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Achieve is a joint publication of  
ACRIA and GMHC.



## Caring for Youth with HIV

Adolescence is a time of dramatic physical, emotional, mental, and social change. The transitions that occur usher youth into the social and sexual world as independent beings. These changes provide opportunities for positive growth experiences, but they also bring new vulnerabilities.

by Lisa Henry-Reid, MD, Lori Wiener, PhD,  
and Ana Garcia, PhD

Unfortunately, young people in the U.S. and other parts of the world are particularly vulnerable to HIV infection. One of the hallmarks of adolescence is the formation of a sexual identity, while another is the propensity for taking risks. When mixed, these characteristics can be dangerous, as reflected in the fact that half of all new HIV infections each year are estimated to occur among youth aged 13 to 24.

### THE CHALLENGES OF ADOLESCENCE

Adolescence is marked by a move toward independence and a challenge to family traditions. But young people do not exist in a vacuum. They are a part of social networks that can make living with HIV easier or harder.

Young people with HIV face the same challenges as their HIV-negative peers, including experimental behavior and development of the skills needed for adulthood. But youth with HIV must address these challenges while living with the stigma of their disease. Their choices regarding intimate relationships, sexual activity, and experimentation with drugs and alcohol are complicated by:

- Fears of rejection
- Side effects of HIV drugs
- Uncertain life span
- Disclosure and transmission
- The impact of loss
- Stigma

Older teens and young adults may be more able than their less mature siblings to take an active role in dealing with HIV. But even they require significant psychological and emotional support. And two

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## ACRIA Trials

### Pomegranate Juice

People who have not taken HIV meds for at least 90 days will drink pomegranate juice or placebo juice daily for 10 to 18 weeks to study its effect on the heart, quality of life, and HIV viral load.

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optimum dose of the drug during pregnancy. Compensation is provided.

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### TAK-652

People who have taken HIV meds before will take this new CCR5 inhibitor for 10 days with no other HIV meds.

### Vicriviroc

People who have not taken HIV meds before will take this new CCR5 inhibitor with other HIV meds for 48 weeks.

For more information on these trials, contact us at 212-924-3934, ext. 121.

## achieve

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## LETTERS TO THE EDITOR

To the Editor:

I was introduced to your publication recently and found it to be more interesting and informative than others I've read. No reason to bad rap others - yours was better suited for my needs.

I am a heterosexual male doing a sentence here in California and would like to receive future issues. Thank you in advance.

Respectfully,

Sergio B.

To the Editor:

I just wanted to compliment you on the Fall 2008 edition of *Achieve*. It was excellent at detailing the current challenges of the U.S. healthcare system, specifically HIV/AIDS prevention and care. I think that may have been the first issue of *Achieve* I've read, to my knowledge. Thanks for laying out the real issues in such an understanding and comprehensive way. I found it an extremely helpful tool in light of the 2008 elections.

I expect to be a regular reader now. I hope to see further information on the challenges of HIV prevention and prevention in its full complexity in future issues.

Keep up the good work!

KAM

Brooklyn, NY

Photos used in *Achieve* imply nothing about the health status, sexual orientation, or life history of the models.

*Achieve* would love to hear from you! Please send your comments to: Letters to the Editor, *Achieve*, 230 W. 38th St., 17th floor, New York, NY 10018, or email them to: [achieve@acria.org](mailto:achieve@acria.org).

other transitions to adult life common to all young people are experienced differently by those with HIV: planning for school and work, and dealing with the adult medical system.

It is critical to help them understand that HIV is a chronic illness that, when successfully managed, can allow for a long and healthy life that includes marriage or long-term relationships, children, and career.

## PROVIDING SUPPORT

A key task in working with young people who have HIV is helping them adjust to their HIV status. Without proper support, adolescents have enormous difficulty staying in care and adhering to treatment. Goals of psychosocial care for youth include:

- Identifying and addressing crises, such as suicidal behavior or homelessness
- Providing access to benefits, entitlements, and services
- Promoting adherence to treatment
- Assessing and expanding social support
- Supporting development of self-care and life-enhancing practices
- Identifying and treating chronic problems like depression and substance use
- Promoting skills to live independently and to make the transition to adulthood
- Reinforcing and sustaining safer sex behaviors
- Encouraging drug treatment, if needed, and supporting recovery

Adolescence is a time of testing limits, marked by risk taking, struggles for independence, experimenting with adult behaviors, impulsivity, and a sense of invulnerability, coupled with awakening sexuality. But normal adolescent behavior that would be relatively safe in other youth can damage the health of a young person with HIV, putting her or him at particular risk and making adherence to treatment difficult.

Adolescents strive for independence, but those with HIV are dependent on doctors, case workers, medicines, etc. Resentment and mixed feelings about such forced dependency are not uncommon and can lead to poor adherence or

## HIV Transmission Routes

Young Males	Young Females
<ul style="list-style-type: none"><li>• Sex with men: 76%</li><li>• Sex with women: 11.5%</li><li>• Injection drug use: 7.5%</li><li>• Sex with men and injection drug use: 4.5%</li><li>• Other: 0.5%</li></ul>	<ul style="list-style-type: none"><li>• Sex with men: 85%</li><li>• Injection drug use: 14%</li><li>• Other: 1%</li></ul>

Young men who have sex with men (YMSM) are at particularly high risk for HIV. The CDC's Young Men's Survey found that 14% of African-American YMSM and 7% of Latino YMSM aged 15-22 have HIV. In the 33 states that report HIV cases, African-Americans accounted for 61% of cases in 13 to 24 year olds. Young women are increasingly at risk – in 2003, they accounted for 50% of HIV cases among those aged 13-19 and 37% of those aged 20-24.

### AIDS Cases

In 2004, an estimated 2,174 young people received an AIDS diagnosis, bringing the total number of youth living with AIDS to 7,761. Treatment advances have contributed to the growth in the number of youth living with AIDS. Between 2000 and 2004, there was a 42% increase in their number.

Minority youth have been disproportionately affected by HIV since the beginning of the epidemic. According to the CDC, in 2004 African-Americans made up 73% of all AIDS cases among youth, and Latinos 14%. In 2004, females made up 43% of AIDS cases among 13 to 24 year olds.

substance use. For adolescents infected at birth, there can be added challenges arising from the fact that they were not expected to survive childhood and therefore were not helped to develop the skills they would need for independent living.

For some youth, the impact of a new diagnosis is immediate. For others, it can take weeks or years for the emotional reality of the diagnosis to be absorbed. The particular traits of adolescence make it even more challenging to cope with HIV. These include a strong sense of invulnerability and immortality, being prone to peer pressure, difficulty grasping the long-term consequences of behavior, and a struggle between a sense of power and a lack of it.

For adolescents who have experienced poverty or living arrangements that brought constant threats and dangers, living with HIV is another burden in their lives. It is often perceived as proof that the world is untrustworthy.

## DISCLOSURE

Adolescents are very concerned about sharing their HIV diagnosis with others. Disclosure of one's HIV status is complex and delicate, and each disclosure comes with consequences. Peer support groups, networks, or interactions may be helpful both before and after disclosure.

Adolescents who disclose their HIV status to peers and family have been shown to have:

- Better psychosocial outcomes
- Fewer symptoms of post-traumatic stress disorder
- Greater likelihood of disclosing to romantic partners
- More confidence with peers
- Greater resources and support from family and friends

On the other hand, sharing one's HIV status with others can result in being shunned and even discriminated against.

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Referral to a mental health professional or a spiritual adviser who is informed about HIV can help adolescents decide when and how to disclose their status. Role playing can be a particularly effective way for teens to practice informing potential sexual partners.

## ADHERENCE

Mental health problems often lead to poor adherence to treatment among adolescents. Adherence rates for adolescents and young adults taking antiretroviral medications range from about 29% to 61%. Adherence is influenced greatly by:

- Disclosure issues
- Peer relationships
- Difficult social conditions
- Substance use
- Family belief system
- Psychological distress, depression
- Complications with day-to-day routines
- Family perceptions of the value of medication

Some young people may have concerns regarding how well medications work for people from their racial or ethnic group. These concerns may come from adults in the family who have misgivings about the treatment of minorities by the health care system. In fact, a recent survey of African-Americans aged 15 to 44 found widespread belief in AIDS conspiracies:

- 53% believe a cure for AIDS is being withheld from the poor
- 44% believe people who take new medicines for HIV are human guinea pigs for the government
- 60% believe that information about AIDS is being held back from the public

Certain cultural groups often rely on traditional approaches to healing, but herbs and other supplements can interact with HIV medications. Also, the visible side effects of certain HIV drugs (such as rashes and changes in body shape) can be a barrier to adherence. Including adolescents in treatment decisions and listening to what they have to say about side effects can lead to better adherence and may improve their quality of life.

## CULTURAL CONCERNS

Racial and ethnic minorities make up a growing number of people living with HIV. The current makeup of AIDS cases in people aged 13 to 19 is as follows:

- 70% African-American
- 15% white
- 13% Latino
- <2% Asian/Pacific Islander and Native American

In many families, certain issues are not discussed with younger members. Secrets regarding substance use or sexual behavior may be off limits. Some families may be hesitant to “air their dirty laundry” and want to maintain privacy. Among African-Americans, this is sometimes related to the historical experience of racism and the need to be cautious because of the risk of mistreatment, sometimes referred to as “healthy cultural paranoia.” The stigma associated with HIV may inten-

sify a family’s need to be protective of its members.

