV infection. Native people have the second highest rates of gonorrhea, chlamydia, and syphilis among all racial groups.

Homophobia can be especially harmful, since it discourages people from seeking services out of fear of being targeted. Urban Natives have access to more services and to the LGBT community, but those who live on reservations are isolated. Local tribal health care centers offer HIV testing, but some people refuse testing out of fear. As a result, they may unknowingly be infecting others. Other issues, such as language and culture, gender identity, and culturally based holistic treatment are also important to address when providing HIV care.

As a colonized population, Native peoples have a long history of mistrust of the government, medical institutions, and service organizations. They have endured significant traumas, such as removal from homelands, divided nations, loss of language and culture through forced enrollment of children in boarding schools, rape, disease, etc. This history continues to influence today’s generation.

Recent Efforts to Combat HIV
The Indian Health Service, a federally-funded health program, recently created a website to inform people about HIV within Native communities. It includes educational information, the ability to search for local service providers, and statistics from a 2006 CDC report on HIV in Native peoples. While the site is a great resource, the out-of-date information highlights the shortcomings of dealing with the epidemic in this community.

Last March, the CDC published a comprehensive report titled HIV Among American Indians and Alaskan Natives. In 2007, National Native HIV/AIDS Awareness Day began an annual tradition of promoting HIV testing. The following year, The Indian Health Service began a nationwide campaign to promote routine testing of all Native populations. Slogans like “Native Tested Proud” and “Know Your Body, Know Your...
The National American Indian and Alaska Native Addiction Technology Transfer Center assisted with the dissemination of the training, “Two-Spirit Then and Now: Reclaiming Our Place of Honor”. This training helps mental health, substance abuse, and HIV care providers work more effectively with Two-Spirit people. Both Native and non-Native participants are given an opportunity to discuss how historical trauma led to the displacement of Two-Spirit people from their communities, and its impact on their mental health, health disparities, and recovery support needs. For more information, email training@ne2ss.org.

Since September 2012, the Substance Abuse and Mental Health Services Administration’s Native American Center for Excellence has been hosting monthly Two-Spirit webinars. In “Depression and Suicide in The Two-Spirit Community”, presenter Karina Walters acknowledged the difficulties that affect the mental health of Two-Spirit people and showed that strong family support networks are key to combating HIV in Native communities. For info on upcoming webinars, email info@nacesap.org, and visit nace.samhsa.gov/TTA/TrainingDocs.aspx to view past webinars.

Not long ago, the Two-Spirit identity was not embraced by either the LGBT community or the Native community. This meant that no data were collected on the Two-Spirit community. With no data, it was nearly impossible to obtain any funding because leaders could not document what they knew was going on in their community. Fortunately, there are now two sets of data on Two-Spirit health.

One of these is the New York State Department of Health’s needs assessment, “Reclaiming Our Voices: Two Spirit Health & Human Service Needs in New York State”. The other is Dr. Karina Walters’ five-year, multi-site health survey of Two-Spirit Native Americans, “The Honor Project”, funded by the National Institute of Mental Health. The Honor Project has found that about a third of transgender Two-Spirit people and MSM reported they were living with HIV. These rates of infection are similar to those in sub-Saharan Africa, as well as to those among U.S. African American MSM, a community with a verified AIDS crisis.

The National American Indian and Alaska Native Addiction Technology Transfer Center is affiliated with the Goodfish Lake Band of the Saddle Lake Indian Reservation, a member of the Goodfish Lake Band of the Saddle Lake Indian Reservation.

Tim Nuttle (Cherokee) is a volunteer and supporter of the NorthEast Two-Spirit Society.

Shannon Finucane is a Jeannette K. Watson Fellow and Public Policy Intern at GMHC.

Harlan Pruden is Director and Co-Founder of NorthEast Two-Spirit Society and is a member of the Goodfish Lake Band of the Saddle Lake Indian Reservation.
Globally, sex workers (those who trade sexual services for money, goods, food, shelter, housing, or other resources) have been identified as a key group in the fight against HIV. But they face many obstacles when gaining access to health and social services. In the U.S., where most sex work is illegal and carries high criminal penalties, fear of prosecution is a barrier to care for sex workers. They can also face strong social stigma and discrimination in social service and medical settings.

Around the world, in places where there are few legal protections, sex workers experience physical violence and coercion while working, making them more vulnerable to HIV. In contrast, when there are greater protections, sex workers are more likely to be able to obtain health services and to practice safer sex. In many U.S. cities, the possession of condoms has been used as a means to intimidate, arrest, and detain sex workers on prostitution charges, undermining the health and safety of sex workers. This tactic also affects those profiled as sex workers, such as transgender women and people who don’t conform to gender norms.

**Stigma in Health Care**

The degree to which sex work is criminalized often dictates sex workers’ ability to negotiate and manage their work. In places where certain forms of sex work are decriminalized, such as New South Wales, Australia, research has shown that sex workers have greater access to health and social services and are less likely to be victims of violence or coercion. But in the U.S., the criminalization of many forms of sex work limits the ability to access health and social services.

