

# Treatment ISSUES

## Disability and HIV: Eliminating Barriers to Sexual Health Care and Education

By Heather Heldman and Hannah Slater

### Introduction

On June 18, 2011, *The New York Times* featured an article by Winstone Zulu, an advisor for AIDS Free World (aidsfreeworld.org) and polio survivor who uses crutches.<sup>1</sup> Zulu is a passionate advocate for the inclusion of people with disabilities in the fight against HIV/AIDS, and makes clear that people with disabilities cannot be excluded or overlooked because of misconceptions about their sexuality. We would like to thank Winstone Zulu for his efforts to bring this issue to the forefront of HIV/AIDS advocacy, and to take the opportunity to explore in depth some of the challenges and consequences that individuals living with physical, sensory, intellectual, or mental disabilities face in accessing sexual health care services, including HIV/AIDS prevention and treatment services.

While this article will discuss some of the specific challenges that people living with various types of physical, sensory, intellectual, or mental disabilities encounter, we note that our discussion is not exhaustive. Much more scientific and policy research is needed to expand knowledge and understanding of these issues. We hope the information presented in this article will spur discussion and motivate equitable actions toward preventing and treating HIV/AIDS among people with disabilities.

### Stigma and Misconceptions

Worldwide, HIV/AIDS prevalence among people with physical, sensory, or intellectual disabilities equals or exceeds general population prevalence.<sup>2</sup> In the United States, people living with disabilities face a greater risk of HIV infection than the population at large.<sup>3</sup> Addressing HIV/AIDS among people with disabilities starts with recognizing that all people are sexual, regardless of whether they are living with disabilities. The next step is confronting stigma and misconceptions. Chief among the many misconceptions that individuals living with disabilities may face are perceptions that they are not sexually active, are

asexual or sexually abnormal, do not have the same physical and emotional needs and desires as non-disabled individuals, and are incapable of understanding sexuality.<sup>4,5</sup> These beliefs, while reflective of the larger fallacy of “ableism” pervasive in many corners of our society, often lead to negative health outcomes because they prevent individuals living with disabilities from accessing essential health services, particularly sexual health services.

Misconceptions and stigma can be particularly harmful when they interfere with access to sexuality education and clinical services. Providing sexuality education, particularly for youth, is essential to lowering HIV transmission and prevalence rates among individuals living with disabilities, but it is also a major challenge. Young people living with disabilities

often miss out on sexuality education offered to their non-disabled peers because they are enrolled in separate classes at mainstream schools, attend specialized institutions that do not include sexuality education in their curricula, or do not attend school at all. Children living with disabilities account for one third of the approximately 72 million children worldwide who do not attend school.<sup>6,7</sup> In addition, community sexual health education campaigns often fail to reach individuals living with disabilities because they do not present information in accessible media formats or venues. For example, people with visual or hearing impairments may miss out on posters, pamphlets, visual demonstrations, television campaigns, billboards, and radio programs transmitting sexuality education information. Lack of access to appropriate information elevates the risk of infection for HIV and other sexually transmitted infections.

In clinical settings, physical, sensory, and intellectual disabilities often compromise standards of care by inhibiting confidentiality and degrading the patient-provider relationship. Individuals living with disabilities may have to bring family members with them to communicate requests for HIV tests or other health care services, may

*Community sexual health education campaigns often fail to reach individuals living with disabilities because they do not present information in accessible media formats or venues.*

be unable to access the physical space of clinics, or may face bias on the part of providers, deterring them from seeking care.

### **Physical Disabilities**

For many people living with physical disabilities, lack of access to sexual health care services is the greatest impediment to protecting themselves against HIV and other sexually transmitted infections.<sup>8</sup> Transportation to and from health care providers can present significant obstacles. Public transportation is often inaccessible to those who use wheelchairs or have limited mobility, and disability parking, ramps, elevators, and wheelchair accommodating doors are not always available. Relying on family members or friends for transportation can inhibit attendance at health care appointments or even deter people with disabilities from seeking sexual health care services in the first place, out of concern that medical confidentiality will be compromised.

Many health care centers do not have equipment, such as examination tables and scales, modified for people who use wheelchairs. One study of physicians' offices found that only 39% of gynecological health care providers had used or purchased an adjustable exam table, and only 2% had a wheelchair scale.<sup>9</sup> These types of deficiencies can lead to incomplete examinations. Another study found that women with high levels of physical disability were 57% less likely to report receiving Pap smears and 56% less likely to report receiving mammograms than non-disabled women.<sup>10</sup> Women with physical disabilities often feel that health care providers lack sensitivity and knowledge about their disabilities. And doctors often do not talk about contraceptives or sexually transmitted infections because they believe their patients living with disabilities are not sexually active. Not surprisingly, this had led many women with physical disabilities to avoid regular gynecologic visits—a step backward in the fight against HIV.<sup>11</sup>

