## **Testimony of Max Siegel**

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Good morning. I am grateful for this opportunity to address abstinence-only-untilmarriage education, a policy that has transformed my life. I share my recommendations on how to improve sexuality education programs as a person living with HIV who has spent the entirety of his young adulthood working to prevent new infections. My goal is to accurately portray the personal impact of this policy while explaining how the lessons I have learned may apply to other young people, who comprise 15 percent of all new HIV infections in this country every year (CDC, 2008). Thank you to Chairman Waxman and the Committee on Oversight and Government Reform for including an HIV-positive young person in today's hearings.

Abstinence-only programs do not work. Beyond the responsibility we have to provide young people with accurate, complete, and lifesaving education about their sexuality, I see no room for failed programs such as abstinence-only education in this time of shrinking public health budgets and increased accountability. Please end this horrible experiment so we can begin the work of saving young people's lives. I experienced abstinence-only-until-marriage education taught by my junior high school gym teacher. In a session, he told me and my male classmates that sex is dangerous and that we should think more seriously about it when we "grow up and marry." He was clear that sex was something only for married people. He was visibly uncomfortable, and he conveyed to us that sexuality was not to be discussed extensively in an educational setting. Even if it were, my gym teacher made it clear that only one kind of sexuality— heterosexuality ending in marriage—was acceptable to talk about. Already aware of my sexual orientation, I found no value in his speech. It did not speak to me and my life. It might as well not have happened.

While most formal abstinence-only education programs in this country are more extensive than the class I experienced, they rely on similarly exclusive and stigmatizing messages that lack basic information about sexual health. My classmates and I required nonjudgmental, practical information that was tailored to our individual needs. I am evidence that the basic abstinence-only lesson I received was ineffective. Multiple studies, including a 10-year federal evaluation, have found that the more expansive abstinence-only programs do not work either.

Unfortunately, this abstinence-only lecture was the only education I received on the subject. As such, I was ill-equipped to make responsible decisions about my sexual health. When I was 17, I began seeing someone six years older than me. The first time we had sex, I took out a condom but he ignored it. I did not know how to assert myself further. I knew enough to suggest a condom, but I did not have an adequate

understanding of the importance of using one, and even if I had more reasons to use a condom, I had no idea how to discuss condoms with my partner. The abstinence-only message did not prepare me for life, and I contracted HIV from the first person with whom I consented to having unprotected sex. I was still in high school.

Did the abstinence-only message make me HIV positive? It did not force me to forgo the condom. But, it did nothing to prevent me from contracting the virus. My coach could have told me that gay people had value and that delaying sex could benefit me too. He could have told me that I could still take actions toward healthy sexual relations even though I could not get married. He could have talked to me about how essential condoms were to stopping the spread of infection among sexually active people, and he could have taught me how to navigate weighty topics such as emotions, love, and condom use within a relationship. These topics also are absent from abstinence-only programs operating today, which puts thousands of young people across the country at risk for disease and teen pregnancy.

I met with a healthcare provider a few months later. Before informing me of my HIV status, the provider asked me about my plans for college. An idealistic teenager, I had a great deal to say about one day earning an advanced degree in a helping profession. The provider responded simply: "Well, after today, you can still *try* to do those things." I knew then that I had HIV. Unfortunately, I had no preexisting knowledge of what my prognosis could be or any of my healthcare options, which is information that should

have been provided for me during my school's sexuality education program. Beyond shock and hopelessness, my initial reaction was extreme guilt.

My friends and family were devastated upon my new disclosure. We had no substantial knowledge about HIV and we quickly developed false and damaging beliefs about my situation. I came to consider it unfair for me to confide in my loved ones for support because, through having unprotected sex with a single individual, I had committed a heinous crime that brought suffering into their lives. I thought that while a single HIV-infected person adversely impacts an entire community, it is this person's lone undertaking no matter their age or circumstance to reconcile the consequences of this disgraceful infection.

It seemed as though I had done something particularly disgraceful, but it never occurred to any of us that I in fact had engaged in fewer behaviors that could put me at risk for HIV infection than the majority of my peers. I wish I could say that my parents did not reinforce such notions. Like many young people's, my parents were in no position to educate me about HIV or AIDS because, although otherwise extremely well-educated, they did not have a comprehensive understanding or knowledge of sexuality and sexually transmitted infections. Instead, they mourned the loss of their child. As a community, we identified contracting HIV as someone's fault. We had no examples for how one might live well with the virus or any other chronic, sexually transmitted infection. None of us had received adequate education around these issues and what arose from my diagnosis was a widespread crisis. This crisis could have resulted in my absence from the medical

continuum, a refusal to disclose my status to future sexual partners, and suicide among other all-too-common occurrences in the lives of people living with HIV. It fortunately did not.