The use of disease as a strategy for colonization, a history of unethical research, and underfunded reservation-based medical care have left many Native Americans distrustful of medical providers. An extended family is the recognized center of Native American life, so it is critical for the provider to identify those who are considered to be family members. Family distrust can become an issue if family members who usually take on the responsibility of making treatment decisions are ignored by the care provider. Without trust by the family, the person with HIV may not trust either the clinician or the treatment. The HIV-positive young person may have access to rites of passage or activities that can help foster growth and development. Adolescence is seen as a preparation to assume community responsibilities and live productive adult lives. There may be community-based programs available to assist with this.



Among Latino youth, particularly Latina teens, the common adolescent desire to fit in may displace many traditional cultural norms, including the protective effects of *familismo* (attachment to the family) and taboos against certain risk-taking behaviors. Many Latino families have a respect for the authority of a health care provider that can help to engage the family in issues around medical care. Language can be a barrier or a valuable tool in building relationships with Latino families. People are often more able to discuss emotion-laden topics in their primary language.

White youth are the minority in most HIV clinics. They often describe “standing out” and are concerned about not fitting in or not being taken seriously because of their skin color and assumptions about their lifestyle.

### CULTURAL BELIEFS & MENTAL HEALTH

Beliefs concerning mental health treatment vary between different cultural groups, many of which reject conventional Western methods. In communities where there is a strong sense of spirituality, families may consult spiritual leaders for help. Some may accept conventional medical treatment while also using approaches grounded in their own traditions.

Among Latinos, the use of spiritualism, Santeria, and other religious approaches to both physical and mental health is common. Community storefronts that offer spiritual readings or the neighborhood *curandero* that promotes the use of herbal treatments, special diets, and spiritual prescriptions can influence people to reject their clinician’s recommendations for psychiatric medications and psychotherapy. Of special concern are the adverse effects and interactions between certain holistic treatments and conventional medications. All people with HIV should give detailed information to their care providers regarding all treatments they are using, including herbs and vitamins.

Among Native Americans, the use of traditional medicine varies from group to group. Traditional practices can include ceremonies specifically for the community or for the individual and family. Traditional medicine represents vast systems of prevention and treatment that operate at several levels, with practitioners who dedicate a substantial portion of their lives to healing. As a

## Stages of Lesbian/Gay/Bi Identity Development

### Stage One: Sensitization

Before puberty, children experience feelings of being different from their peers, based on gender role choices or behaviors. Few see themselves as sexually different before age 12.

### Stage Two: Identity Confusion

After puberty, adolescents become aware of same-sex thoughts and feelings. Negative stereotypes of homosexuality lead to cognitive dissonance and confusion as they struggle to make sense of their emerging identity. Many hide their sexual identity, or adopt a bisexual identity.

### Stage Three: Identity Assumption

During mid- to late adolescence or early adulthood, youth begin to self-identify and disclose their sexual identity (come out) to other gay people. Over a period of several years, they interact with lesbian and gay peers, and positive experiences strengthen self-esteem and dispel negative stereotypes. Access to an organized LGBT community provides opportunities for socialization, developing relationships, and finding positive role models. They learn a variety of strategies to manage their stigmatized identity.

### Stage Four: Commitment

Self-acceptance generally leads to incorporating sexual identity into all aspects of one’s life, usually during adulthood. Sexual identity is shared increasingly with non-gay friends and close family members. But integration depends on various factors, including access to support and positive role models, personal strengths and vulnerabilities, and experiences with discrimination.

result of the trauma of colonization and subsequent abuse, Native Americans have long been at risk for behavioral, emotional, and mental health problems. With the strengthening of tribal culture in recent years, there has been an increase in the availability of tribal services and culturally sensitive mainstream mental health services.

### SEXUAL ORIENTATION

Lesbian, gay, bisexual, and transgender (LGBT) adolescents come from all racial and ethnic groups, economic levels, and religions. They live in large cities and small towns, and are members of single-parent, two-parent, blended, and foster families. They are student leaders, athletes, and active members of civic groups as well as school dropouts and street youth. For the most part LGBT youth are indistinguishable from their heterosexual peers – in fact, most are invisible.

The struggle to develop and integrate a positive adult identity – an important task for all adolescents – becomes an even greater challenge for LGBT youth, who

learn from earliest childhood the profound stigma of a homosexual identity. Unlike many of their heterosexual peers, LGBT youth have no built-in support system or assurances that their friends or family members will not reject them if they acknowledge their sexuality. The social and emotional isolation experienced by LGBT youth is a unique stress that increases vulnerability and the risk of developing a range of health and mental health problems.

The psychosocial stresses to which LGBT adolescents are particularly prone include:

- limited knowledge among providers about sexuality
- stress from coping with stigma
- lack of support or overt hostility from family and friends
- need for secrecy
- lack of appropriate outlets for socialization and exploration of sexual identity (which can lead to high-risk, anonymous behaviors)
- lack of clear HIV prevention messages that include LGBT youth

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For many members of ethnic minority groups, race and ethnicity are core parts of personal identity. By the time an adolescent becomes aware of a same-sex orientation, that identity is already well established. In a society that discriminates on the basis of race and ethnicity, strong connections with family and ethnic community are essential for survival, but support is rarely available for an adolescent's homosexual identity.

Only among some Native American groups is homosexuality acknowledged in language and lore as part of cultural tradition, although even in many of these communities acceptance has largely been replaced by more negative mainstream attitudes. The stress of managing multiple levels of stigma, including race, ethnicity, homosexuality, and gender, requires additional sensitivity and knowledge of community resources.

### OTHER STRESSES

For young people who are at risk for HIV, the normal stresses of adolescence are often aggravated by poverty, violence, racism, homophobia, broken families, homelessness, and child abuse. These greatly increase their risk of becoming substance users or developing mental disorders, which can lead to risk-taking behaviors that may expose them to infections, including HIV.

Adolescents with HIV also face other problems such as loss and bereavement, cycles of wellness and poor health, barriers to care and social services, anxiety, and depression. Poor coping skills or difficulty adapting to their diagnosis makes them vulnerable to abusing alcohol and other substances.

Children with HIV have an increased risk of central nervous system diseases, leading to mental, language, physical, and behavioral impairments. Each of these conditions can have a significant impact on the ability to learn and on academic achievement. For example, poor memory may be related to psychological distress, but can also be a symptom of HIV-related cognitive impairment.

Youth with HIV are at increased risk of psychiatric illness during childhood

and early adolescence, and a diagnosis of major depression during adolescence appears to be on the rise. Youth with psychiatric illness also may be particularly vulnerable to HIV infection, since low self-esteem may increase the probability of risky behavior.

One of the greatest health disparities in the U.S. is the lack of mental health and substance use treatment services for adolescents. In 2002, it was estimated that 1.4 million young people between the ages of 12 and 17 needed substance use treatment. Only 7% of substance use centers provided services for patients younger than 18, however, so only 10% of the youth needing these services actually received them. The scarcity of affordable mental health and substance use services increases risks of HIV infection, untreated mental health issues, academic failure, and homelessness.

### MENTAL HEALTH STIGMA

People with mental disorders often feel stigmatized by their illness and can experience shame, grief, and anger over their diagnosis. In addition to their HIV diagnosis, adolescents in particular can perceive psychiatric care as stigmatizing. Many already see themselves as stigmatized because of their appearance, behaviors, and attitudes, so they may be resistant to accepting mental health services.

In recent years, mental health providers have recognized the importance of bringing the service to the patient in an effort to minimize barriers to care: At-home therapy provides services to children, adolescents, and their families where they live. Although not ideal for everyone (some patients tightly guard their privacy and prefer that staff not visit them at home), this approach can be useful for some stable families. It also avoids referring adolescents to mental health services in the community, where they are known to their peers and neighbors.

Alternative approaches can be tried in the event a mental health provider is not available in a particular community. Information on how to obtain support via the internet can fill this gap, especially for those living in rural areas. Some websites offer valuable resources that address

many of the concerns associated with a new diagnosis and provide updated information on current treatments. Several youth sites have chat rooms with instant messaging. If a young person is reluctant to seek services in the community for fear of recognition, this cyber approach may be a good alternative. Having an array of choices appeals to youth who are seeking to be more involved in the decision-making process regarding their health.

### THE RIGHTS OF YOUTH

The parents of an adolescent generally have the legal right to consent to treatment, although many conditions exist in which the adolescent may provide consent. Adolescents have a right to confidentiality in almost all situations in which they have the right of consent. Some situations do arise in which the clinician must assess the patient's competence and determine whether a parent or guardian should be notified.

Open communication between adolescent and adult caregiver is important, but providers are bound by the principle of patient privacy. This can become complex when culture-based family practices are introduced. For example, in some cultures, the family plays a strong role as a unit in the decision-making process, and excluding family members from that process is viewed as disrespectful. It is best to ask privately whether the teen wants a parent or guardian present, as this acknowledges their position of authority within the family.

