



Necessity of Care

Barriers to Care

Tenants of Cultural Competency

Gearing up for the Future

DELIVERING CULTURALLY COMPETENT CARE TO THE YOUNG ADULT PATIENT

Jeff, a 21-year-old Latino man living in southern Florida, seems like anyone else his age. He enjoys spending time with friends, watching movies, playing videos games, and making plans for the future. But unlike many other young adults, Jeff has HIV. Born with the virus, his life revolves around the nausea and dizziness caused by the highly active antiretroviral therapy (HAART) pills he takes every day. He recently dropped from 115 to 84 pounds in a matter of weeks. "I'm so weak these days. I can't just get up and go anywhere," he says. "When I leave the apartment, I like to plan things days in advance and know exactly what I'm going to be doing."

During a recent conversation, Jeff's voice sounded quiet and thin. He says he'd like to change drugs, but has to wait until new medications come on the market. He explains, "I found out I had HIV when I was 11; but never took the pills. Back then, I didn't understand why it was so important."

Around that time, Jeff's life began to spiral out of control, making treatment adherence seem almost impossible, and developing resistance to most first-line drugs.

I lost both my parents to AIDS so I left home at a young age. I had my own place in high school; but often had trouble paying the rent. I had school problems. I spent days without food in the house. With that much going on, treatment didn't seem that important—especially when you don't feel sick or feel like you don't need it. Like me and some kids I knew, you might wait until it is almost too late.

Getting ill, Jeff says, "was a wake-up call" to get into care and take his treatment seriously. A friend, concerned by the dramatic downturn in his health, took Jeff in, and members of an HIV support group he used to attend visit him often. But the greatest motivator to stay in care, Jeff says, is Ana Garcia, assistant professor of clinical pediatrics and Ryan White Part D pediatric coordinator at the University of Miami, Miller School of Medicine.

DID YOU KNOW?

- ▶ Nearly 40 percent of all new HIV cases occur among youth and young adults age 13 to 29.¹
- ▶ Youth, whether infected behaviorally or perinatally, often experience similar barriers to care
- ▶ Walk-in appointments and extended clinic hours make it easier for young adults to stay engaged in care.



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For many young people, navigating everyday life is further complicated by dealing with their HIV disease. Taking pills at certain times and getting to appointments can feel impossible. Many face stigma, abuse, and homophobia, sometimes from those closest to them. We are concerned with helping these young people enter and stay engaged in care.

Today, nearly 40 percent of all new HIV cases every year occur among youth and young adults. A majority of these newly-infected young people are from African-American and Latino communities, which have been disproportionately impacted by the AIDS epidemic since it began.

Perhaps most alarming is that many young adults living with HIV never knew they were at risk for infection, let alone that they were infected. People living with undiagnosed HIV are more likely progress to AIDS, transmit the virus to others, and undermine their overall health outcomes. Reaching this population, therefore, demands that providers become culturally competent in addressing the unique needs of this group. It also means understanding that one's identity, and the way one accesses health care, is not static, but constantly changing over time. That is why we're devoting this issue of *HRSa CARE Action* to examining the special needs of, and the cultural competence needed to treat, young adults.

Deborah Parham Hopson
HRSa Associate Administrator for HIV/AIDS

HRSa CARE Action

Publisher

U.S. Department of Health and Human Services
Health Resources and Services Administration, HIV/AIDS Bureau
5600 Fishers Lane, Room 7-05
Rockville, MD 20857
Telephone: 301.443.1993

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Garcia, who says she "has to get on" young people like Jeff to stay in treatment, has worked with children, youth, and young adults living HIV/AIDS since the 1980s. Jeff says,

Ana always calls to check up on me; she's very helpful in keeping you going. She reminds you of appointments the day before, asks if you need a ride, if you're going to make it. She is never in a rush and isn't focused only on just your treatment and medications. In the past, my doctors and nurses didn't ask me about what's going on in my life—nothing. Ana isn't like that. She cares about what's going on with you and shows it by sitting there, getting to know you better, showing you the love and support you need.

In Washington, DC, Justin Goforth, director of the Medical Adherence Unit in the Gay Men's Health and Wellness Clinic at Whitman-Walker Health, demonstrates the same dedication to clients. A veteran nurse and program director in AIDS treatment for nearly 20 years and also HIV positive, Goforth has an innate understanding of the challenges faced by youth and young adults accessing care. One case in particular stands out for him:

I remember telling an inner-city African-American teenager named Richard² that he had HIV and syphilis. He needed penicillin treatments for the syphilis, but he didn't come in for them. I tracked him down through a local youth center and found out that his mother had died a month after he learned his status. His grandparents then kicked him out of the house for being 'gay with AIDS.'