Over the past decade, several studies have focused on stigma as a barrier to health care access for people in the sex trade, particularly their difficulty in disclosing about sex work to a health care provider. Sex workers are unlikely to discuss this with a health care provider, friends, or family, often due to negative experiences or fears of disapproval, and this can have a profound impact on their physical or mental health. Nonjudgmental and affirming health care for sex workers results in more positive health outcomes and improves their ability to manage stigma.

Many health care providers have only limited training in how to work with such a sensitive population or do not know how to deal with sex-related issues in general. Many providers either know little about sex workers – because no one has ever disclosed to them – or are afraid to ask for fear of appearing ill-informed. Sex workers who do disclose are often met with either misinformation or mistreatment. A study published in 2010 surveyed over 2,200 medical students and found that over 53% felt they had not received enough training in medical school to address their patients’ sexual concerns. These students were also more likely to report not being comfortable talking to patients about sexual health, drawing a correlation between education and comfort regarding sexual issues.

This lack of formal training, coupled with limited comfort speaking about sexuality, means health care professionals will base their care upon preconceived notions about sex workers, often the result of biased media coverage or harmful stereotypes. These notions can be highly problematic, filled with misunderstandings of sex workers’ lives.

**What Works for Sex Workers**

We need to support more effective HIV interventions in the U.S., similar to the...
strategies used in some other countries. Efforts to fight HIV among sex workers have been successful in Bangladesh, the Philippines, India, the Dominican Republic, Nicaragua, Thailand, South Africa, Cote d’Ivoire, Benin, and Ukraine. These programs offer substantial evidence that targeted, comprehensive HIV prevention programs are effective in reducing HIV transmission and in making sex work safer. They make testing and treatment services readily available, provide condoms and promote their use, and utilize interventions that include outreach, peer education, and community empowerment.

Some HIV prevention efforts have focused on labor empowerment, such as the development of workers’ cooperatives. These cooperatives support the connection between positive labor conditions and positive health outcomes for sex workers. Research supports interventions that use a community empowerment model. But the criminalized nature of sex work in the U.S. keeps many from supporting these strategies among sex workers, for fear of being denied funding and considered supportive of prostitution.

Using sex workers’ input in decisions regarding their health care is a recurring theme in successful HIV interventions globally. Research also suggests that peer education works best for sex workers when it is paired with direct services (to address needs beyond prevention) and community empowerment (to make programming sustainable and relevant). Peer-led programs can adapt health messages to fit the community’s needs and build relationships with hard-to-reach groups. They have been linked to increases in knowledge about HIV, as well as reduction of risk behaviors.

**Fighting HIV With, Not Against, Sex Workers**

The National HIV/AIDS Strategy emphasizes prevention services that limit the spread of HIV from those already infected. Federal funds use a “seek, test, treat, retain” approach for finding people with HIV who do not know they are infected and linking them to care. But what does this strategy look like when applied to sex workers?

For sex workers in the U.S., the notion of being sought for HIV testing may be frightening, especially considering that sex workers have long been forced into medical and social programs, rather than being willing participants. In U.S. prisons, sex workers have faced mandatory testing, and those who test positive can face extreme isolation from other inmates. Within public health settings, there exist deep historical misconceptions of sex workers as vectors of disease and vice. The historical association of disease and deviance with sex work has stigmatized sex workers as inherently “dirty” and in need of social correction.

For over a century, these misperceptions have led to many attempts to “reform” or aid sex workers, isolating them and creating a threat to public health. At the beginning of the AIDS epidemic, the panic-driven efforts of lawmakers led to proposals such as California Bill 2319, which would have required mandatory HIV testing for sex workers and felony charges for prostitution-related offenses. In an effort to both identify and profile sex workers, this bill would have set a precedent for testing any person even suspected of prostitution.

Globally, sex workers in Greece and Malawi have faced forced HIV testing sanctioned by the state. In 2012, Greek police began targeting sex workers, forcing them to undergo HIV testing. They also posted the names and photographs of those who tested HIV positive on official police websites. These actions were condemned by the U.N. Programme on AIDS, Amnesty International, the Global Network of Sex Work Projects, and the Global Network of People Living with HIV/AIDS. In Malawi, 14 sex workers decided to sue the government and challenge the constitutionality of forced HIV testing. This legal case was among the first of its kind to make its way through the courts.
The Anti-Prostitution Pledge

Though the U.S. government has acknowledged the need to engage sex workers and protect their rights as important pieces of HIV prevention programs, laws that criminalize sex work continue to create conditions that hinder these very programs. Fortunately, one such barrier—the so-called “anti-prostitution pledge”—no longer stands in the way. The anti-prostitution pledge required organizations seeking PEPFAR (President’s Emergency Plan for AIDS Relief) funds to have a policy opposing prostitution. The pledge limited or eliminated partnerships with sex workers and the organizations that support them, as well as forced some organizations to conceal their work with sex workers or refrain from publishing important efforts with sex workers.