Certain issues, such as physical or sexual abuse within the family, drug use, poor mental health, STIs, pregnancy, and homosexuality, will be difficult to introduce into discussions with certain parents or guardians. Mental health care providers can provide extra support in addressing these sensitive issues with parents and other family members. Discussion of these issues may cause anger, sadness, disbelief, and anxiety in the parent. Follow-up counseling is important for helping to ensure their emotional well-being. ■

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*Adapted from hivcareforyouth.org, edited by Donna Futterman, MD, and Stephen Stafford.*



# Young, Positive, and Homeless

To understand the impact of homelessness on youth and HIV, we turned to two New York City experts with hands-on experience.

Kate Barnhart is the former Director of Sylvia's Place, an emergency shelter for lesbian, gay, bisexual, and transgender (LGBT) youth, and Carl Siciliano is the Executive Director of the Ali Forney Center, which provides housing and supportive services to homeless LGBT youth.

## How widespread is the problem?

**Carl:** Nationally, a 2002 estimate found close to 1.7 million homeless and runaway youth, most between the ages of 15 and 17. Just about 6% of them identified as LGBT. The New York City Council recently counted over 3,000 homeless youth in the city, and a third of them are LGBT. Homeless youth in general are at greater risk for HIV than their peers, and homeless LGBT youth are at particular risk. The National Coalition for the Homeless estimates that the rate of HIV infection is 3% to 20% higher among the homeless.

**Kate:** Homeless youth have a higher risk of getting HIV because many turn to “survival sex” at some point. Whether they’re having sex for money, drugs, or a place to stay, they’re often not in a position to demand a condom. A large number have lived with older sexual partners. Although they may consider these relationships romantic, being dependent on another

person for housing makes them vulnerable, especially when it comes to safer sex. We have had several cases of young people who lived with older “boyfriends” who demanded unsafe sex, only to discover the partners’ HIV status later, by finding things like medication or ADAP cards.

**Carl:** Many survive through sex work. Even those who don’t do sex work tend to have many sexual partners. Studies show that LGBT homeless youth have higher rates of substance use. They also suffer from higher rates of mental illness, and experience more violence and trauma. These factors create a perfect storm of risk factors. In fact, about 25% of the clients receiving emergency housing and drop-in services at our center are known to have HIV.

## Does just being homeless increase their risk of getting HIV?

**Carl:** Being homeless increases the instability of their lives, and there are fewer

than 100 beds available to this population in New York City. So LGBT youth find themselves in a fearful, chaotic situation that makes it very difficult to cope with a positive test result. It seems very clear that the lack of safe emergency housing is the greatest cause of their high rate of HIV. Unstable housing is also the greatest barrier to their learning their HIV status and responding in a healthy manner.

**Kate:** Homeless young people are also likely to use drugs and alcohol. This increases the risk of getting HIV, whether directly, through shared needles, or indirectly, by removing inhibitions and impairing decision-making skills.

Homeless transgender youth face other risk factors. Since they lack the stability and resources needed to make their gender transition under a doctor’s care, they may turn to street sources for hormones and silicone, and may inject them with unclean syringes.

All of these risks can be lowered by using harm reduction methods, but this requires education. Since many homeless adolescents drop out of school, whether because of the homelessness itself, anti-gay/anti-trans harassment, or for other reasons, school-based HIV education may not reach them. Most youth shelters and drop-in centers offer HIV testing and education, but this only reaches those who use these services.

## Do we need more HIV testing efforts?

**Carl:** It would stand to reason that these young people should be tested. But they often view testing with fear and anxiety. I recall a young homeless trans woman who asked for an HIV test. When we did pre-test counseling, she said that if she got a positive test she would kill her boyfriend, who she thought infected her. We didn’t test her, but instead offered her mental health counseling. Well, she went to another test site, found out she was HIV positive, and came back to our center and stabbed her boyfriend. Luckily, he was not seriously injured.

**Kate:** Far from lacking access to HIV testing, homeless youth are, in my opinion, over-tested. According to our intake database, 95% of our clients report that they’ve been tested recently. Many get

*continued on next page*

tested several times each month, which does not make much sense medically but does make sense for someone who needs an incentive like a subway fare card.

Incentives bring other problems, too. A young person focused on getting one may not be thinking of the possibility of testing positive. One young man at our shelter took an HIV test to get \$5 for lunch money, tested positive, and tried to hang himself in our bathroom that night. This is an example not only of the potential problems of incentives, but also of the lack of follow-up services for those who do test positive.

**Carl:** Even after pre-test counseling, three of the last ten people to test positive here were hospitalized because of a desire to commit suicide. This is clear evidence of the need to link HIV testing with mental health counseling.

Testing is dangerous without establishing trust, and that means addressing more pressing issues like homelessness first. Providing a sex-positive environment that is accepting and confidential builds a sense of community and trust. For example, one of our clients, A.J., was kicked out of his mother's house because of his sexual orientation. He turned to sex work to support himself and began binge drinking to cope with depression. After bed-hopping for some time, he heard of the Ali Forney Center and came in for an intake.

A.J. was tested for HIV within a month of his arrival and found out he was positive. We were able to provide housing and primary care, along with mental health counseling. But while he had stable housing and access to regular health care, A.J. would fall out of mental health therapy frequently. He was battling depression and still occasionally did sex work. He was not disclosing to family, friends, or sex partners.

After many discussions with us, he restarted mental health therapy, and this time stuck with it. He developed new coping skills for his depression. After time, he also began to accept his HIV diagnosis and was able to start to disclose to important people in his life. Two years after learning his diagnosis, A.J. now has

permanent housing, adequate health care, and a job. He still goes to therapy, and discloses to his sex partners.

**So testing doesn't help unless young people get the services they need. Are those services available?**

**Kate:** While there are several excellent programs for young people with HIV, connecting our clients with these programs takes work, like convincing them to attend, getting their documents (many homeless youth lack birth certificates,

**Even after pre-test counseling, three of the last ten people to test positive here were hospitalized because of a desire to commit suicide. This is clear evidence of the need to link HIV testing with mental health counseling.**

Social Security cards, etc), completing referral paperwork, and escorting them to the first appointment, at least. And while they wait to be accepted, the shelter or drop-in program must do the work of supporting them through the initial crisis, even though these programs often do not receive funding for these services.

There is an urgent need for services that can be obtained quickly, with little or no documentation, on a walk-in basis. Walk-in services are especially needed for mentally ill and substance-using youth, and those involved in sex work. These individuals often have great difficulty keeping appointments due to the chaotic nature of

their daily lives and the lack of basic items like watches, appointment books, calendars, or alarm clocks. If you're sleeping on the subway, it can be difficult to know what day it is, never mind what time it is. And homeless young people who are aware that they have an appointment frequently do not have the subway fare to get there. Services for homeless youth are most successful when provided where they gather, or within walking distance.

**Is it possible for a homeless young person to get good medical care?**

**Kate:** They do have difficulty obtaining medical care in a consistent manner. They often rely on emergency rooms or see medical providers only haphazardly – a medical van one week, the doctor at a shelter the next – depending on what program they are currently attending.

Adherence to medication is also a huge issue for homeless youth. It's hard for a young person in a shelter to take medication confidentially, since residents may be required to give medication to staff for safekeeping or may be seen by peers. Some meds require refrigeration, with often only a shared refrigerator available. Young people living on the street or moving from place to place may have their possessions stolen, including medications that are very difficult to replace.

**Carl:** Access to emergency housing is critical in getting clients to a place where they can accept a positive test result and stay in care. Housing provides a way to reduce continued harm from sex work and drug use by giving them much more stability in their lives. It's clearly linked with better health outcomes for people with chronic illnesses. It is the bedrock on which access to care, HIV treatment, and entry into the job market are built.

**Kate:** We recently had a young man disappear from a shelter, leaving behind his medications. By the time he returned (he had been staying with a man he met in a bar), he had missed so many doses that it was necessary to change him to a new regimen. Medication side effects can be especially difficult for homeless kids since they lack easy access to bathrooms and must rely on public restrooms or share a shelter bathroom with many others. Also, most youth shelters require clients to be



out of bed by a certain time and are closed during the day, so there is no opportunity for rest if needed.

#### How do they deal with disclosure?

**Carl:** Many LGBT youth experience rejection when they come out about their sexuality. They sometimes end up homeless as a result. And those with HIV find it hard to disclose their status, often for the same reasons that kept them from getting tested. It comes as no surprise that many are afraid of yet another layer of rejection. HIV is still heavily stigmatized, and disclosure comes with great risks. For example, family and friends often find it hard to cope with such news, and turn to others for comfort. Too often, news spreads quickly and youth find themselves betrayed and full of shame.

Family and friends often incorrectly expect that simply being LGBT will lead to HIV infection, and HIV is still misunderstood as a death sentence. Young people with HIV often feel like they let themselves and their loved ones down at a time when their spirits need lifting. And these young people not only have to deal with rejection and homelessness, but

many are born in low-income neighborhoods with high crime rates. They may already have a fatalistic sense of what the future brings. Testing HIV positive turns an already bleak vision of one's future into "doom."

#### How does having HIV affect their self-esteem?

**Kate:** A large majority of our clients experienced childhood sexual abuse or rape. This is a documented risk factor for later HIV infection, since it can reduce personal boundaries and sense of self-worth. Self-worth among homeless youth is also negatively affected by other traumatic experiences, including emotional and physical abuse in childhood, death of caretakers, homophobic and transphobic harassment, violence on the street, and police brutality. Homeless young people are frequently arrested for offenses ranging from sleeping in public places to more serious crimes, and they are at risk for being raped in jail – particularly transgender women, who are housed in male units.