Goforth stayed in touch with Richard, encouraging him to get in care, as well as helping him schedule his first appointments and fill his initial prescriptions. He also connected him to services that would keep him off the streets.

THE NECESSITY OF CARE

Culturally competent Ryan White providers like Garcia and Goforth are essential in delivering services to people living with HIV/AIDS (PLWHA) ages 18 to 24. Most of these young people are from African-American/Black and Latino communities, which have been disproportionately impacted by HIV/AIDS since the epidemic began, and continue to bear the burden of HIV incidence in the U.S. today. According to the U.S. Centers for Disease Control and Prevention (CDC), approximately 50,000 new HIV cases occur nationwide every year:

- Nearly 40 percent of these infections occur among youth under the age of 30.^{3,4}
- Sixty percent of HIV-positive youth are African-American/Black, and 20 percent are Latino.^{5,6}

- Youth represent the only age group still experiencing increases in HIV cases. In fact, new HIV cases rose 21 percent among youth, driven by a 34 percent increase among young men who have sex with men (YMSM).^{7,8}

Perhaps most alarming: the number of HIV-positive youth enrolled in care is far less—by as much as 60 percent—than the number of young people estimated to be HIV-positive.⁹ HIV incidence and prevalence among this population are fueled by socioeconomic and cultural determinants which have created powerful barriers to care.

BARRIERS TO CARE

Perinatally-Infected Young Adults

AZT (zidovudine) and HAART therapies have helped thousands of young PLWHA infected through perinatal transmission survive into adulthood. After nearly two decades of care, however, many of these patients are physically and emotionally exhausted from the rigors of daily HIV treatment. Jeff explains,

My doctors are always saying, ‘take your medication, take your medication, take your medication.’ They seem to think it’s easy to take fat humongous pills twice-a-day. They have no idea how *not* easy it is. They don’t get the side effects, the nightmares. They should have to take it sometime and experience it. They would understand that it’s not just medication ... we have to do this routine forever. We don’t feel normal; we feel different.

Many rebel against “feeling different” by stopping care. As Goforth says, “These teens and young adults are resentful about being HIV positive, particularly when they enter their sexually active years and have to deal with telling others about their status and possibly being rejected. They’re like ‘Why do we have to deal with this?’”

This frustration is often fueled by grief: like Jeff and Richard, many have lost close family members, mostly to AIDS, including one or both parents.¹⁰ They often served as caretakers for sick family members, looking after younger siblings; managing the household; and taking their medications without assistance at a young age.¹¹ Many experienced frequent hospitalizations and school absences growing up, as well as physical and developmental delays related to HIV drug therapy during infancy and early childhood, which only increased their sense of isolation. When they did go to school, many acted out of frustration due to the difficulties they experienced with the schoolwork and social situations they encountered.¹²

A large number of perinatally-infected PLWHA do not learn they are HIV-positive until they are teenagers. As in Jeff’s case, parents may not tell children about their infection because of fears that they may disclose their status—and that of family members—to others. Some fear dealing with children’s questions—and anger. In many instances, grandparents and guardians of young PLWHA understand the disease very little themselves, and are simply overwhelmed with

the responsibilities that come with caring for a chronically ill child.¹³

As a result, these young people often comprehend little about HIV and how to take care of themselves.^{14,15} What they do know, however, is that “growing up they had something so bad, ‘we can’t talk about it, even as a family,’” explains Goforth. “The message of shame is so unbelievably intense for these kids.”

This sense of shame and ignorance about their condition can undermine their transition into adult HIV care from Ryan White-funded adolescent HIV units and facilities. They tend to build strong relationships with their adolescent care providers, whose small caseloads often allow them to provide hands on guidance and personal support. Young patients and their families also receive wraparound services, and may have access to recreation rooms where they can take their medication and relax in a safe space, as well as make friends with other adolescents living with HIV. Though these facilities take great pains to prepare their patients for transition into adult care, these young adults frequently encounter case managers and doctors with much heavier case loads who are unable to provide the level of assistance they had become accustomed to as an adolescent.^{16,17,18,19}

As Lawrence Friedman, director of the Division of Adolescent Medicine in the Department of Pediatrics at the University of Miami, Miller School of Medicine, explains, “The transition to adult care is sometimes easier for the patients than it is for the adult care providers, who often are frustrated by what they perceive as a cavalier attitude toward appointments and medications.” To address this perception Friedman explains, “We have to explain to case managers that [young adult PLWHA] are not being disrespectful; that developmental and psychological issues are often to blame. They are technically adults, but not necessarily ‘adult’ in the sense that they are accustomed.”