### **Sensory Impairment**

Research discerning current HIV/AIDS prevalence rates among people with various types of sensory impairments is lacking. However, one recent study revealed that HIV prevalence among the deaf population is nearly twice as high as that among the hearing population in Maryland (United States).<sup>12</sup> For people with sensory impairments, particularly hearing impairments, communication is the primary barrier to health care access. People with hearing impairments may use American Sign Language (ASL) as their primary mode of communication, and learn English as a second language. Because ASL is not based on English and has very different grammar and syntax, many ASL users have lower English literacy than the general

population.<sup>13</sup> This makes written health informational materials, typically written at a reading level that surpasses that of the average ASL user and constructed with few illustrations, difficult to comprehend and minimally useful.<sup>14</sup>

Health care providers may believe that lip reading and note writing are adequate ways of communicating with patients with hearing impairments, but both of these techniques have significant drawbacks. Similar to comprehending written health informational materials, both lip reading and note writing require a high level of English literacy, especially when health care professionals use technical medical terminology.<sup>15</sup> Some people with hearing impairments may not be physically able to write due to an illness or other disability, and accents, mumbling, fast speech, facial hair, and medical masks may complicate lip reading. Interpreters are not always available, in part because health care professionals do not understand or fulfill their responsibility to ensure effective communication by finding and hiring interpreters.<sup>16</sup> Conversely, when interpreters are present or family members or friends are brought to appointments to facilitate communication, some patients with hearing impairments feel that their confidentiality is compromised, inducing situations where medical error may result from inaccurate or incomplete information.

For people with visual impairments, many common forms of sexual health information such as videos, pamphlets, and

visual demonstrations are inaccessible. Health care providers infrequently provide materials in other formats such as large print, braille, illustrations, and audio tapes. Some people with visual impairments report difficulty filling out forms, navigating clinics, and receiving written communications such as test results, prescriptions, or medicine labels, and feel that health care staff are not fully aware of their needs.<sup>17</sup> One educational priority for people with visual impairments is correct condom use, which is often demonstrated visually rather than explained orally or interactively.<sup>18</sup> A failure to communicate this type of important information completely and accurately puts people with visual impairments at risk for HIV and other sexually transmitted infections.

### **Intellectual Disabilities**

The lack of adequate sexual health education for people with intellectual disabilities is reflected in the research about their knowledge of HIV/AIDS. In one study, young adults with mild or moderate intellectual disabilities demonstrated significant gaps in knowledge about HIV/AIDS and risk reduction methods as compared to a control group of non-intellectually disabled students.<sup>19</sup> They also exhibited maladaptive attitudes regarding HIV risk and condom use, and when presented with hypothetical risk

***Doctors often do not talk about contraceptives or sexually transmitted infections because they believe their patients living with disabilities are not sexually active.***

situations they were more likely than non-intellectually disabled peers to present unsafe sexual solutions.<sup>20</sup>

Intellectual disabilities also put individuals at risk for HIV infection because they increase vulnerability to sexual abuse. In many cases, the criminality, culpability, and moral repugnance of such abuse are clear. In other cases, sexual abuse is more difficult to prevent and detect because of the challenge of discerning ability to consent to sexual activity and the confluence of victim and perpetrator roles. The United States Department of Justice reported that 68% to 83% of women with developmental disabilities experience sexual assault during their lifetimes.<sup>21</sup> The effects of sexual abuse of people who are living with intellectual disabilities may be compounded by hurdles to obtaining police intervention, legal protection, or prophylactic care—communication or access hurdles that non-disabled individuals do not face.

### Serious Mental Illness

Data on HIV/AIDS prevalence among people with serious mental illness continue to evolve. In the 1990s, studies found that people with serious mental illness faced elevated risks for HIV infection, estimating that prevalence ranged between 4% and 23% in urban institutional settings.<sup>22</sup> Since then, other studies have focused on the epidemiology of serious mental illness and HIV comorbidity. Broadly, this research has found that HIV prevalence among people with schizophrenia and other types of serious mental illness is higher than that of the general population, but not as high as earlier studies predicted. In 2001, a multi-site study in the U.S. found HIV prevalence among people living with serious mental illness to be 5% in metropolitan areas and 1.7% in non-metropolitan areas.<sup>23</sup> Another recent study that utilized Medicaid claims found that almost 2% of beneficiaries diagnosed with schizophrenia in eight metropolitan areas had also been diagnosed with HIV/AIDS, though there was wide geographic variation in prevalence.<sup>24</sup> One of the factors that may elevate risk of HIV infection among people living with serious mental illness is substance abuse, as approximately 34.5% of people living with serious mental illness engage in at least one type of substance abuse.<sup>25</sup>

In one study, people with schizophrenia exhibited greater gaps in knowledge about HIV/AIDS than the general population, and certain misconceptions about HIV transmission were correlated with HIV risk behavior.<sup>26</sup> However, research has demonstrated that sexual health education for people with severe mental illness can be effective, confirming that provision of accurate information about HIV and sexuality is critical to the health of people with mental illness.<sup>27</sup>

### Strategies for Addressing Barriers

While the problems outlined are numerous and complex, none are beyond remedy. Implementing change to lower risk of HIV infection and expand access to HIV/AIDS care and treatment services for people living with disabilities begins at the individual level. Recognition of sexuality as a human constant, regardless of disability, is imperative. Training and education for health care providers on physical, sensory, and intellectual disability issues is also critical. This may encompass expanding providers' knowledge of how to adapt communication for maximally productive interaction with people who are living with disabilities and educating providers about additional community health care resources that are available for people who are living with disabilities. Changes in health care provision must incorporate the desires of patients—the first step for providers may be to ask patients living with physical, sensory, or intellectual disabilities how they can be better served. Outside of the clinical setting, additional resources and greater support services are needed for health educators.