**Carl:** As we mature, we tend to gain ego strength and a sense of self that comes from who we know ourselves to be. Teens

are less likely than adults to have gained this ego strength. They are more likely to allow their sense of worth to be based on how others view them. As a result, they can be deeply afraid of the stigma of HIV. Homeless LGBT teens already face terrible rejection from their families and communities. They often find much of their self-esteem in their sexual desirability. Being desired sexually is one of the very few areas where they feel wanted and in control.

As a result, many of these young people will refuse to return to a program where the staff or other clients know they have HIV. Often, when a young person is given a positive test result, that's the last time she or he is seen at that program. In addition to providing a barrier to testing, this refusal to be seen by others as HIV positive also creates a barrier to housing designed for people with HIV. They think living there "outs" them in the eyes of others.

#### What needs to be done to address this problem?

**Kate:** It's essential that youth with HIV have access to stable housing so that they can consistently participate in health care and support services, eat nutritionally sound meals, get adequate amounts of rest, and avoid the daily stress of trying to find somewhere safe to sleep. The current New York City policy of restricting HIV/AIDS Services Administration (HASA) housing to people with an AIDS diagnosis greatly affects young people, since they are usually recently infected. This policy forces them to remain homeless until factors related to their homelessness interfere with their treatment to such an extent that they develop AIDS and are finally eligible for HASA housing.

**Carl:** Efforts to provide care for HIV-positive youth work best with a full range of services, so the program is not stigmatized as HIV-specific. Homeless LGBT youth are at such high risk of HIV infection because of the catastrophic merging of risk factors that homelessness adds to their lives. Addressing their homelessness is an important first step toward HIV testing and care. The terrible lack of safe and appropriate emergency housing for homeless LGBT youth is a public health crisis that we must address if we ever hope to stem the spread of HIV. ■

# Street Work

**I didn't use drugs at all in Colorado. But when I came to New York, I started with weed and then tried coke a couple of times. Later, it really got out of control. It was easy to find, and cheap – \$5 a hit.**

by Kevin Bowman

I grew up in Colorado. I was in a foster home at the age of 16 because my parents were getting a divorce and I was acting crazy – so my father placed me in a psych hospital for three months. When I was released he told me I could not come back home because I was “uncontrollable.” So I moved into a foster home with a really nice family. I spent a year there and then I got moved to another family. When I turned 18, my father said I could move back in but only if I got a job. I got a job at the airport, and then at Taco Bell.

I saved up and was about to get my very first apartment, when two of my friends asked me to move to New York City with them. Having been in foster care, I felt disconnected from my family, and they always talked to me negatively, so there was no point in staying just to be with them. We wanted to better our lives and make our dreams come true.

I didn't use drugs at all in Colorado. But when I came to New York, I started with weed and then tried coke a couple of times. Later, it really got out of control. It was easy to find, and cheap – \$5 a hit. I always said I had control over it and I knew what I was doing, but then it became unbearable – people could see changes in my personality, my behavior, and my body. I was losing weight.

My friends wound up moving back home, leaving me by myself. I had money when I got here, but used it up staying in hotel rooms. I wound up homeless and had to go to Covenant House. That was scary and I didn't want to be there. I'd never slept in a room with 15 people before. Then I turned 21 and couldn't stay there anymore.

I got into prostitution when a couple of trans girls I knew asked me if I wanted to learn how to make

quick money. When you're homeless you feel like you don't have anything, so the quickest way to make money was to prostitute. We found clients online. They were older, professional men, willing to pay a lot for me to do things I thought were weird, like playing with urine, handcuffs, whips, things like that. It was never at their homes, always at a hotel room. They never asked about HIV, so I never said anything either.

Six months after coming to New York, I found out I was HIV positive. I was shocked, but inside my head, I knew what I had done as soon as they told me. I had set myself up for it by having unsafe sex. I was young, not listening and wanting to do my own thing. I thought I knew everything.

**I pretended that prostitution didn't affect me, but it affected me so much that I went and used drugs. I put myself in a box I couldn't get out of – when you're a prostitute, you do this for this amount of money, and nothing else is said.**

In Colorado, there was no education about HIV in school. I learned everything I knew about it in New York, through presentations at the shelter and at drop-in centers I went to. I think it was too late, though. I had already had unprotected sex in Colorado, with my boyfriend, a guy that people said was positive. I didn't listen to them because I didn't really know what it meant or how you got HIV. I asked my boyfriend about it a few times, but didn't get a response.

I was 17 and he was 23, and we met at club. We slept together the first night and used a condom, but when but when we became boyfriends, we stopped using them. I think if they had had education about HIV in school it would have made a big difference. I try not to think about my boyfriend and what he did, because I would want to go back and fight and ask a lot of questions.



Photo © Lucky S. Michaelis

On the outside I pretended that prostitution didn't affect me, but on the inside it affected me so much that I went and used drugs. I put myself in a box I couldn't get out of – I was trapped. At that point, I really didn't care – when you're a prostitute it's just kind of, you do this for this amount of money, and nothing else is said. And then I punished myself by doing drugs.

But when I told my sister, she told my father and they really pressured me to stop. I also found people who were willing to help me without having sex with me. Covenant House referred me to Sylvia's Place, an LGBT shelter. When I walked into Sylvia's, it felt like a nightclub, with music and a lot of young adults who were dancing and having fun.

I went to rehab and Narcotics Anonymous, and my life starting looking better. Housing Works got me into its program, with case management and housing. It was good for the first three months, but then I got involved with the wrong people in the building, relapsed, and started smoking crack. I couldn't stay there because if I did I would keep using, so I went back to Sylvia's

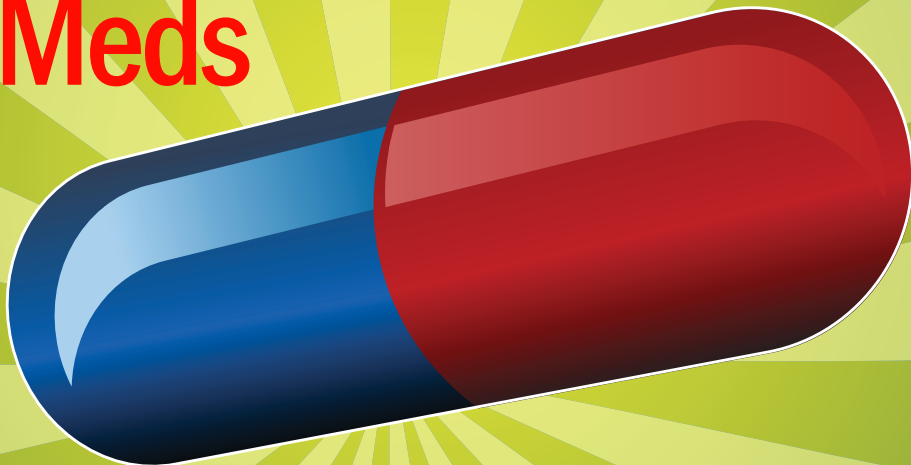
place until I got into an SRO. I went to find someone to sell me weed, but what I found was crack and I started smoking again.

So, I moved into Streetworks Overnight, where you can get a little more sleep than you can at Sylvia's. They helped me get into a residential program for people with the virus. They found me a nice, responsible, positive roommate – a girl, because I don't want to mess my life up because of a guy.

I've had a very crazy life. I was killing myself day by day with the things I was doing. I'm hoping that with my new apartment, my job as an intern at ACQC, and I hope going back to school, things will get better. I now have two months clean.

I always wanted to be the center of attention, even negative attention. Being in rehab showed me that knowing and loving yourself and taking care of yourself are the best gifts you can have in life. I know I only have one chance to live and I don't want to mess that up with drugs and sex. I've learned that you can be the center of attention in a positive way and leave a legacy. ■

# Growing Up With Meds



**In 1996, combination HIV therapy gave us the ability to suppress HIV and allow the immune system to rebuild itself. After years of struggling with treatments that were only partially effective, we finally had the technology to dramatically alter the course of HIV disease. This created a new reality: living with HIV.**

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by Alice Myerson, CNPN, ANP, MSN

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**T**he treatments were complex back then: many pills taken two or three times a day, some with food, some without, many with serious side effects. We learned what providers who worked with persons with chronic illnesses already knew. Taking medicines every day and sticking to a regimen for life is not easy: It's not easy for the young or for the old or middle-aged; not for the rich or the poor; not for white, black, or brown; not for people with HIV, diabetes, or hypertension. Adherence is an issue for all people. It is a human problem.

In 2009, almost three decades into the epidemic, we have more and better treatments, and six different classes of medications. We can tailor regimens to the needs of each individual. We have simple, once-a-day regimens with fewer pills, and the side effects can often be controlled.

But adherence is not just a question of taking medications every day. It is a

process that occurs over time. It is the process of integrating medical treatments into the structure of one's life. It means living a healthy life, every day, no matter what.