Behaviorally-Infected Young Adults

Perinatal transmissions have decreased dramatically since the 1990s. The majority of young adult PLWHA today contract HIV through sexual contact during adolescence—a time when most people are learning their sexual identities and taking risks.^{20,21} Many never realized they were vulnerable to HIV or knew that they were infected, even though HIV is the tenth leading cause of death for youth and young adults today.^{22,23}

Part of this ignorance reflects the little coverage HIV has received in the media in recent years. Behaviorally-infected youth have not “grown up” with the disease, and have no memory of the first wave of AIDS deaths during the 1980s.^{24,25} Many believe AIDS can be cured by a pill, and the demands of HAART are foreign to them.^{26,27} HIV prevention can also be difficult with this group, since many youth, particularly in underserved communities report high risk behaviors and experiences, such as: having sex before age 13, more than four sexual partners by age 18, and forced or unwanted sexual

experiences.^{28,29} Girls and YMSM of color, who live in communities with high rates of seropositivity, are particularly at risk for infection with HIV and sexually-transmitted diseases (STDs).^{30,31,32} Those already infected are at risk for reinfection with another strain of HIV, known as superinfection, which can complicate treatment and care regimens.³³ Goforth describes the situation as a vicious cycle:

From my experience, Black YMSM often get involved with older Black gay men ... who take care of them, pay their bills. There is a power dynamic there that does not allow younger guys to say, 'Let's use a condom,' and they end up infected. The same thing most likely happened to the older guy in the relationship when he was a teenager, and, if it isn't stopped, probably will take place again when the teen gets older. What kind of prevention messages do you send out in situations like this? What do you say to people like my son who was infected with HIV at age 14 or 15 by a 30-something year old man?

Young adult PLWHA often are asymptomatic and unconnected to care until they begin to feel HIV-related symptoms or happen to enter an acute care facility or hospital emergency room for a different reason. Their initial encounter is often with overworked clinicians unprepared to meet the unique needs of young people infected with HIV or to communicate risk-reduction messages. And even one such encounter with an ill prepared clinician can ultimately undermine the young person's overall health outcomes, accelerate their progression to AIDS, and make them more likely to transmit the virus to others.^{34,35,36}

For many of these young people, entering HIV/AIDS care marks the first time they have had a primary care physician and routinized health care. Going to the doctor is a skill, explains Garcia, "We have to teach our young people how to track their health, and take notes and ask the doctor questions." Garcia and Friedman both say this group finds managing their appointments and taking medications on time difficult. They have erratic lives and uneven work schedules, and routinely miss meetings with their primary care providers and specialists resulting in long periods between visits and running out of medications.^{37,38,39} Another factor that makes a challenging situation even worse is that some young people have been taught to fear medical providers by their families and communities, and many believe that their doctor will violate their privacy and disclose their status.^{40,41} It is not surprising that many behaviorally-infected young adults experience treatment burnout early.^{42,43}

Common Barriers to Care for All Youth

Regardless of how they were infected, young adult PLWHA face many of the same barriers to care, including poverty, under- and unemployment, unstable housing, and limited educational attainment.⁴⁴ Substance use is often an issue, particularly among HIV-positive young men, who turn to marijuana and methamphetamine to increase their appetite and

ease their fatigue, respectively.⁴⁵ These drugs, however, are addictive and lower users' inhibitions, increasing their likelihood of engaging in unprotected sex.^{46,47}

Young adults often fall out of care, because, as Jeff says, they want to be normal and not medicated all the time. They also avoid telling others about their status because of their very real concerns of rejection, abuse, and abandonment.⁴⁸ Many youth, like Richard, face being kicked out of their homes. Goforth also recalls a young transwoman living with HIV whose mother only allows her to use disposable plates and silverware when she visits. He says,

Young adults living with HIV have internalized a lot of the stigma around HIV. LGBT [lesbian, gay, bisexual, and transgender] kids are told that homosexuality is a sin. Our straight kids with HIV are told that promiscuity is a sin. These young people need real support and information about safer sex, relationship negotiating skills, disclosure skills, finding some peace with their own HIV status.

Those in relationships are reluctant to tell partners, particularly if they want to have children of their own one day. To keep their HIV a secret, they often skip appointments and doses of medication, even though treatment adherence can greatly reduce the likelihood of transmitting the virus to their partners and from progressing to AIDS themselves.^{49,50,51} Goforth says some of his patients even hide their medications in vitamin bottles—a practice that could result in inadvertent misuse by the patient or accidental ingestion by others. Their fear of "being found out" continues even while at the clinic. They try to be inconspicuous in the waiting room and when using the pharmacy, and have complained about recent renovations that have made this space more open. He says, "Even though I obviously know my son's status, and so do his friends, he has never taken his meds in front of me."

TENANTS OF CULTURALLY COMPETENCY

Ryan White HIV/AIDS Program grantees and providers deliver culturally competent care to young adult patients in a variety of ways, depending in part upon the epidemiology of their local epidemic and their organizational structure. Each clinical program incorporates three important components: *understanding*, *flexibility*, and *partnership*.