According to the U.N., less than 1% of global funding to prevent HIV is spent on sex workers, despite high infection rates. The pledge not only financially limited the services available to sex workers, it also undermined approaches in health and social services that were based on human rights. And it stood in sharp contrast to successful interventions outside of the U.S. that provided better health outcomes by including sex workers, such as VAMP, the sex worker-led health project of SANGRAM in India.

Since the pledge not only prohibited the use of any government money to “promote or advocate the legalization or practice of prostitution” but also required that almost all recipients of funds refrain from any speech the government deemed “inconsistent with” the policy, the provision violated First Amendment rights. Fortunately, the U.S. Supreme Court recently declared the pledge unconstitutional.

How the Supreme Court’s decision affects HIV efforts in the U.S. remains to be seen. The unconstitutionality of the pledge in the U.S. does not affect its use internationally, where the vast majority of PEPFAR funds are spent. Additionally, the portion of the pledge that states that no funds “may be used to promote or advocate the legalization or practice of prostitution” remains. In the past, this prohibition has been used by USAID to decide whether legal assistance for sex workers can be seen as “promoting” sex work, discouraging organizations from providing legal help to address sex worker abuse and exploitation.

The U.N., WHO, Human Rights Watch, and other organizations worldwide have publicly declared the decriminalization of sex work as being in the interest of human rights. But it’s uncertain whether the Supreme Court ruling that the pledge is unconstitutional will bring us any closer to ending the criminalization of sex work in the U.S.—the primary barrier to health and well-being for sex workers.

In the past, the Pledge has been used to discourage organizations from providing legal help to address sex worker abuse and exploitation.

Conclusion

In global efforts against HIV, countries that have made significant investments in programs for sex workers have reduced or stabilized their rates of HIV infection, demonstrating that these interventions are effective tools. Within the U.S., however, punitive laws, policing based on profiling, and discrimination remain persistent barriers to care for sex workers at risk of HIV, fueling the epidemic.

Working to end the stigma and discrimination experienced by sex workers, particularly in public health settings, is a critical component of fighting the HIV epidemic. The success of public health policy depends upon the cooperation of those affected. Though sex workers continue to be at high risk for HIV, reaching and engaging them can be complicated. Unfortunately, funding for programs for sex workers continues to decrease or be limited by federal restrictions. With the Supreme Court’s ruling on the unconstitutionality of the anti-prostitution pledge, there is hope that research will now emerge to support such interventions in the U.S., increasing interest in serving this vital population in the fight against HIV.

Despite the limitations we have faced, community-led efforts to empower sex workers continue to grow. Saint James Infirmary, the first and only clinic for sex workers in San Francisco, recently celebrated 20 years of creating a “community space for all sex workers, where safety and health care was regarded with the utmost importance.” In New York City, Persist Health Project (Providing Education and Resources in Support of Individuals in the Sex Trade) was founded in 2012 by a group of current and former sex workers, trafficking survivors, and allies, who provide care coordination and health education for people in the sex trade. Hook Online (hookonline.org), an online resource for men in the sex trade, and the recently launched NSWP+ (nswp.org/nswp-plus), a program of the Network of Sex Worker Projects, offer online global opportunities for sex workers to engage with each other and with affirming support systems.

Recently, sex workers and allied organizations in New York and California have advocated for bills that would make it illegal to arrest sex workers or people profiled as sex workers for carrying condoms. The effort was supported by reports from the PROS Network (Providers and Resources Offering Services to sex workers) and Human Rights Watch. Working with anti-trafficking organizations, LGBT anti-violence groups, and youth organizers, sex workers were able to pass A2736, the “No Condoms as Evidence” bill in the New York State Assembly. Though there is still work to be done to pass the bill in the NYS Senate, and to ensure that sex workers are genuine partners in efforts against HIV, these steps forward are encouraging in the fight for human rights and access to health care for sex workers in the U.S.

Sarah Elspeth Patterson is the Co-Founder and Care Coordinator of Persist Health Project.
As a sex worker, I had a range of experiences trading sexual services. It began as a way to support myself in college, and I worked as few hours as possible, to leave time for schoolwork and my other job as an English tutor. But I stayed in the sex industry after school ended, looking for jobs in my area of study and sometimes volunteering for a magazine written by people in the sex trades. I knew other sex workers and felt great community with them, both working and socializing.

But working for others in the industry (rather than for myself) sometimes forced me to compromise my own comfort level or desires to appease their needs. Sometimes I was coerced by managers – they would pressure me to see clients I didn’t want to see or engage in activities I didn’t agree to. It’s not like you have a Human Resources department when you work at a dungeon or a brothel. Since I was working in an industry that is illegal and also stigmatized, I felt like I didn’t have a choice in the matter. That’s what I was told when I spoke up. When you don’t have the rights that most workers have and you know what you’re doing is illegal, it’s hard to ask for what you need and just about impossible to file any sort of complaint.