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**Joey lived with an addicted mother who never took meds. Lonnie's mother took meds, but there were six children in the house and Lonnie's problems were one of many. Shauna was raised by her grandmother and we used to hear her grandmother screaming in the background, "If you don't take your medicines, you're going to end up like your mother, dead."**

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Everyone's life situation has an impact on how that person adapts to illness and on the ability to adhere. Women with young children, for example, often forgo their own treatment because they are so busy taking care of their children that they forget to take care of themselves. Older people who live alone often have difficulty taking medicines because of confusion stemming from the large number of different pills they may have to take. Adolescents often displace their anger towards illness. The pills become the enemy and the adolescent exercises control by refusing treatment.

Can young people infected with HIV take medicines consistently? What are the challenges they face? How can we help them overcome these challenges and learn to live well despite having HIV?

## Understanding Adolescence

Adolescence, the period between the end of childhood and the beginning of adulthood, is characterized by movement and growth, conflict and rapid change. Physical growth happens quickly, and it takes the developing brain time to catch up. There is a disconnect between body and mind.

This disconnect makes it difficult for adolescents to manage illness. The way the illness looks is often more disturbing to an adolescent than the illness itself. These youth often don't have the words

to explain symptoms or the skills to take actions. They think concretely, in the moment. They lack the ego strength to feel empowered to exert positive control over their lives.

Although they strive to be independent, often kicking and screaming about their choices and their right to make them, they rely on adults to help them negotiate illness and the health care world. They need adults who will hang in there with them, no matter how hard they push them away.

To understand some of the challenges adolescents with HIV experience better, let us examine three stories, composites of the many young people who have come through my program.

### **Rosie: The Importance of Family**

Rosie was born with HIV, but had never been told. When she was 12, her mother asked me, “What should I do? How do I tell her? Will she hate me?” When she brought Rosie in, she said, “Tell her – you have to tell her now.”

Rosie was extremely relieved when I did. She had been aware that there was a family secret for as long as she could remember. She had been taking medications since she was a baby and had seen the Combivir ads on the bus shelters. “Did they think I was stupid?” she asked quietly. “I never brought it up because I didn’t want to hurt my mother’s feelings.” Now she had a name for what was wrong with her. The reason for taking the medications was out. She could talk about the secret.

Rosie lived with her grandmother, her mother, and her stepsister. Though her parents were not together, her father was always involved and she spent most weekends with him. Rosie had never been ill or hospitalized. The only symptoms she had were a small buffalo hump and a thick neck, side effects of Zerit. We stopped the Zerit and switched Rosie to Atripla. She keeps her hair long, and at least the problem hasn’t gotten worse.

Her mother was on methadone and never took HIV meds. Rosie watched her become ill over the next two years. Her mother died when Rosie was 14.

We expected Rosie to act out and stop taking her medications. That is how so

## **Core Components of Successful Adherence**

- Acknowledgement of illness
- Belief in the benefits of treatment
- Sense of self-worth
- The power to make choices
- A sense of future
- Daily routines
- Support from others
- The skills and resources to take medicines:
  - Stable housing, food, and other basic necessities
  - Access to medical care
  - Health insurance
  - Knowing how to use the pharmacy
  - Knowing how to read the labels
  - Knowing what to do in emergencies and how to handle side effects

## **Obstacles to Adherence**

- Poor adjustment to illness
  - Anger
  - Denial
  - Conflict
- Belief that medicines don’t work
- Fear of side effects
- Depression
- Mental illness
- Substance use
- Social isolation
- Lack of resources and skills necessary for taking medicines
  - Lack of food, housing, and other basic necessities
  - No access to medical care
  - No health insurance
  - Difficulty reading and understanding direction

many children infected at birth behave. She had suffered the trauma of the death of her mother. Her body was somewhat deformed and she knew the medicines caused this. We were prepared.

But Rosie did not stop her meds. Yes, she expressed anger toward the changes in her body. “Sometimes, it just makes me soooo mad.” But when we discussed the desire to stop, she said, “Are you

crazy? I don’t want to die like ...”

In our team meetings we asked, “What makes Rosie different?” Joey lived with an addicted mother who never took meds. Lonnie’s mother took meds, but there were six children in the house and Lonnie’s problems were often lost in the din. Shauna was raised by her grandmother, and we used to hear her grandmother screaming in the background, “If you don’t take your

*continued on next page*

medicines, you're going to end up like your mother, dead." None of these young people were able to take medications and all of them have died.

Rosie's family is different. Even at her lowest points, Rosie's mother brought her in for medical care. Her grandmother took care of both of them. No one ever yelled at Rosie about the medicines. They saw the medicines as a gift from God. The household in which Rosie grew up before the death of her mother was organized and structured. The transition to her father's home was smooth. Rosie was given a choice between staying with her grandmother or with her father, and she chose her father. Everyone expects Rosie to go to school, have friends, do the things teenagers are expected to do, to participate in life. And Rosie knows, from the experience of her mother, what it means not to take her medications.

Having supportive adults in the lives of young people – having structured, organized, normalized routines and expectations – are the building blocks of adherence.

#### **Antonio: Acknowledging Illness**

Antonio tested positive for HIV when he was fifteen years old. He had been in a relationship with an older man and heard through the grapevine that the man was HIV positive. He tested at a community-based program but quickly disappeared.

Luckily, Antonio joined a peer education program when he was 17. He was an excellent educator, always on time, grasped the material well, had positive relationships with his peers, and was committed to educating youth about the risks of unprotected sex and HIV.

Toward the end of the program, Antonio disclosed his secret to the social worker in charge of the group. She brought him to our medical program and remained available for support.

The shame Antonio experienced – his isolation, his fear – are indescribable. He grew up in a Puerto Rican family, one of ten children. Although he was always aware of his sexual identity, his father tried to beat it out of him. He felt ugly



and deformed. Children teased him because of his dark skin. He had no sense of belonging, of being valued simply for being who he was.

He experienced HIV as a punishment for being gay: "I knew better. I got what I deserved." His identity as a young gay Latino, already fragile, was shattered by the diagnosis of HIV. He built a persona around himself, acting the illusion of a perfect self.

He had kept the secret for two years before we met him. The process of engaging him in care took another two years. He lived transiently and was often hard to find. He wouldn't come in for routine visits without extensive outreach by our staff. Even when he had a cough and a fever of 102, it took two weeks to get him to come in for treatment. He disclosed to no one and could not say out loud, "I have HIV."

But viruses don't care about readiness. HIV marches to its own beat. Antonio's CD4 count dropped from the low 400s to less than 200 by the time he turned 19. Although we explained the reasons for starting medicine, and Antonio understood what we were telling him, he wouldn't even take Bactrim to prevent PCP (pneumonia).

Accurate information is an essential tool for making reasonable choices. But education does not always change behavior, so much of which is governed not by reason but by emotion and unconscious drive. If education did change behavior, everyone would wear condoms. No one would ever fall in love. And certainly no one would ever smoke a cigarette.

When Antonio turned 20, his CD4 count fell to 45. We referred him to the dentist for a purple lesion behind his back teeth and, sure enough, Antonio had Kaposi's Sarcoma. At that point, the disease became real. It's easy to deny HIV, even AIDS, but cancer? No way. Antonio recognized the real threat of suffering and death. He was able to acknowledge the dreaded AIDS. HIV meds suddenly represented life, hope and a future. "What are you waiting for?" he asked himself, and he has not missed a dose since.

The ability to see and plan for the future, the ability to understand consequences, the courage and the will to live are markers of the maturity of young adulthood. Antonio caught on to it just in time. He was ready to move forward, committed to building a life. "Medicines," he says, "are like

brushing my teeth. I don't even think about it any more."

#### **Anya: The Mental Health Connection**

Anya comes from a war-torn African country, and does not know what happened to her mother or father. She came to the U.S. at age 14 and lived in a refugee camp until a relative was located. Her aunt took her in, but when Anya tested positive for HIV her aunt placed her in the custody of the NYC Administration for Children's Services. Anya believes she contracted HIV through a blood transfusion.

Anya started HIV meds back when the standard of care was to treat early, no matter what the CD4 count. She was very quiet. Her English was limited and she made little eye contact. She took her medications without question for three years and maintained an undetectable viral load for that time.

But problems began to unfold when she turned 18 and was removed from her foster mother. Her aunt decided to take her back, but the relationship was short-lived. Anya's housing status became very unstable. She moved from place to place and stopped taking her meds. She complained of a variety of aches and pains. She also said that her caregivers were withholding food – accusations that were unfounded. Her CD4 counts remained in the 300s, and she was planning on resuming meds once her housing situation stabilized.

Anya had her first breakdown when she was nineteen. She began hearing voices that told her to jump in front of an oncoming train. She was very withdrawn and tearful. She was admitted to the hospital with a diagnosis of major depression with psychotic features.

Getting Anya to accept her mental illness was the next great hurdle. She did well when she took her antidepressants and antipsychotics. But as soon as she felt better, she stopped them. "If I feel well, why do I have to take them?"

How do you explain mental illness as a lifelong problem that won't go away without treatment? How do you explain that the brain is like a muscle that has wounds and scars from all the traumas of life, causing symptoms like voices that

aren't there and overwhelming feelings of despair. As Anya grappled with this, her CD4 count began to drop and she developed HIV-related arthritis. She wanted to take HIV meds, since it was easier to understand and accept HIV than mental illness. But every time she started gaining control over the virus, the voices came back, telling her to kill herself.