Understanding. Successful treatment provision begins with an understanding of the individual lives of young adult PLWHA—that their age, treatment experience, community-background, and personal experiences all play a role in their accessing and staying in care.⁵² Creating this bias free environment often requires that provider staff mirror, or at least possess a strong understanding of, the cultural and linguistic backgrounds of their patients. Staff and volunteers who culturally reflect the community of patients they serve helps to establish a welcoming clinical environment that encourages young adult PLWHA to prioritize their care and treatment.⁵³ As Friedman explains, "As providers, we must be accepting of different races, ethnicities, and sexual minorities [and] recognize

how ... high-risk sexual behaviors may contribute to health issues.”

Providers also must be prepared to work with patients with different cultural norms around the nature of disease and treatment. Delivering services to young adult PLWHA from diverse communities may mean letting go of Western notions of medical practice, such as keeping strict appointment schedules and maintaining professional detachment from patients. Reaching young adult PLWHA requires providers to find ways to create a personal connection with their patients that will help them bridge the differences between their respective worldviews, and encourage the patient to be treatment compliant.⁵⁴

Many providers leverage assessment tools sensitive to cultural norms of racial, ethnic, and sexual minorities to learn more about the needs of their patients, and identify co-morbid conditions. These tools are not simply handed to patients to fill out, which can come across as cold and clinical, but completed together through a conversation between clinician and patient. The clinician working with the patient to complete forms is particularly important if the patient has a difficult time with English, or has general reading comprehension issues. In this manner, patients and providers can solidify their relationship, while the provider gains insight into the patient’s needs and challenges. Patients, in turn, feel like full partners in their treatment, rather than objects of a provider’s demands and directives.^{55,56}

Flexibility. As Garcia explains, flexibility within the context of culturally competent care can be described almost as exemplary customer service. “Young adult patients often are still a little unsophisticated about managing their care. They can be intimidated by older adults and don’t understand that everyone isn’t going to bend over backward for them.” Garcia adds, “They may not understand what it means to keep track of appointment times or that they need to share changes in their health with medical providers.”

The often chaotic lives of young adult PLWHA may make it difficult for them to get to clinics on time. Patients who regularly attend medical appointments may often feel that the doctor is in a rush to get somewhere else. Providers working with young patients are encouraged to offer extended hours of operation, as well as to accept walk-in appointments, efforts that increase the odds of patients meeting with their providers and achieving optimal health outcomes.

In addition to longer hours, culturally competent providers often hold extended one-on-one appointments with their patients, allowing them to discuss their concerns without feeling hurried and unheard.^{57,58} During this time, patients can talk about challenges they are having in their lives, such as work and relationship issues, that may make treatment adherence difficult. Side-effects from medications may be discussed as well, and adjustments made. Perhaps most importantly, clinics often will keep young adult patients’ medications on-site, offering them a private space in which to take them. This

service, in turn, allows clinicians to track the treatment adherence of their patients, alerting them to possible complications if they do not return as scheduled, and provides them a safe place to take their medication without judgment.

Flexibility also means ensuring that patients’ partners are included in appointments and decision-making if requested by the young adult PLWHA. Including partners also offers the provider greater insight into patients’ lives, and ensures that an additional person in the patients’ support network has been informed about the treatment regimen.

Culturally competent care also involves recognizing when young adults are not thriving in adult care. In these situations, the patients are often referred or returned to the more hands-on environment of adolescent care, which allows patients to stay until they are 25 years old.^{59,60} Most are behaviorally infected young adult PLWHA with mental health and substance use issues, while others are perinatally-infected young adults who did not adjust to adult care after their transition.^{61,62} This move often gives these patients additional time to learn how to navigate primary care without undermining their health outcomes overall.

Partnership. Providers delivering culturally competent care to young adult PLWHA understand the importance of partnerships. Internally, all staff members—including administrative personnel, doctors, specialists, nurses and counselors—are part of a team that serves as the “face” of the agency. They work collectively to provide care that is sensitive to the unique ethnic, social, and linguistic backgrounds of their patients. The care team includes everyone who interacts with the patients from the front desk staff member who can converse in Spanish when assisting Latino young adult PLWHA, to the physicians who take the time to ask patients about their current housing situation, as well as their medication adherence.⁶³

Many providers also build informal and formal relationships with other Ryan White HIV/AIDS Program participants and community-based HIV/AIDS service entities to help identify young adult PLWHA entering the continuum of care through other points-of-entry. This interconnected referral network often includes:

- HIV counseling, testing, and referral (CTR) sites
- Emergency rooms and urgent care centers
- Substance abuse treatment programs
- Detoxification programs
- Adult and juvenile detention facilities
- Sexually transmitted infection (STI) clinics
- Federally-qualified health centers
- HIV disease counseling and testing sites
- Mental health programs
- Homeless shelters
- Public health departments

- Hemophilia diagnostic and treatment centers
- Migrant health centers
- Community health and family planning centers
- Nonprofit private agencies providing comprehensive primary care to young adults at risk of HIV.