After college, I got involved a man who also worked in the industry and began working for his company. The relationship was very negative for both my emotional and physical safety. I considered calling the police many times but never did, out of fear of being shamed, not being believed, or even being arrested due to my work. I never saw the police as people who could help me. Many people I have spoken to through Persist have shared similar experiences. Some are also dealing with issues like racism, homophobia, and transphobia, especially when dealing with social services or law enforcement. Others are undocumented or have limited family support.

I was “outed” to my mother, and she told me she would never forgive me. That made me afraid to disclose to most anyone else. I also never felt safe discussing my work with any health care providers, fearing they would not understand and would judge me and change the way they treated me as a patient. Before I began working, I learned that people should be tested every 6 months to a year if they are sexually active, and so I started asking for regular testing from my OB/GYN. He asked me why “a girl like me” needed so much testing. I knew from then on not to go to people who would respond like that, and I became much more careful about what I told doctors about myself.

When I started working, I ended up disclosing less and less about myself, even the sex I was having in my personal life or the kinds of people I was having sex with. I had also heard horror stories from other workers of providers telling them what they did was wrong or disgusting, of health care providers making assumptions about them being messed up because of their work or treating them differently after they knew. And though I always made safe choices at work, I had harder times setting boundaries in my personal life, so I just refrained from being honest about either.

I never felt safe discussing my work with any health care providers, fearing they would not understand and would judge me and change the way they treated me as a patient.

When I got my first full-time job that could support me without sex work, I left the industry, not just because I wasn’t fulfilled by the work anymore, but also because I was tired of dealing with the stigma. Hiding what I was doing from those around me was exhausting. Working other jobs while managing a second identity was also draining. Even now that I’ve left sex work, disclosing my history to those who have not done sex work is still difficult.
Now, as a peer counselor for Persist Health Project, my understanding of myself has changed. I am able to provide care for others in the same way that my friends in the sex trade looked out for me when I was working. I provide information, try to listen without judgment or assumption, and advocate for them when they need someone to have their back.

Persist is a New York City community health partnership of health educators, social workers, nurse practitioners, and human rights advocates, all of whom have either experience in the sex trade or are allies. We connect people in the sex trade to affirming and non-judgmental health care providers. We believe that taking control of our health through education is an act of empowerment and a tool for positive change.

Working as a peer counselor has also allowed me to see the public debates about sex work and sex trafficking in a different way. So much of what we see in the media portrays all sex work as violence against women, so it can be so hard to understand how trafficking – the use of force, fraud, or coercion for the purpose of exploitation – actually affects sex workers. For example, the media tell us that no people, or at least very few, choose to do sex work – that they only work in exploitive working conditions. I chose to do sex work, but that doesn’t mean I didn’t experience coercion. My work with Persist has shown me that the reality is more complex and that people’s lives have many layers of truths.

As I guide people toward health care – whatever that is, based on what they need or want for their lives – I realize how much all our lives are a mixture of choice, circumstance, and coercion. Health is so much more than just seeing a doctor. It’s how we treat each other and how we are able to move in the world. I have seen how health is adversely affected by shame and stigma, which can also lead to negative health outcomes for people of color, LGBT folks, and people with HIV. That’s why it’s so important to me to create a safe space for all sex work experiences – positive, negative, or somewhere in between – to be heard and validated. I am proud to work for an organization that focuses on the actual lives of those we serve and recognizes the diversity of experiences they can have when trading sexual services.
HIV-negative adults over 70. For HIV-positive people with multiple conditions like arthritis, high blood pressure, and diabetes, it can be difficult to handle taking the many medications required. Tips for dealing with this include having a “brown bag” session with their doctor to see if it’s okay to combine all their medications. This means putting all their prescription drugs, over-the-counter drugs, vitamins, and herbal supplements (which can react with HIV meds) into a brown bag and bringing it to their doctor.

While many challenges to the care of older adults with HIV remain, there has been much progress on the issue, including the creation of guidelines to address their medical needs (aahivm.org/hivandagingforum).

**Depression and Isolation**

Depression is a concern for people with HIV, especially among older adults. People are more at risk for depression as they get older, and it can be a barrier to care, since people with depression are less likely to take care of their own health. Almost half the people surveyed in ROAH reported being depressed at some point in the previous year. Untreated depression can have serious health consequences, since it is known to weaken the body’s defenses. It can also lead to not taking HIV meds as directed, which can cause drug resistance and lower CD4 counts. Health care providers need to develop better strategies to diagnose depression and to reduce the stigma of getting mental health care. Depression is treatable, and more programs for people with HIV should target and treat it.

Social support is critical in helping people cope with chronic illness, but it can be difficult for some older adults to obtain. As people age, they can experience losses of spouses, partners, and friends, as well as employment. In addition, chronic health problems can make it difficult for people to get out of the house or leave their neighborhood, limiting the activities they once enjoyed. Many older adults with HIV report receiving support but say they need more.