Soon after diagnosis, I decided to pursue a career in the prevention and treatment of the virus. I thought I had little time on this planet and that I was automatically in a unique position to help people because of my status. I have gone on to earn national recognition for my HIV-related endeavors. I hope I have demonstrated that those living with HIV can be relevant, meaningful members of society—even though the abstinence-only messages I received failed to teach me otherwise. The most personal career choice I made was to assume the role of an HIV counselor and to provide rapid HIV antibody testing to the general public. Working in HIV counseling and testing for three years, I gained a great deal of insight into the shared experiences of individuals living with HIV. These experiences cut across gender, race, and class, and I learned to pay particularly close attention to individuals' unique needs and perspectives.

That which makes me proudest in my life has been my willingness to be present for those who were otherwise alone. I have never averted my eyes from a client's suffering. I have not allowed discomfort to prevent me from addressing the needs of those around me and, as an educator, from reacting in ways that are proven to be helpful. Sexuality education should be no different. Adults should not allow their moments of discomfort to supercede the needs of youth for complete and accurate information.

Sexuality education programs must be as specifically focused as my counseling sessions. Programs must be tailored to meet the needs of individual students, the majority of whom will be sexually active before high school graduation. They should encourage abstinence while providing useful information about the potential consequences of sexual activity. Students of all ages should recognize abstinence as a primary mode of maintaining one's sexual health, but they must be given tools in addition to abstinence that will equip them for later life. These tools should be discussed in language that is accessible to students' particular ages by educators with whom students can identify and communicate openly. We must facilitate critical thought about sexuality in terms of keeping students healthy and, ultimately, alive.

Sexuality education programs should promote skills related to self-esteem, condom use and negotiation in terms of maintaining health as a priority, and self-efficacy while being inclusive of varying sexual orientations and gender identities. They must instill knowledge of local healthcare services, including the availability of HIV counseling and testing, and they should contribute to peer-led dialogue about healthy sexual behaviors, including abstinence. These programs must acknowledge relationship violence, which increases one's risk for HIV infection and is most commonly reported among married women (Lichtenstein, 2005). One's decision to abstain will not be honored in the presence of violence and coercion. Young people should be prepared for the wide array of emotions, not all of which will be bad, that result from engaging in sex. Ageappropriate and comprehensive sexuality education should be built into each grade level as sexuality is an issue of daily life. Effective sexuality education requires well-informed

educators who posses the professional skills to be able to deliver this important information in a confident and understanding way.

Students should leave sexuality education programs equipped and inspired to discuss HIV in terms of risk and transmission. Sexuality education should help individuals who are not living with HIV better understand the realities of a positive status for the purpose of preparing individuals who test positive later or have peers who are diagnosed for the medical and psychosocial ramifications of the virus. This requires a well-rounded portrayal of the lives of HIV-positive individuals. Students should have increased awareness about HIV and the bidirectional relationship between HIV and society. These programs should assume that many lessons arise from the AIDS pandemic. Themes such as stigma, isolation, discrimination, and unequal access to education and healthcare services are global and worthy of examination. Educators and policymakers must ask themselves: What effect does cultural legacy have on the marginalized communities most impacted by AIDS? Is it important to consider others' contexts in a holistic sense, including a history of sexual violence and family abuse, while striving to instill healthy sexual behaviors? Our leaders and role models are sacrificing young people's long-term survival in order to avoid momentary discomfort.

What I experienced in my junior high gym class is a routine example of the messages of abstinence-only-until-marriage programs that children across our country are still experiencing every day. On top of being proven ineffective for students (most of whom identify with traditionally heterosexual views of sex and gender), these programs also

ignore the needs of lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth, and even condemn them. The message I received in junior high was essentially that deviant life choices such as homosexuality or sex outside of marriage are not to be acknowledged. Furthermore, my educator implied that said deviants could never engage in sex in a healthy manner since non-heterosexual couples cannot "grow up and marry."

Acknowledging that sexual minorities may be as healthy as anyone else is by no means an endorsement of their behaviors; however, abstinence-only programs utilize government dollars to actually lash out against LGBTQ young people. From a healthcare perspective, it is important for the scrutiny of abstinence-only programs to concentrate on the consequences of abstinence-only programs' condemnation of sexual minorities, including men who have sex with men, who are at high-risk for HIV infection. This government-funded condemnation impacts majority-identified community members as well. Many men who have sex with men, especially young men and men of color, will not disclose their sexual interactions with other men due to the negative social consequences of acknowledging their behaviors (CDC, 2003). Nondisclosers are more likely to contract HIV, less likely to receive HIV testing, and more likely to have sexual contact with women (CDC, 2003). Even if one does not place value on educating LGBTQ individuals about reducing their risk for HIV infection, these individuals inexorably overlap with heterosexual-identified community members. The diversity of sexual orientations and gender identities in our world is irreversible. For everyone's survival, we must realize that a failure to attend to the needs of these individuals is a

failure to perceive the risk that befalls anyone who might be deserving of life-saving education.