This multifaceted gateway helps engage patients with culturally competent providers who have made a concerted effort to provide most, if not all, of the care services they might need. This integrated system of care or “medical home” is often a one-stop-shop, where patients can access their pharmacy and counselor under the same roof as their primary care doctor. Services not offered onsite are made available by referral, preferably through a nearby provider; it may also be important when referring out young adult patients to give them a point of contact by name to ask for at the new facility.⁶⁴

GEARING UP FOR THE FUTURE

Ryan White HIV/AIDS Program providers and grantees will continue to create, advance, and further hone culturally competent care that engages young adult PLWHA through *understanding, flexibility, and partnership*. In the near future, cultural competence will require proficiency in the ever-expanding realm of technical communication. As discussed in the June 2011 edition of the HRSA CAREAction newsletter, “Social Media and HIV”⁶⁵ providers are leveraging the power of online social networks and mobile-based communications to interface with patients, particularly those under age 25 in communities of color.⁶⁶ Many of these patients do not own computers, but access the Internet through Smartphones.

Text messages, tweets, Facebook profiles, YouTube videos, and other electronic mediums of communication can enable an agency and its personnel to develop a more immediate relationship with their patients. As Goforth explains, you have to do more “these days than go to bars and offer testing and counseling. HIV prevention, testing and recruitment into care extend beyond posters in the bathroom.” He continues, “We have to find systematic ways to use this technology to maintain contact with young people in care. Most likely, their first sexual encounter will be arranged through the Internet. Also, I know that people my son’s age will not answer a telephone call, but they’ll reply to a tweet or a text.”

And for care, social networking empowers agencies to send regular appointment and medication reminders, while patients can keep in contact with their doctor on issues such as side-effects. Patients become full-fledged partners in their care, not simply “retained” and passive recipients. Having a treatment team in place will improve health outcomes for young adult PLWHA as they grow older, and is imperative for youth who transition from adolescent to adult care at a later age.

In the future, Ryan White HIV/AIDS Program providers and grantees will continue delivering innovative methods of culturally competent service delivery targeting young adult

ONLINE RESOURCES

AIDS Education Training Center (AETC) National Resource Center: www.aids-ed.org

HRSA, HAB Website: www.hrsa.gov/culturalcompetence/index.html

Technical Assistance for the Ryan White Community TARGET Center: www.caretarget.org

Transitioning from Adolescent to Adult Care HRSA CAREAction newsletter: www.hab.hrsa.gov/newspublications/careactionnewsletter/june2007.pdf.pdf

Transitioning HIV+ Youth From Adolescent to Adult Care: Adolescent Provider Toolkit: www.careacttarget.org/library/TransitioningYouth_AdolescentProviderToolkit.pdf

U.S. Centers for Disease Control and Prevention’s National Information Prevention Network: www.cdcnpin.org/scripts/population/culture.asp

PLWHA and other hard-to-reach populations. This expertise has helped mitigate the impact of HIV domestically, and is informing the work furthering the goals of the National HIV/AIDS Strategy, particularly around increasing access to care and improving health outcomes for PLWHA and reducing HIV-related health disparities. Ultimately, delivering culturally competent care to young adult PLWHA extends beyond organization programs and procedures.

It is, as Garcia explains, about one’s “passion for working with young people. You have to have patience. Young people can make you lose your mind and you’re not always going to be successful, but you’re there because you have love for them and want to help.” And it’s this help that keeps patients like Jeff engaged in care, adherent to treatment, and, despite all the challenges, optimistic about the future.