Studies have shown that older adults with HIV may not have the social supports that people without HIV have. Family is often a main source of caregiving, but some research has demonstrated that many older adults with HIV do not have family to rely on. Some LGBT adults are separated from their families because of their sexual orientation. But regardless of sexual orientation, HIV-positive older adults are much less likely to be partnered than the general population. They also are more likely to live alone – some research has shown as many as 75% of those with HIV over 50 are living by themselves. Not receiving emotional and functional support can result in loneliness, and people in ROAH reported significantly more loneliness than the general population.
Transgender individuals had the highest rates of loneliness, followed by men. More programs that support socialization could be a key factor in fighting these issues.

Stigma
HIV stigma is widespread, and it continues to be linked to “taboo” behavior. Older women and heterosexual men may face different stigma issues – many people are unaware that they are at risk for HIV, and this can increase stigma for those with HIV or for those trying to protect themselves. Stigma can increase the stress of disclosure, and people with HIV who do not disclose find it harder to obtain the services needed to manage their HIV and other conditions.

HIV-positive older adults are much less likely to be partnered than the general population. They also are more likely to live alone – some research has shown as many as 75% of those with HIV over 50 are living by themselves.

A study of older clients of GMHC in New York City asked about the barriers they encountered when trying to receive services. A quarter reported they were afraid they would not get treatment or that their HIV status would be disclosed without their permission. Over 40% felt that service providers “don’t like people like me”, and that number rose to 65% for the women in the study. Over half of the respondents did not know where to get services, were unable to get free services, had to wait too long for services, and did not think services were available locally. Finally, having to care for others and difficulties making appointments were reported by 25% of people in the study. Providers, including aging providers, need more cultural competency training to meet the needs of their HIV-positive and LGBT clients.

Retention in Care
Staying in care is critical, yet fewer than half of people with HIV are consistently in care. The Continuum Engagement Model, which was developed to rank retention in care for people with HIV, breaks down users of health care as regular, sporadic, and non-engagers. A regular user is defined as someone who makes an appointment every six months and doesn’t miss more than two appointments a year. A sporadic user is someone who completes only one appointment a year, misses at least two appointments a year, and uses an urgent care clinic once a year. Non-engagers are people who have an initial visit but do not return after that. A 2010 study found that among people with HIV, 25% were regular users, 32% sporadic users, and 43% non-engagers.

Providers should be aware of the factors that negatively affect people’s ability to stay in care:

- current or prior injection drug use
- low social support
- lack of engagement with the health care provider
- unemployment
- mental illness
- child care needs
- transportation needs
- hospitalization

The benefits of staying in care are well documented:

- increased access to HIV medications
- improved adherence
- suppression of viral load
- improved immune function
- less chance of drug resistance
- reduced health care costs
- less risky sexual behavior
- less risk of an AIDS diagnosis

There is some good news: Research finds that older adults are more adherent to HIV medications than younger people. And once connected to care, older adults are more likely to stay connected.

What can be done to assist people who are newly in care to help them become regular users of services? For one thing, health care providers need to increase their outreach efforts. This includes reminder calls, regularly updating patients’ contact information, maintaining emergency contact numbers, conferring with other providers, and phone counseling by peer educators. Also, providers should consider using health care navigators, who assist patients in negotiating the difficulties of the health care system – things like making appointments, lack of transportation, inconvenient appointment times, long waits for appointments, and conflicts with work or family responsibilities. The good news is that care coordination helps keep people in care and that support systems improve retention in care. Teams of doctors, nurses, social workers, aging service providers, and patients must work together for successful outcomes.

Conclusion
Too many barriers remain for HIV testing of the older adult population. These barriers can be reduced through prompting doctors to have conversations with their patients about sexual health. Doctors should also receive LGBT cultural competency trainings so that they avoid making assumptions about their clients. Lastly, the CDC should recommend HIV testing for all adults, not just those under the age of 65. For older adults living with HIV, more can be done to decrease obstacles to care. This can include more research on aging with HIV and programs that include socialization and support individuals as they face other illnesses. Health and social service providers need additional training in HIV to increase knowledge and decrease stigma towards those with HIV. Finally, teams of providers should work together to assist keeping HIV-positive individual in care and therefore better health.

Liz Seidel is a Research Scientist at ACRIA
by William McColl

A year and a half ago, on World AIDS Day 2011, President Obama committed the U.S. to getting “to zero” in the AIDS epidemic. This reflected earlier statements from Secretary of State Hilary Clinton, who called for the creation of an “AIDS free generation” and said, “this goal would have been unimaginable just a few years ago.” These statements also reflect the commitment of the U.S. to increase access to treatment and reduce new infection rates through the first National HIV/AIDS Strategy that had been adopted in 2010.

New evidence that using HIV drugs earlier can not only help people with HIV live longer and healthier lives but also help prevent new infections has influenced policymakers. These studies show that, in theory, the epidemic could be ended if enough people with HIV can be found, linked to treatment, and helped to lower their viral load.