Anya has been hospitalized four times over the past three years. She is now 22. During her last hospitalization she was able to express the rage that has been building up inside for her entire life. She is mature enough to recognize that the antipsychotic medicines control the symptoms of her mental illness just as the HIV medications control the arthritis, fatigue, and illness caused by the virus.

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**Anya did well when she took her antidepressants and anti-psychotics. But as soon as she felt better, she stopped them. How do you explain mental illness as a lifelong problem that won't go away without treatment? How do you explain that the brain is a muscle that has wounds and scars from all the traumas of life, which cause symptoms like voices that aren't there and overwhelming feelings of despair?**

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She has been living in supportive housing for the past two years and is trying to find something more permanent. She recognizes that she needs support in handling the complexity of both illnesses. She hopes to find work that will allow her to be productive and more self-sufficient. With advocacy by the many social workers who have been involved in her care, she is in the process of becoming an U.S. citizen. She wants to be able to vote in the next election.

#### **Conclusion**

These three studies demonstrate the array of problems that young people with HIV

face. Rosie had to deal with the illness in the context of the death of her mother and had to make a transition from one house to another. Antonio experienced physical abuse, rejection by his family, and homelessness prior to his diagnosis of HIV. Anya experienced the traumas of war, loss, displacement, and possibly rape.

HIV infection is just one item in the long list of challenges these young people face. Our program strives to treat HIV in the context of each youth's life. We are privileged to have a multidisciplinary team consisting of physicians, a nurse practitioner, social workers, a psychiatrist, a nutritionist, and an HIV counselor. We rely on each other to work with our clients on the many problems they experience.

We build on the strengths of our clients and develop positive, professional, and supportive relationships with them. Each client who comes into our program is valued and special. We believe that the relationships we build with our clients, based on trust, value, respect, and honesty, lay the foundation for their ability to adapt to living with HIV, to integrate the diagnosis into their lives, and to adhere successfully to HIV therapy. ■

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*Alice Myerson is the Clinical Coordinator of the Adolescent AIDS Program at Montefiore Hospital in the Bronx.*

# Living with “The Monster”

by Raven Lopez

I first found out I had HIV twelve years ago, when I was six years old. My mother told me when we were at a doctor’s appointment. She was in tears and I started to cry with her. She turned to me and said, “Raven, you were born with HIV.” I started to cry because I always used to see people in Africa dying from AIDS.

So the first question I asked was, “Are we going to die like those people on TV?” She said, “No, there’s medicine out there that will take care of us. But this is something that will stay with you forever, until they find a cure.” So I said, “OK,” and acted like nothing happened.

The next day I went to school and told my teacher, “Hey, I got HIV.” She made a funny face at me and put me in the corner of the classroom and told all the other kids, “Don’t talk to Raven. She is a bad girl.” I started to cry. Every time I had to use the bathroom she would call another teacher into the classroom to take me. I never used to go on any class trips, because I had HIV. My mother always asked me, “Raven, why can’t you go on any class trips?” I told her that I told my teacher I was HIV positive, and I told her what she did to me. My mother said, “Raven, your teacher is being mean to you.” So she went up to the school and spoke to the principal. He told her, “If you guys were not so open about your status maybe she would not be treated like this.” So my mom took me out of that school.

When we told the pastor at our church, she took it okay. She started praying for us, because at that time I was dealing with a little sickness. So she prayed and did spiritual baths for us and stuff like that.

People always noticed me as the “HIV girl” because my mother was very open with her status. We’ve been on TV, Ricky Lake and Oprah, and in *POZ* and *Seventeen* magazines. So when I went to a different school, this time it was kids making fun of me. This one girl cut my hair. She said, “Raven, you’re going to die soon so let me cut your hair.” And I let her because I thought this is how living with HIV was going to be.

I got tired of being treated like this. I said to myself, “I have to put my foot down.” I let people know I was born with this and you cannot get it from being my friend. So you know what I did? I went out to teach my peers about HIV and AIDS, and when I started doing that I got friends. As I grew older, people started treating me differently. They were nicer to me and had respect for me.

But everything changed when I got into high school. When I was a freshman, this senior wanted to talk to me, but I said no. So he got mad at me and when I went into the lunchroom he got on a table and said, “Nobody talk to Raven because she got the MONSTER!” People started throwing food at me and laughing. I ran out of the lunchroom and went to the bathroom to cry and cry.

I said, “Why me? It’s not my fault. Why don’t people understand that I was born

with this?” This was the day before my birthday, and I called my mom and told her what just happened. She was so upset that she called my school, but the principal didn’t even care.

The next morning, which was my birthday, I went to school with my mother. When I pulled up in front of my school I saw people in front holding up signs saying, “Raven, We Love U! We got your back.” It was like 100 people in front of my school. I felt so

I told my teacher, “Hey, I got HIV.” She made a funny face at me and put me in the corner of the classroom and told all the other kids, “Don’t talk to Raven. She is a bad girl.” I started to cry. Every time I used the bathroom she would call a teacher into the classroom to take me. I never used to go on any class trips, because I had HIV.



loved that day and I turned to my mother and said, "Thank you, mommy." She even called a press conference on my birthday.

The boy that said I had the monster was surprised that I had so many people who had my back. He said, "Raven, I am sorry for what I did." I said, "No. Get out my face. We're not friends - you're an evil person." He was so hurt. After that, everybody wanted to be my friend.

With people that I think are nice, I will say up front, "Let me tell you one thing right now. I'm HIV posi-

tive and either you want to be my friend or not." Some people say, "Oh, Raven, you are just saying that to make me feel sad for you." So I'll bring in a *POZ* magazine, and when they will see it for themselves they get emotional and all that stuff.

But I do get scared because I don't know how they're going to react. They might say, "Get out of here. We don't want to be your friend any more." And I think that it will get around school. But I know how to deal with stuff like that now.

Having HIV has not stopped me from dating. If I like a boy I will ask, "If you had a girlfriend that you really loved and then she told you she had HIV, what would you do?" If he says, "I wouldn't go out with her - I wouldn't talk to her," then I know not to tell him. But if he says, "If I really loved her, I would stay with her," then I know I can tell him.

The first thing I do is say, "Listen, one thing you need to know about me is that I am HIV positive. I was born with this." When I tell them they are so surprised. They say, "Raven, you don't look like it." I say, "HIV doesn't have a face," and they usually accept me for who I am. Sometimes they say, "Raven can we just be friends?" I say, "Sure, no problem."

One boy I told was scared that he had it at first. But my mother told him that he didn't. We did have sexual intercourse, and we used protection. But there was a lot of stuff going on between us, not just because of HIV. He didn't really know what to do with himself, so I said, "Whenever you're ready to come back, you can." Right now he's dating another girl, so I don't know.

I say to myself, "You know what? I am going to hold my head up high and let people know that you should not stop being what you want to be in life just because you are HIV positive." I will teach my peers about this until the stigma stops and until we find a cure. ■

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# Dealing with Disclosure

We sat down with Luna Luis Ortiz, who has worked with at-risk and HIV-positive youth for 20 years, to discuss how disclosure issues affect his work.

When I was diagnosed with HIV at the age of 14, I dealt with it and had an optimistic attitude. I found strength in family support, in my photography, and later in working at the Hetrick-Martin Institute, a center for lesbian, gay, bisexual, and transgender youth in New York City.

But my mom and dad were afraid and confused. They didn't understand how people got HIV. At home I had my own cup, spoon, fork, and plate. My mom would clean the toilet with bleach every time I used it. Over time, they started to understand. I know it was a difficult time for them but it wasn't easy for me, either.

## How does stigma affect the ability to disclose?

HIV stigma exceeds what most of us have the capacity to understand. People are punished for simply living with HIV. It endangers your housing, your job, and your relationships. I have been blessed since I have not had to deal with much HIV stigma. I purposely strategize my life. I surround myself with people who understand. I've created an environment that reflects my way of thinking: "I have AIDS, but I am nobody's victim, and am I not going to tolerate any disrespect."

Most of my experiences with stigma came from dating. Some guys didn't want to deal with an HIV-positive boyfriend. I would always get them with my famous line, "I told you I have HIV, but you've already been with people who didn't tell you." Then I would leave them there thinking about it.

## Has the issue of stigma improved since you learned you had HIV?

Well, 22 years is a long time for someone who was told he had only two years to live! Much has changed since the early days. We have laws that protect us now. We have rights. We have social services and many more agencies that support us and are able to help people with HIV. People are more educated about HIV. But I do know that HIV stigma still exists.

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Disclosing their status can lead to rejection by family and friends, being forced out of their homes, or losing their jobs. But there are also success stories. I've seen some families offer real support – friends, too.

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## What has been your experience with dating?

Being HIV positive and dating is not easy. It definitely isn't easy to deal with when most of the community already knows my HIV status due to campaigns that use me as a spokesmodel. I have met some great guys who I've had great relationships with, but I've dealt with many more who simply did not want to date me because I have HIV. I always disclose up front though, so I don't have to deal with emotional attachments.

## When do you tell new friends or partners?

I always tell them in the very beginning. I think I tell them early on because I got it from someone who didn't tell me, so I feel

the need to tell the world. It's very natural for me to say it within minutes of meeting a person. I have never been ashamed, and I feel it is such a big part of me as a person, that it wouldn't be fair not to introduce my virus.