- ¹Prejean J, Song R, Hernandez A, et al. 2011. Estimated HIV incidence in the United States, 2006–2009. *PLoS ONE*. 6(8):e17502. Available at www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502. Accessed August 4, 2011.
- ²Name has been changed for confidentiality reasons.
- ³U.S. Centers for Disease Control and Prevention (CDC). Youth risk behavior surveillance—United States, 2009. *MMWR*. 2010;59(SS-5). Available at www.cdc.gov/mmwr/pdf/ss/ss5905.pdf. Accessed May 30, 2011.
- ⁴CDC. HIV surveillance in adolescents and young adults 2006–2009. August 2011. Available at <http://www.cdc.gov/hiv/topics/surveillance/resources/slides/adolescents/slides/Adolescents.pdf>. Accessed August 2011.
- ⁵Slide set: HIV/AIDS surveillance in adolescents and young adults (through 2006). 2006. Available at www.cdc.gov/hiv/topics/surveillance/resources/slides/adolescents/slides/Adolescents.pdf. Accessed July 15, 2011.
- ⁶Ibid. Tables 1–3.
- ⁷CDC. *Fact sheet: estimates of new HIV infections in the United States, 2006–2009*. July 2011. www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf. Accessed August 21, 2011.
- ⁸Prejean J, Song R, Hernandez A, et al. 2011. Estimated HIV incidence in the United States, 2006–2009. *PLoS ONE*. 6(8):e17502. Available at www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502. Accessed August 4, 2011.
- ⁹AIDS Alliance for Children, Youth and Families. *Finding HIV-positive youth and bringing them into care*. 2005. Available at [www.nastad.org/Docs/Public/Resource/2006327_Finding%20HIV-Positive%20Youth%20\(AIDS%20Alliance\).pdf](http://www.nastad.org/Docs/Public/Resource/2006327_Finding%20HIV-Positive%20Youth%20(AIDS%20Alliance).pdf). Accessed August 5, 2011.
- ¹⁰Chabon B, Futterman D, and Hoffman ND. HIV infection in parents of youths with behaviorally acquired HIV. *Am J Public Health*. 2001 Apr;91(4):649–50.
- ¹¹Smith R, et al. Effects of perinatal HIV infection and associated risk factors on cognitive development among young children. *Pediatrics*. March 2006;117(3):851–62.
- ¹²Foster C and Fidler S. Antiretrovirals in adolescents with perinatal HIV-1: long-term complications of HIV and antiretroviral therapy. *Expert Rev Anti Infect Ther*. 2010;8(12):1403–1416.
- ¹³Seery P, et al. Adolescents with HIV: issues for practice. *Pediatric nursing*. July 2001;13(6): 13–14. Available at www.healthinfo4u.org/rcn_pdf/PAeNs/paed%20july%20p13-14.pdf?issn=1365-2524&vol=9&page=228. Accessed May 20, 2011.
- ¹⁴Veinot T, et al. “Supposed to make you better but it doesn’t really”: HIV-positive youths’ perceptions of HIV treatment. *Journal of Adolescent Health*. March 2006; 38 (3): 261–267.
- ¹⁵Seery P, et al. Adolescents with HIV: issues for practice. *Pediatric nursing*. July 2001;13(6): 13–14. Available at www.healthinfo4u.org/rcn_pdf/PAeNs/paed%20july%20p13-14.pdf?issn=1365-2524&vol=9&page=228. Accessed May 20, 2011.
- ¹⁶AETC National Resource Center; New York, New Jersey AETC; Texas/Oklahoma AETC; and Florida/Caribbean AETC. *HIV perinatally-infected adolescents: a developmental approach*. 2003. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272. Accessed August 2011.
- ¹⁷Okumura M, et al. Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*. April 2010;125(4): e748–e754.
- ¹⁸François-Xavier Bagnoud Center, UMDNJ, HRSA and National Institutes of Health. *Guidelines for the use of antiretroviral agents in pediatric HIV infection*. August 11, 2011. Available at aidsinfo.nih.gov/contentfiles/PediatricGuidelines.pdf. Accessed August 20, 2011.
- ¹⁹Miles K, Edwards S and Clapson M. Transition from pediatric to adult care services: experiences of HIV-positive adolescents. *AIDS care*. April 2004;16(2): 305–314.