On top of this commitment there has also been legislative action that could expand access to treatment and care for many people with HIV. Beginning in 2014, states will be allowed to expand Medicaid coverage to people earning below 138% of the federal poverty level (about $15,000 for a single person).

Interestingly, Medicaid expansion under the Affordable Care Act (ACA, also known as “Obamacare”) also accomplishes one of the earliest goals of HIV treatment advocates. Previously, Medicaid required that people have low incomes and a disability. This was a problem for people with HIV, since Medicaid required an AIDS diagnosis for access to the very drugs that can prevent AIDS. The health care reform law ends this foolish requirement.

Private Insurance

The law also requires changes to the private insurance market. It creates an insurance marketplace in each state that allows comparison shopping of insurance plans. It eliminates exclusions on pre-existing conditions like HIV, and prohibits yearly and lifetime caps on benefits. It requires people who are not eligible for Medicaid to purchase private insurance, but provides subsidies to help people who earn less than 400% of the federal poverty level do so.

In short, health care reform has the potential to allow tens of thousands of people with HIV to gain access to HIV treatment and care, particularly through Medicaid. It eliminates Medicaid’s main barrier to HIV treatment and creates much greater access to the private insurance market for people with HIV.

Prevention

These developments also come with strong incentives to find ways to prevent new infections. People with HIV are living longer and healthier lives, so their number has grown to more than 1.2 million in the U.S. As a result, the cost of their care has also grown. Dr. David Holtgrave, an expert in HIV funding and prevention from Johns Hopkins University, estimates that each case of HIV costs $355,000 just for treatment over a lifetime. As a result, the cost of the epidemic continues to expand. For Medicaid alone, funding has risen from just $10 million in spending in 1983 to over $6 billion in 2012.

The goal of ending the epidemic is an extremely strong position. The President verbally committed to ending the epidemic and created a plan with strong goals that move in that direction. The ACA creates real access to treatment and eliminates barriers to care. New science shows that we can begin to prevent new cases of HIV (and lower costs) by strengthening treatment capacity. What could possibly go wrong?

Unfortunately, there has not been a similar level of commitment in Congress. The political goals of conservatives clash with those of the President over the level of government involvement in public life and the amount of overall federal spending. As a result there has been direct opposition to implementation of the ACA by conservatives. The Republican-controlled House of Representatives has voted to repeal the ACA almost 40 times. Additionally, the Supreme Court ruling on the ACA made Medicaid expansion optional, and nearly 20 states will likely decide not to expand. Many people with HIV in those states will continue to rely on other programs for treatment, notably the Ryan White Program.

Sequestration

At the same time there has been a strong effort to cut all government spending. Though our ongoing budget crisis had resulted in cuts to other programs, HIV research, treatment, and prevention had generally been flat-funded. This is because HIV is a policy priority of the President and both parties.

But this year is different. Under the Budget Control Act of 2011, Congress and the President agreed to automatic spending cuts to reduce the federal deficit by $1.2 trillion over ten years. The cuts, known as “sequestration”, would be split equally between defense and non-defense spending. They were supposed to be so tough on both parties’ priorities that Congress and the administration would be forced to negotiate a better deal.

Unfortunately, that did not happen and $26 billion in non-defense cuts were implemented, including much HIV treatment, prevention, and research. This means about 5% cuts for all HIV funding. Secretary of Health and Human Services
Kathleen Sebelius has estimated that prevention cuts under sequestration would result in approximately 424,000 fewer HIV tests by health departments.

The Ryan White Program, the largest program for HIV care and treatment, is not immune from these cuts. In 2013 the program lost about $144 million out of a total of $2.4 billion. This is a real problem, since the program covers HIV care for at least half a million people every year who don’t have health insurance. It also covers support services such as transportation, nutrition, legal help, translation services, and case management. And it contains a billion dollar program called the AIDS Drug Assistance Program (ADAP) that funds drugs for people who don’t have insurance or Medicaid. Secretary Sebelius has estimated that cuts to ADAP would result in 7,400 fewer people having access to HIV drugs. Clearly this is a public health issue that the community must immediately address.

Preserving Ryan White

The Ryan White Program is the most prominent legislative accomplishment of the AIDS community. It is named as a living memorial to Ryan White, a teen who became a celebrity as he battled HIV stigma.

The community has argued that Ryan White must be stable while people make the transition to other coverage through the ACA. Unfortunately, it is currently up for its regular review by Congress in a process known as reauthorization. Given the Affordable Care Act, the role of Ryan White has come into question. Some Members of Congress have asked whether Ryan White funding, particularly drug funding, duplicates funding in the ACA.

It is true that both Ryan White and the ACA do cover medical services, drugs, and support services. But Ryan White picks up where the ACA leaves off. In short, it will help to address gaps in care, ensure that care remains affordable, and provide HIV services to people left out of health care reform. It already interacts with Medicaid and private insurance in that way. About 1975% of people who use Ryan White services have access to some type of health insurance.