## How does your personal experience inform your work?

I know what it is like to deal with being young and gay with HIV. You face rejection by friends and family for being gay so you leave home, but get kicked out of group homes because you're gay – and then you test positive for HIV in a street van somewhere. It's hard enough being a teenager with, say, acne and self-image issues. But being gay, young, and HIV positive is very hard.

I keep a youthful approach to the work I do in HIV prevention. I keep up with their lingo and use it to talk to them. I'm careful to avoid unwelcoming body language, since they read discomfort very quickly. I make them feel comfortable. I become like them because I once wore their shoes. I've become a "go-to" person for young people whenever they find out their status. My work has always been focused on youth, and I do it with

an open heart. And sometimes I find that young people just want to be heard.

## How do you help young clients who find out they have HIV?

I've seen many young people deal with all the emotions that come with their diagnosis. The biggest challenge is trying to convince them that it's not a death sentence. Their personal challenges include learning to live with HIV; deciding when to start taking medication; finding safe, stable housing; dealing with a lack of love from family; and not getting support from friends. I have seen young people go from thinking that their dreams were over to a

point where they are living their dream. I love to see young people take control of their HIV status.

#### What challenges does disclosure bring?

Disclosing their status can lead to rejection by family and friends, being forced out of their homes, or losing their jobs. Their families may hold them personally responsible for their situation, and they can experience isolation, violence, and loneliness. But there are also success stories. I've seen some families offer real support – friends, too.

#### Does the family ever discourage disclosure?

Yes. Most parents do not want the rest of the family to know the child's HIV status. This usually happens because family members do not understand the disease, but instead believe the myths about how HIV is transmitted. There is also prejudice based on media reports on the epidemic. The fact that AIDS is incurable heightens fears about sexuality, illness, and death.

I myself dealt with these issues. My mother told me not to tell my brother or sister about my HIV because "they wouldn't understand." Six years later I told my brother that I had HIV, and he was shocked. At the time, I was writing newspaper articles and was on television talking about HIV and youth. So I simply told him as if it were no big deal, with a matter-of-fact attitude I adopted from ACT UP. He just stared at me. But when we got out of the car, he hugged me. He couldn't believe that my parents didn't want him to know. The rest of the family slowly found out from my mother's side of the family. HIV was not new to them – my mother's youngest sister, my favorite aunt, was also living with AIDS. My dad's side of the family seemed to be a little bit more close-minded.

#### Can keeping their status a secret interfere with treatment?

Stigma, denial, and nondisclosure are barriers to preventing further infections. Providing adequate medical care, support, and treatment helps to lower that risk. Unfortunately, many young people do not consider HIV treatment because they keep their status a secret. They may avoid HIV clinics if they're worried about



#### House of Legacy International

being seen there. And having to hide your HIV meds from roommates or family is a real barrier to adherence.

#### How do you deal with clients who have not disclosed to their partners?

Usually I have discussions about relationships, trust, and commitment with them. It's important that they understand what a relationship is and how crucial honesty is in a successful partnership. I work with young people who are afraid of rejection and refuse to tell their partners about their HIV status, but they have safe sex with them and are working toward telling them. I never pressure them into doing something they're not ready for.

I have been noticing more infections due to nondisclosure. I have also noticed a large number of young people – in their teens and twenties – getting infected while in a relationship. Most times I try to help young people cope with HIV stigma and help them to a place where they feel safe disclosing.

#### You're active in the House and Ball community. Is disclosure an issue there?

The House and Ball community is a subculture of young people who organize "balls" at which drag and other performers are judged in a number of categories. Disclosure in the House and Ball scene is rare. I have been in this scene since 1988 and I have only heard of five openly HIV-positive members, even though there have been well over 500 deaths since the 1980s. The House and Ball scene mirrors the HIV epidemic today. Young black and Latino gay men have the highest rates of HIV, and that is who primarily makes up the House and Ball community. GMHC and The House of Latex project have done great work with this population over the years, but there is still an air of silence towards HIV in this community. ■

*Luna Luis Ortiz is a Community Health Specialist with the Institute for Gay Men's Health at GMHC.*



# HIV EDUCATION IN THE SCHOOLS

by Jaime Gutierrez, MPH

**H**IV education in middle schools and high schools is critical to prevent HIV infection among youth. According to the Centers for Disease Control and Prevention (CDC), 13 to 29 year olds made up more than a third of people with HIV in the U.S. in 2006; the highest infection rate of any age group. African-American young adults accounted for 60% of all new infections among 13-24 year olds. Men who have sex with men (MSM) made up 80% of new infections in this age group. In spite of these figures, the CDC found that only 16% of young adults reported testing for HIV in 2006.

Young people are more likely to become infected with HIV by having sex

than any other method. The CDC's Youth Risk Behavior Survey (YRBS) found that after a steady decrease in teenage sex in the 1990s, there has been no change since 2001. In fact, YRBS reports that almost half of all high school students reported having sex in 2007. But 18% of sexually active youth reported not using prevention the first time they had sex.

African-American and Latino students report having more sex than their white peers. They also had their first sexual experience at a younger age, with 16% of African-American and 8% of Latino students having sex before age 13, compared to 4% of their white peers. Nearly a quarter of high school students that have sex reported drinking alcohol or using drugs, making it difficult to make safer sex decisions. In 2007, the National Center for Health Statistics

reported that teen pregnancy increased for the first time since 1991.

Additionally, oral and anal sex are increasingly practiced by youth as forms of contraception. Over half of 15 to 19 year olds report having had oral sex. According to a 2007 study of 350 sexually active 12-18 year old African-American females, 20% had anal sex with someone they considered a boyfriend and 12% with a casual sex partner. Only 21% of females used a condom for anal sex, compared to 33% for vaginal sex. Surprisingly, 61% used condoms with

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Oral and anal sex are increasingly practiced by youth as forms of contraception. Over half of 15 to 19 year olds report having had oral sex.

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their boyfriends compared to only 47% with casual sex partners.

Anal sex is more risky than vaginal sex in terms of sexually transmitted infections (STI). While these young people are preventing pregnancy, they are exposing themselves to STIs, including HIV. Not surprisingly, a recent national study found that one in four girls ages 14 to 19 have an STI, as did nearly half of African-American girls.

## THE NEED FOR HIV EDUCATION

The end of the decrease in teenage sexual activity coincided with an increase in federal spending on "abstinence only" sex education. Abstinence-only education teaches that having sex before or outside of heterosexual marriage is wrong and harmful. But it ignores the needs of sexually active youth. Abstinence-only education prohibits teaching about STI and pregnancy prevention unless the lesson emphasizes condom failure rates.

According to the Sexuality Information and Education Council of the United States (SIECUS), the best predictor of condom use

is a positive attitude toward condoms. The Guttmacher Institute reports that in 2002, 62% of sexually active female teens learned about pregnancy and STI prevention, compared to 72% in 1995. They also report that fewer than half of sexually active black females and only a third of sexually active black males received prevention messages before their first sexual encounter.

Public opinion favors sex education that includes HIV information. According to SIECUS, 100% of parents of junior high school students and 98% of parents of high school students believe STI education is appropriate in sex education. They report similar levels of support for HIV education. Parents believe that sex education helps their children avoid STIs and HIV. SIECUS reports that 82% of 15 to 17 year olds and 75% of 18 to 24 year olds also want this information. They also want information on how to bring up sexual health issues like STIs with partners.

Only 30% of U.S. voters believe that the federal government should fund sex education programs that only teach abstaining from sexual activity. However, the Bush Administration decreased domestic HIV prevention funding by over \$70 million from 2003 to 2006, and increased annual funding for abstinence-only education by \$176 million.

Many states have policies that mandate sex education in public schools. However, all the policies emphasize abstinence over contraception. For example, 23 states are required to stress abstinence, compared to 14 states that are only required to cover contraception. None of the 50 states are required to stress contraception. Additionally, 35 states are required to provide STI and HIV education, but none are required to stress contraception. Of the 50 states, 26 states stress abstinence compared to 17 states that are only required to cover contraception as STI/HIV education.

### HIV EDUCATION IN NEW YORK

Since 1987, New York State has mandated that all public schools provide HIV/AIDS lessons to students in grades K-12. In 1991, New York City expanded the mandate to require that all city schools provide five yearly lessons on HIV for students in grades K-6 and six yearly lessons for students in grades 7-12.

But adherence to the HIV education requirements by schools throughout the city and state remains very much ad hoc. A 2003 investigation by then New York Assemblymember Scott Stringer found that 63% of NYC schools failed to meet the city's requirement that students receive sex-ed classes from teachers certified in health education. His conclusion was that the requirement to give HIV instruction in every grade was being met "unevenly at best". The investigation also found a lack of trained teachers, teacher discomfort regarding HIV lessons, and inconsistent use of curricula.



That same year, a survey of 495 high school students done by Youth Organizers United found that only 6% reported receiving the six mandated HIV lessons and 30% said that they had not received any HIV education. 71% reported that their school did not have an HIV Education Team and 31% reported that their school did not have a Health Resource Room where students could access condoms.

To the frustration of many advocates, not much has changed since those reports. One major obstacle is that no city or state agency seems to have the legal or regulatory muscle (or political will) to enforce the mandates or to penalize school districts that fail to comply. As a result of the lack of monitoring and enforcement, it is hard to know the extent to which young people in schools in New York State are

getting HIV prevention education, but the evidence is not promising.