- ²⁰Hazra R, Siberry G, and Mofenson L. Growing up with HIV: children, adolescents, and young adults with perinatally acquired HIV infection. *Annual review of medicine*. February 2010;Vol. 61: 169–185.
- ²¹AETC NRC; New York, New Jersey AETC; Texas/Oklahoma AETC; and Florida/Caribbean AETC. *HIV perinatally-infected adolescents: a developmental approach*. 2003. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272. Accessed August 2011.
- ²²CDC. Youth risk behavior surveillance—United States, 2009. *MMWR*. 2010;59(SS-5). Available at www.cdc.gov/mmwr/pdf/ss/ss5905.pdf. Accessed May 30, 2011.
- ²³Magnus M, Jones K, Phillips G 2nd, et al. YMSM of color Special Projects of National Significance Initiative Study Group. Characteristics associated with retention among African-American and Latino adolescent HIV-positive men: results from the outreach, care, and prevention to engage HIV-seropositive young MSM of color special project of national significance initiative. *J Acquir Immune Defic Syndr*. 2009;53:529–536.
- ²⁴CDC. *Web-based injury statistics query and reporting system*. 2007. Available at webappa.cdc.gov/sasweb/ncipc/leadcaus10.html. Accessed August 1, 2011.
- ²⁵CDC. Youth risk behavior surveillance—United States, 2009. *MMWR*. 2010;59(SS-5). Available at www.cdc.gov/mmwr/pdf/ss/ss5905.pdf. Accessed May 30, 2011.
- ²⁶Weatherspoon K. Young adults becoming victims of growing apathy over HIV/AIDS. *Medill Reports*. June 4, 2009. Available at news.medill.northwestern.edu/chicago/news.aspx?id=133407. Accessed May 24, 2011.
- ²⁷Catz SL, et al. Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology*. 2000;19(2), 124–133.
- ²⁸CDC. Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9–12: youth risk behavior surveillance, selected sites, United States, 2001–2009. *MMWR*. June 6, 2011. Early release, volume 60. Available at www.cdc.gov/mmwr/pdf/ss/ss60e0606.pdf. Accessed August 1, 2011.
- ²⁹Ryan C. and Futterman D. *Lesbian and gay youth: care and counseling*. HRSA, HAB. 1997. Available at www.ask.hrsa.gov/detail_materials.cfm?ProdID=1140. Accessed on August 1, 2011.
- ³⁰*Treatment adolescents with HIV: tools for building skills in cultural competence, clinical care, and support. Fundamentals of adolescent care and cultural competence*. Available at hivcareforyouth.org/adol?page=md-module&mod=intro-01-01. Accessed June 1, 2011.
- ³¹Fair CD, et al. Indicators of transition success for youth living with HIV: perspectives of pediatric and adult infectious disease care providers. *AIDS care*. 2011;9:1–6.
- ³²Prejean J, Song R, Hernandez A, et al. 2011. Estimated HIV incidence in the United States, 2006–2009. *PLoS ONE*. 6(8):e17502. Available at www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502. Accessed August 4, 2011.
- ³³Collins S. *HIV reinfection cases reported at 17th Conference on Retroviruses and Opportunistic Infections (CROI), February 16–19, 2010, San Francisco*. Published June 2010. Available at <http://i-base.info/htb/10502>. Accessed August 25, 2011.
- ³⁴Cavaleri M., et al. Barriers to HIV care: an exploration of the complexities that influence engagement in and utilization of treatment. *Social work in health care*. 2011;49(10): 934–45.
- ³⁵Myers JJ, Shade SB, Rose CD, et al. Interventions delivered in clinical settings are effective in reducing risk of HIV transmission among people living with HIV: results from the Health Resources and Services Administration (HRSA)’s Special Projects of National Significance Initiative. *AIDS Behav*. 2010;14: 483–492.