Massachusetts, which expanded Medicaid and access to private insurance over the last ten years, is a good example. As reforms were implemented, some Ryan White resources were moved to cover premiums and co-pays and to cover other medical and support services not covered by Medicaid or private insurance. In fact, Massachusetts continues to use its entire share of Ryan White funding. According to the Treatment Access Expansion Project (TAEP), new HIV diagnoses fell by 46% in Massachusetts between 2006 and 2011. TAEP and others attribute this result at least in part to health care reforms’ expansion of coverage in Massachusetts.

Some legislators ask why HIV programs should be singled out to have extra coverage for insurance premiums, deductibles, and co-pays when other diseases do not. The community’s primary answer is that HIV is an infectious disease with deadly consequences. Ensuring that people with HIV have access to treatment is a way to prevent its spread. The U.S. must remove as many barriers to HIV prevention and treatment services as possible.

The President verbally committed to ending the epidemic and created a plan with strong goals that move in that direction.

Reauthorization

The reauthorization of the Ryan White program has been seen as a sign of the HIV community’s ability to exert leadership and for Congress to convey its support. Many people with HIV and others who work in the HIV community were concerned when the administration said that the next reauthorization would be delayed past September 30 (the date that the current authorization runs out) and even to the end of the year. Fortunately, the program will continue to exist without a reauthorization and will continue to be funded. And there continues to be relatively strong support from both Republicans and Democrats.

The current political climate is one of the reasons for the delay. It’s difficult even for the most determined Congresspeople to move legislation through this highly divided Congress.

The most recent Congressional session passed fewer bills than any Congress since the 1940s, and the current Congress may pass even fewer.

Advocates are also concerned about the turnover in Congress since the last reauthorization. In fact, 165 new members of the House of Representatives (38%) and 25 new Senators (25%) have been elected since the last reauthorization in 2009. Many of these new members do not see HIV as one of their top issues, and the community must make the case that Ryan White must be kept intact as the ACA is implemented.

Conclusion

The community is working hard to create a future vision of Ryan White as a public health measure that should be integrated into the ACA. Members of Congress must understand that merely being able to gain access to treatment does not mean we will be able to find more people with HIV and help them obtain treatment. Providing support and enabling people to make educated decisions about HIV will be more important than ever.

However unlikely Congress is to adopt it, the President’s budget would be a good blueprint. It states, “...as the number of insured RW clients increase, RW grantees will more easily be able to use a greater percentage of their grants to support services not covered by public or private insurance but which are essential to getting people living with HIV into care and on medications that suppress the virus and help prevent the spread of the epidemic.”

The vision of reaching the goals outlined by the President – of getting “to zero” and to “an AIDS-free generation” – is the best opportunity to move forward. Ryan White continues to have strong support from both parties. It will be needed both in states that expand Medicaid and in those that don’t. The community must remain focused on maintaining and expanding HIV prevention, treatment, and research; ensuring Medicaid and private insurance expansion; maintaining Ryan White while the ACA is implemented; providing an imaginative vision of the future of Ryan White; and working to commit Congress to ending of the epidemic.

William McColl is Director of Political Affairs at AIDS United.
In the first workshop, Dr. Brennan-Ing was joined by Britta Larson of the Center on Halsted and Nadia Underhill from the Heartland Alliance, a Chicago-based anti-poverty organization. Ms. Larson described SAGE-Works, an employment program created to meet the needs of older LGBT adults. SAGE-Works provides skills assessments, technology training, seminars, career counseling, and employer outreach to help older LGBT adults find employment. Ms. Underhill reported on a joint project of the Center on Halsted and the Heartland Alliance to provide LGBT-friendly senior housing in the Chicago area. The units were designed with input from the community, and the project was funded by the City of Chicago.

In the second workshop, Dr. Brennan-Ing reported on a Chicago study on sexual activity and risk among LGBT adults 50 and older. Most (88%) remained sexually active, with similar rates of sexual activity among women and men. This differs from other studies of heterosexual older adults, which find men much more likely to be sexually active than women. In the Chicago study, about two-thirds reported sexual activity two or three times per month. Less than 10% reported vaginal intercourse, but over a third had had oral sex in the past year. Anal intercourse was less common, with only 20% of men reporting this activity. More than half of the men and women reported one or more sexual problems in the previous year. While 55% of men said they would be likely to discuss their sexual health with a doctor, only 25% of women stated they would do so.

In conclusion, Dr. Brennan-Ing noted that older LGBT adults remain sexually active in later life, and will require support from health care providers to maintain healthy sexuality. Rates of unprotected sex in this group are high and need to be addressed through targeted prevention programs. And older lesbian and bisexual women appear to be reluctant to engage providers on sexual issues requiring outreach and education to this community and a better understanding of barriers to care.
Fighting for Ryan White

In the last issue of Achieve, we warned about across-the-board automatic cuts to the federal budget known as “sequestration”. These cuts, which went into effect on March 1, total $85 billion in the current federal fiscal year that ends September 30 and affect virtually every federal program. Cuts to HIV programs include $17 million from HOPWA, $62 million from the CDC, and $144 million from Ryan White, even as the need for these programs continues to increase.