### CONCLUSION

As of 2009, 25 states have chosen to reject federal funds that support abstinence-only education. However, much remains to be done to stem the spread of HIV among youth. Abstinence is certainly one way of preventing pregnancy, STIs, and HIV. But the provision of heterosexually-biased, incomplete, misleading, and medically incorrect information about sex before marriage and contraception does a

great deal of harm. As a result, abstinence only programs have proven ineffective at reducing the rates of STI/HIV infection or teenage sex.

Sex education in the U.S. denies students the information necessary to make smart decisions about the sex they are having and completely disregards the needs of lesbian, gay, bisexual, and transgender students. The expansion of age-appropriate sexuality education that is inclusive of all students and that stresses HIV, STI, and pregnancy prevention in addition to abstinence is essential to reversing the negative trends in adolescent sexual health we have seen in recent years. ■

*Jaime Gutierrez is Associate Editor of Achieve and Assistant Director of Public Policy at GMHC.*

## Teens and Testing

Over a third of new HIV infections in 2006 occurred among those aged 13 to 29. This is the highest percentage of any age group. One reason for this may be found in the *Youth Risk Behavior Survey* of U.S. high school students, done from 1991 through 2007. It found that the percentage of students who used a condom during their last sexual encounter has not changed since 2003. This breaks the trend of increased use from the previous 12 years. The survey also reported that over 10% of students were not ever taught about HIV in school, while nearly half of all 15 to 18 year olds say they are sexually active.

Sexually transmitted infections (STIs) and unwanted pregnancies are also worrisome. The Kaiser Family Foundation reports that over 9 million young people (15 to 24 years old) were infected with at least one STI in 2000. This represents nearly half of all new cases. Unfortunately, less than a third of teens 15 to 17 years old have been tested for an STI. According to the CDC, 25% of teenage girls have at least one of the four most common STIs. This is not surprising given the Kaiser findings that nearly 25% of female teens and 18% of male teens reported not using any method of contraception during their first sexual encounter.

In 2006, the CDC revised its rules on HIV testing. The rules recommend routine HIV screening for all people aged 13 to 64. The recommendations also state that such screening must be voluntary, with the patient's full knowledge and consent. In 2008, The American College of Physicians urged doctors to screen all patients 13 and older for HIV, whether or not they engage in risky behaviors.

According to a 2009 report from the Guttmacher Institute, all 50 states and the District of Columbia allow minors to be tested for STIs with their consent. But consent laws differ by state. HIV testing and treatment is included within STI services in 31 states where minors can consent. Additionally, 18 states allow doctors to inform parents of a minor's HIV-positive test result. Iowa requires such notification.

Eleven states have specific age limits for STI services:

**12 years and over:** Alabama, California, Delaware, Illinois, Vermont

**14 years and over:** Hawaii, Idaho, New Hampshire, North Dakota, Washington

**16 years and over:** South Carolina

## Martin Delaney 1945 - 2009

ACRIA and GMHC note with great sadness the death of Martin Delaney after a long battle with cancer. Marty was a pioneer of AIDS activism, the founder of Project Inform, and an inspiration to many. We can think of no more fitting tribute than to quote from "The Delaney Declaration" – a document that he wrote last year:

*The entire human population benefited from the way AIDS first struck the gay community. Many people wanted to blame the spread of AIDS on gay people, but the facts are exactly the opposite.*

*When AIDS hit the gay community...it struck a group of people who were already organized politically...it struck a population that already knew it had to fight for its rights.... It knew it had to take care of its own because no one else would. It knew it had to fight back or die.*

*We were in San Francisco, Los Angeles, New York.... We were in the scientific community; we were in the NIH... We were in the drug companies and in Congress.... We hollered about AIDS in the media, we went to the FDA and the NIH, we marched in Washington, got people on*

*committees and proposed new ideas and new ways of thinking about science and the treatment of people with terrible diseases.*

*WE changed the rules, first for ourselves but ultimately for everyone facing a life threatening disease. WE wouldn't just listen to our doctor either. We recognized that they worked for us, that we were in charge of our lives and our bodies. We taught each other to demand that our doctors act as partners, not as dictators.*

*We became a voice that could counter, when necessary, the messages of the drug companies...and everything the companies did that affected us. As activists, we formed teams to speak up for our community regarding clinical trials.*

Thousands, if not millions, of people with HIV across the globe are alive and healthier today because of Marty's efforts. We express our profound gratitude for his courageous and persistent leadership and take comfort in knowing that he inspired so many to join and continue the fight against AIDS.

## Memo to Washington: Ban the Bans

**M**uch of today's medical care depends on a steady supply of blood from healthy donors. Despite shortages in the nation's blood banks, the Food and Drug Administration (FDA) continues to adhere to its ban on male donors who have sex with men. Under FDA guidelines, a man who has had sex with another man (MSM) since 1977 is permanently ineligible to donate blood.

The ban on MSM blood donors, enacted in 1985, is a holdover from a time when panic and discrimination drove health policy. In the twenty-four years since the ban was enacted, scientific knowledge on blood screening and assuring the safety of transfusions has grown significantly. Thirteen tests (11 for infectious diseases) are performed on each unit of donated blood; these tests include screening for Human Immunodeficiency Virus (HIV). In December 2008, the FDA approved a new blood screening test that can even detect HIV-2, another strain of the virus which is uncommon in the U.S. In years prior most HIV testing and screening mechanisms were not sophisticated enough to detect HIV-2. This recent development is further indicative of scientific progress, and yet the blood ban remains.

In April 2008, Representative Sam Farr from California called on the FDA to reassess its policy on this discriminatory ban, adding that, "The science doesn't seem to support that policy decision." This comes after a petition by the American Association of Blood Banks, America's Blood Centers and the American Red Cross to the FDA to repeal its prohibition. The groups also suggested reducing the severity of the ban, calling for a 12-month deferral of blood donations after sexual contact among men. Yet the FDA will not reverse the policy. According to its logic, the risk of accepting blood from a gay man, even one who is totally monogamous or has been celibate for ten or more years, is too great.

The cost of discrimination is high. Less than 5% of healthy Americans eligible to donate blood actually do so. In 2007, blood supply was at a five-year low in New York. In California,

officials in one school district have recently indicated that they may end blood drives in city schools if students are compelled to disclose information about their sexual activity. Many gay men have expressed their discomfort during workplace blood drives, where they are forced to either disclose personal information or be perceived as unsupportive of the blood drive. While this policy stigmatizes gay and bisexual men, in fact society as a whole pays the price.



Another example of an outdated and discriminatory measure is the HIV travel and immigration ban. The ban currently bars HIV-positive noncitizens from entering the U.S. – even for a stopover. The ban also disqualifies HIV-positive noncitizens living in the U.S. from lawful permanent residence (commonly known as a “green card”) except in the most limited circumstances. People denied a green card because of their HIV status confront a dilemma: go “home,” where they often will not have access to effective HIV treatment, or violate U.S. law by remaining here where treatment is available and where they can hope to extend their lives.

In early 2008, advocates worked to include repeal of the statutory HIV entry ban as an amendment to the reauthorization of the President's Emergency Plan for AIDS Relief (PEPFAR). PEPFAR provides funding to countries with high HIV prevalence rates, is widely popular among politicians on both sides of the aisle, and was touted as a success of the Bush administration. PEPFAR reauthorization was signed into law in July 2008 and included language to repeal the entry ban. While the 1993 statute was repealed, however, the 1987 regulation banning entry of HIV-positive persons remains on the books. Repeal of this regulation, the final step needed to end the ban fully, has not yet been accomplished.

During his presidential campaign, Barack Obama confirmed his support for repeal of the HIV travel and immigration ban in response to a survey sent by AIDSVote.org. While key officials in the Bush administration indicated they were acting to repeal the regulation, HHS declined to make the rule change before Bush left office. We urge the Obama administration to move quickly to start a rule-making process that will amend the regulation and fully lift the HIV travel and immigration ban. ■

# Free HIV Trainings

ACRIA offers free HIV-related trainings in NYC as a NYS DOH AIDS Institute Regional Training Center.

For a list of all the trainings and to download a registration form, visit:

[www.acria.org/treatment/rtc.html](http://www.acria.org/treatment/rtc.html)

You may also contact Gustavo Otto for more information at 212-924-3934, x129.

For listings of all trainings offered by the NYS DOH AIDS Institute, visit:

[www.nyhealth.gov/diseases/aids/training](http://www.nyhealth.gov/diseases/aids/training)

# Clean Needles Now!

## A CALL TO ACTION

Syringe exchange programs (SEPs) are proven to reduce the spread of HIV. HIV infection through Injection Drug Use (IDU) has decreased by 80% in the U.S. since the start of SEPs, and those exposed through IDU have reduced needle sharing by using SEPs. However, the federal government currently has a ban on funding for syringe exchange, even though experts note that even a small increase in funding will have a significant impact on HIV infection rates among IDUs.

Call your member of Congress and register your opposition to the ban. Urge them to support Congressman Serrano's Community AIDS and Hepatitis Prevention Act in the U.S. House of Representatives today. For more info, visit:

[www.gmhc.org/policy/federal/fedagenda08.pdf](http://www.gmhc.org/policy/federal/fedagenda08.pdf)

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