- ³⁶Hidalgo J. *Identifying, linking, engaging and retaining young MSM of color in HIV care: findings of the HRSA young MSM of color SPNS initiative and implications for Ryan White Program grantees and providers*. 2010. Washington, DC: George Washington University, YES Center. Available at www.careacttarget.org/2010_rw_grantee_meeting/papers/A-23C.pdf. Accessed June 15, 2011
- ³⁷National Multicultural Center, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for African-Americans*. 2002. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-95. Accessed May 2011.
- ³⁸National Multicultural Center, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for Asians and Pacific Islanders*. 2002. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-489. Accessed May 2011.
- ³⁹National Multicultural Center, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: a cultural competency model for American Indians, Alaska Natives, and Native Hawaiians toward the prevention and treatment of HIV/AIDS*. 2002. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-93. Accessed May 2011.
- ⁴⁰Chabon B, Futterman D, and Hoffman ND. HIV infection in parents of youths with behaviorally acquired HIV. *Am J Public Health*. 2001 Apr;91(4):649-50.
- ⁴¹National Multicultural Center, University of Texas Health Science Center and National Council of La Raza. *BE SAFE: A cultural competency model for Latinos*. 2005. Available at www.aids-ed.org/aidsetc?page=etres-display&resource=etres-94. Accessed May 2011.
- ⁴²Washington State Department of Health, Division of Community and Family Health, Office of Maternal and Child Health, Children with Special Health Care Needs Program. *Primary care providers' perspectives on serving young adults with special health care needs*. July 2009. Available at www.doh.wa.gov/cfh/mch/documents/PCPreportJuly09.pdf. Accessed July 20, 2011.
- ⁴³Tinsley B, Lees N, Sumartojo E. Child and adolescent HIV risk: familial and cultural perspectives. *Journal of Family Psychology*. March 2004; 18(1): 208-224.
- ⁴⁴Rao D. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS care*. 2007; 19(1): 28-33.
- ⁴⁵Hosek SG, Harper, GW, and Domanico, R. (2005). Predictors of medication adherence among HIV-infected youth. *Psychology, health, and medicine*. 10(2):166-179.
- ⁴⁶Christiani A., Hudson, A. L., Nyamathi, A., Mutere, M. and Sweat, J. Attitudes of homeless and drug-using youth regarding barriers and facilitators in delivery of quality and culturally sensitive health care. *Journal of Child and Adolescent Psychiatric Nursing*. 2008;21: 154-163.
- ⁴⁷Cavaleri M., et al. Barriers to HIV care: an exploration of the complexities that influence engagement in and utilization of treatment. *Social Work in Health Care*. 2011;49(10): 934-45.
- ⁴⁸Rao D. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS care*. 2007; 19(1): 28-33.
- ⁴⁹Washington State Department of Health, Division of Community and Family Health, Office of Maternal and Child Health, Children with Special Health Care Needs Program. *Primary care providers' perspectives on serving young adults with special health care needs*. July 2009. Available at www.doh.wa.gov/cfh/mch/documents/PCPreportJuly09.pdf. Accessed July 20, 2011.
- ⁵⁰Tinsley B, Lees N, Sumartojo E. Child and adolescent HIV risk: familial and cultural perspectives. *Journal of Family Psychology*. March 2004;Vol 18(1): 208-224.
- ⁵¹Hosek SG, Harper, G.W., & Domanico, R. Predictors of medication adherence among HIV-infected youth. *Psychology, health, and medicine*. 2005;10(2):166-179.
- ⁵²CDC. *Establishing a holistic framework to reduce inequities in HIV, viral hepatitis, STDs, and Tuberculosis in the United State: An NCHHSTP white paper on social determinants of health*. 2010. Available at www.cdc.gov/socialdeterminants. Accessed August 15, 2011.
- ⁵³Goode T, et al. *Implementing the CLAS standards to reduce HIV disparity – parts 1 and 2*. AETC, National Multicultural Center and the National Center for Cultural Competence, Georgetown University Medical Center. June 2011. Available at www.aetnmc.org/CLAS_Module_Webinar_Version_6_29_11-dll_modified.pdf. Accessed July 29, 2011.
- ⁵⁴Borek N, et al. Involving vulnerable populations of youth in HIV prevention clinical research. *JAIDS*. 2010;54: S43-49.
- ⁵⁵Futterman D, et al. *Not enough time, not enough experience, not aware of risk: why healthcare providers don't routinely test youth for HIV*. Available at www.aids-ed.org/pdf/references/adol_provider_testing.pdf. Accessed May 14, 2011.
- ⁵⁶Ngo-Metzger Q, et al. Cultural competency and quality of care: obtaining the patient's perspective. *The Commonwealth Fund*. October 2006. Volume 39. Available at www.commonwealthfund.org/usr_doc/Ngo-Metzger_cultcompqualitycareobtainpatientperspect_963.pdf.
- ⁵⁷Washington State Department of Health, Division of Community and Family Health, Office of Maternal and Child Health, Children with Special Health Care Needs Program. *Primary care providers' perspectives on serving young adults with special health care needs*. July 2009. Available at www.doh.wa.gov/cfh/mch/documents/PCPreportJuly09.pdf. Accessed July 20, 2011.
- ⁵⁸Scal P and Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*. 2005;115(6): 1607-1612
- ⁵⁹HRSA, HAB. Transitioning from adolescent to adult care. *HRSA CAREAction*. June 2007. Available at <http://hab.hrsa.gov/newspublications/careactionnewsletter/june2007.pdf>.
- ⁶⁰Friedman, Lawrence. Interview. June 2011.
- ⁶¹Washington State Department of Health, Division of Community and Family Health, Office of Maternal and Child Health, Children with Special Health Care Needs Program. *Primary care providers' perspectives on serving young adults with special health care needs*. July 2009. Available at www.doh.wa.gov/cfh/mch/documents/PCPreportJuly09.pdf. Accessed July 20, 2011.
- ⁶²Peter NG, Forke CM, Ginsburg KR and Schwarz DF. Transition from pediatric to adult care: internists' perspectives. *Pediatrics*. 2009;123(2): 417-423.
- ⁶³Rajabiun S. Keeping at-risk persons living with HIV/AIDS in care: a qualitative study of staff perspectives. *Journal of HIV/AIDS and social services*. 2011;10(2).
- ⁶⁴Hortsmann E, et al. Retaining HIV-infected patients in care: where are we? Where do we go from here? *Clinical infectious diseases*. 2011;52(suppl_2): 5214-5222.
- ⁶⁵HRSA. Social media and HIV. *HRSA CAREAction*. June 2011. Available at www.hab.hrsa.gov/newspublications/careactionnewsletter/june2011.pdf.
- ⁶⁶HRSA. Social media and HIV. *HRSA CAREAction Newsletter*. June 2011. Available at www.hab.hrsa.gov/newspublications/careactionnewsletter/june2011.pdf.