Young, straight women also are in need of education that includes, but is not limited to, abstinence. I have worked with various individuals who contracted HIV within marriage. Many of these individuals were women who had children, and some of these children were infected at birth. Women of color are at particular risk. According to the Centers for Disease Control & Prevention, Latina women have nearly the same HIV/AIDS rate (15.1) as white men (16.7) (CDC, 2008). Among African American women, the rate (56.2) is almost four times as high (CDC, 2008). Abstinence-only programs neglect the needs of women of color through curricula that reinforce gender roles and emerge from a context of ethnocentrism. Abstinence-only programs frequently portray sexually active young women as dirty, scarred, and inferior. Regardless, staying faithful to one's partner will not protect a woman whose husband or boyfriend has been incarcerated when rates of HIV infection among inmates is exponentially higher than in the general population. And a woman asking her husband to respect her decision to abstain from sex or to use a condom is not consistent with abstinence-only programs teaching sex as an expectation within marriage or that condoms do not work.

Sex education must be appropriate for as many populations as it plans on helping, and HIV prevention must respond to the state of our domestic epidemic. I have assumed the responsibility of trying to help the women and children with whom I have worked to the best of my abilities, but there is no sufficient reason why this completely preventable

infectious disease should have impacted any of our lives. After six years of living with HIV and striving to prevent sexually transmitted infections in others, I strongly believe that it is society's responsibility to provide young people with all the tools they will need in order to lead healthy lives. Any American infected with HIV is a societal failure.

More individuals have this virus now than ever before in history. Most children born with HIV no longer die; they are growing into adolescence and adulthood. Within and outside of marriage, these young people must know how to prevent transmission of HIV to their sexual partners and how to protect themselves from further co-infection, other sexually transmitted infections, and unintended pregnancy. Understanding proper condom use is imperative to their wellness and to that of others'. Abstinence-only programs stigmatize individuals living with HIV through conveying inaccuracies about the virus' transmission, such as by stating that HIV may be transmitted through skin-to-skin contact (Duran, 2003, p.19). Rarely have I encountered a sexual health forum in which youth *or* older adults in the audience could collectively identify the four fluids that are known to transmit HIV. If asked, would you be able to do so?

Popular abstinence-only curricula rely on scare tactics, which do not work and adversely impact individuals who are diagnosed with HIV or even other sexually transmitted infections. One abstinence-only program has utilized an in-class exercise in which students roll a die to represent the risks they take by having sex and, in the case of the die landing on four, the leader of the exercise told students that they have AIDS and, "You're heading to the grave. No cure" (Hughes, 1998). What does this do for adolescents who

are already living with HIV, or whose parents may be HIV positive, except cause fear? HIV-positive young people could be harnessed as powerful peer educators as they are more frequently in other countries. Instead, fear of them further discourages all individuals from discovering their status and fails to encourage individuals to follow the Centers for Disease Control & Prevention's recommendation that everyone ages 13 to 64 receive routine HIV testing (CDC, 2006). Abstinence-only curricula do not meet the needs of individuals who are living with HIV, whether they are aware of their status or not.

One of the most common barriers to effective HIV prevention among youth that I have encountered is apathy toward one's risk for infection. How are we to expect young people to recognize HIV as a legitimate concern when our policymakers and educators ignore overarching evidence that HIV prevention interventions must be administered in a comprehensive manner? The claim that comprehensive sexuality education encourages sexual activity among youth – despite evidence to the contrary – is an indication that policymakers are not aware of young people's willingness and capacity to make responsible decisions about their sexual health. This claim is counterintuitive to the numerous HIV-negative client success stories that I might tell, and it has not been proven in research. Comprehensive sexuality education programs are shown to increase the use of condoms and contraception while reducing a young person's number of sexual partners and pushing back the age of sexual debut (Kirby, 2007; U.S. Department of Health and Human Services, 2001).

I came to recognize the importance of condoms from my personal and professional experiences. Although condoms are not 100% effective at preventing HIV, they do come close. I have never screened a client HIV-positive who used condoms correctly and consistently. Unfortunately, abstinence-only programs are only allowed to note contraception or condom use in terms of failure rates. Research shows that abstinenceonly students are less likely to use condoms or contraception when they do have sex (Bearman & Bruckner, 2001) and are less likely to seek medical attention in the presence of a sexually transmitted infection (Bearman & Bruckner, 2005). The Mathematica Policy Research conducted a large, comprehensive study of students in abstinence-only programs that showed these students to be no more likely to stay abstinent than individuals who do not undergo any sexuality education whatsoever (Mathematica Policy Research, 2007). The evidence shows that comprehensive sexuality education is more effective at keeping our young people abstinent than abstinence-only.

In summary, please stop funding abstinence-only programs and start funding comprehensive sexuality education. As a tax-paying young person living with HIV, I urge you to use our federal dollars for programs that actually do protect our sexual health.

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