And this is just the beginning. Unless Congress and the President agree on a better budget with a more balanced approach that includes tax increases, sequester cuts could total $1 trillion over the next ten years. In this context, it’s critical that we focus on preserving one of the most important federal programs for people with HIV in the U.S.: The Ryan White CARE Act.

Ryan White’s current Congressional authorization expires on September 30, 2013. But since it doesn’t have a “sunset clause”, the program will remain in its current form as long as Congress funds it. Many federal programs, including HOPWA and the Older Americans Act, also operate without the need for reauthorization – they operate even if the programs have not been updated during a reauthorization process. The Obama administration and many HIV advocacy organizations are in favor of allowing Ryan White to continue without reauthorization at this time.

We think that’s the right approach for several reasons.

First, it’s unlikely that this divided and dysfunctional Congress could pass any major piece of legislation, including a sensible update to and reauthorization of Ryan White. This lifesaving program has typically been passed by fairly wide, bipartisan majorities in Congress. But many new House and Senate members know little or nothing about HIV and the vital programs on which so many people rely. And many of these same members were elected on platforms devoted almost entirely to cutting the federal budget. With bipartisan cooperation at an all-time low, particularly when it comes to spending for domestic programs, we have little reason to believe that the current Republican majority in the House will work with Democrats in the Senate and with the White House to ensure the long-term future of Ryan White. So pushing for reauthorization in this Congress risks igniting a firestorm of cuts and bad law fueled by ignorance or hostility.

Second, we are at a critical point in the roll-out of the Affordable Care Act (ACA). Medicaid expansion is starting in the states that have chosen to participate and new health insurance marketplaces are launching across the country later this year. Advocates, our supporters in Congress, and the Obama administration want to see how Ryan White will intersect with the ACA. California has provided an early example of how a state can make use of Ryan White funds under Medicaid expansion. Fortunately, the Secretary of Health and Human Services was able to grant California much leeway in how to spend its Ryan White funds. This flexibility must be maintained and even expanded when reauthorization does occur.

Third, we must make clear for Congress that the ACA alone will not meet the needs of people with HIV, particularly in states that don’t expand Medicaid. As of this writing, 27 states have not yet decided to take the Medicaid expansion offered by the ACA. While Ryan White is a vital lifeline for all people with HIV, it will be especially important in those states, and Congress needs to hear that – in personal and powerful stories from the front.

We need to understand better how the ACA will affect Ryan White clients living in states that are moving to expand Medicaid under the ACA and those that aren’t. How can Ryan White’s “wrap-around” services, like transportation and nutritional support, supplement those that clients get with better access to ACA-defined health insurance? How will Ryan White clients make the transition to expanded Medicaid or the new insurance marketplaces without jeopardizing or interrupting care from their current providers? What kind of collaborations among providers will need to happen to ensure continuity of services? We must explore these unknowns before we move to reframe Ryan White so as to ensure that people with HIV continue to thrive. And we must decide what changes are needed in Ryan White and create a strategy to get them.

The annual federal budget battle is happening now and Ryan White faces significant threats. Some in Congress may cite the ACA as justification for additional cuts to Ryan White, falsely claiming that Ryan White duplicates services. Our present challenge is simply to keep the existing Ryan White program as “fully” funded as possible for the federal fiscal year that begins October 1. The Obama administration requested $2.4 billion. That’s $164 million more than the current year’s budget, but less than the $2.67 billion advocates believe is necessary. Just before we went to press, a Senate subcommittee proposed $2.37 billion, which is $51 million more than the current year.

We strongly urge all people who care about HIV services and the Ryan White program to make themselves heard during this all-important budget process. Call, write, or email your Senators and Representatives. Take action with others to send a clear message to Congress. They need to hear from you loudly and strongly! Early in the epidemic, people with HIV and their advocates demanded the Ryan White CARE Act be passed. Their voices were heard, and now the torch has passed to us. Together we can ensure the future of Ryan White and the lifesaving services it provides to people with HIV. ■
A new LGBT Smokefree Initiative launches in New York City

Lesbian, Gay, Bisexual and Transgender (LGBT) adults smoke cigarettes at rates nearly 70% higher than the general population.

The tobacco industry has a long history of targeting the LGBT community by capitalizing on mental health vulnerabilities and the bar culture to promote smoking.

People with HIV who smoke are now losing more years of life to diseases caused by smoking than the virus.

In NYC, LGBT and HIV service providers, and health organizations have come together to form a new LGBT Smokefree Initiative (NYCSmokeFree.org/LGBT).

Quitting smoking is the single most important thing you can do for your health. Remember, it is never too late to stop smoking. There are health and financial benefits to quitting, no matter your age or health condition.

Help is one call away at 1-800-QUIT-NOW (1-800-784-8669).