While many health educators who work with people who are living with disabilities, particularly intellectual disabilities, want to facilitate sexual empowerment, they also struggle to balance limitations that result from inability to consent and vulnerability to

sexual abuse.<sup>28</sup>

It is important to keep in mind that the challenges individuals with physical, sensory, or intellectual impairments face in accessing HIV/AIDS prevention and treatment resources will vary depending on the social, cultural, and economic environment in which they live. Nevertheless, as we have discussed, there are primary barriers that are consistent across environments. Additional scientific research on HIV/AIDS and disabilities is needed to gain a more accurate landscape of this portion of the HIV/AIDS epidemic, and to develop and implement new effective, inclusive, and cost-efficient policy changes.

*Heather J. Heldman is an Arthur Russell Morgan Fellow for International Human Rights at the University of Cincinnati College of Law. She holds a B.A. in Ethics, Politics, and Economics and an M.P.H. in Global Health from Yale University.*

*Hannah Slater is a third year History of Science, History of Medicine major and Global Health Fellow at Yale University.*

*For correspondence:  
hjhheldman@aya.yale.edu  
hannah.slater@yale.edu*

***Recognition of sexuality as a human constant, regardless of disability, is imperative.***

EDITOR: ROBERT VALADÉZ

ASSISTANT EDITOR: NATHAN SCHAEFER

ART DIRECTOR: ADAM FREDERICKS

*GMHC Treatment Issues*

is published by GMHC, Inc.

All rights reserved.

Noncommercial reproduction is encouraged.

GMHC Treatment Issues

446 W. 33 Street, New York, NY 10001

gmhc.org

© 2011 Gay Men's Health Crisis, Inc.



## References

- Zulu, W. "I Had Polio. I Also Have Sex." Editorial. *New York Times*, 19 June 2011, New York ed., WK10. <<http://www.nytimes.com/2011/06/19/opinion/19zulu.html>>.
- UNAIDS (2009) Disability and HIV Policy Brief. Geneva, UNAIDS.
- US Department of Health and Human Services. [http://www.hhs.gov/od/about/fact\\_sheets/stdchapter25.html](http://www.hhs.gov/od/about/fact_sheets/stdchapter25.html)
- UNAIDS (2009) Disability and HIV Policy Brief. Geneva, UNAIDS.
- Rohleder P. "Educators' ambivalence and managing anxiety in providing sex education for people with learning disabilities." *Psychodynamic Practice*, 2010; 16(2):165–182.
- UNESCO (2007) Education for All Global Monitoring Report 2008 UNESCO Paris.
- UNAIDS (2009) Disability and HIV Policy Brief. Geneva, UNAIDS.
- Morrison EH, George V, Mosqueda L. "Primary care for adults with physical disabilities: perceptions from consumer and provider focus groups." *Family Medicine*. 2008;40(9):645–651.
- Grabois EW, Nosek JA, Rossi CD. "Accessibility of primary care physicians' offices for people with disabilities." *Archives of Family Medicine*. 1999;8:44–51.
- Chan L, Doctor JN, MacLehose RF, Lawson H, Rosenblatt RA, Baldwin LM, et al. "Do Medicare patients with disabilities receive preventive services? A population-based study." *Archives of Physical Medicine and Rehabilitation*. 1999;80(6):642–646.
- Becker H, Stuijbergen A, Tinkle M. "Reproductive health care experiences of women with physical disabilities: a qualitative study." *Archives of Physical Medicine and Rehabilitation*. 1997;78 (12 Suppl 5):S26–S33.
- Hanass-Hancock J and Satande L. "Deafness and HIV/AIDS: a systematic review of the literature." *African Journal of AIDS Research*. 2010; 9(2):187–192.
- Erting, C. J. "Deafness and literacy: Why can't Sam read?" *Sign Language Studies*. 1992;75:97–112.
- Bat-Chava Y, Martin D, Kosciw JG. "Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people." *AIDS Care*. July 2005;17(5):623–634.
- Barnett S, McKee M, Smith SR, Pearson TA. "Deaf sign language users, health inequities, and public health: opportunity for social justice." *Preventing Chronic Disease*. 2011;8(2). [http://www.cdc.gov/pcd/issues/2011/mar/10\\_0065.htm](http://www.cdc.gov/pcd/issues/2011/mar/10_0065.htm). Accessed September 20, 2011.
- Lezzoni LI, O'Day BL, Killeen M, Harker H. "Communicating about health care: observations from persons who are deaf or hard of hearing." *Annals of Internal Medicine*. 2004;140: 356–62.
- Nzegwu, F. (2004) "The experience of visually impaired users of the NHS." Guide Dogs for the Blind Association.
- Philander JH, Swartz L. "Needs, barriers, and concerns regarding HIV prevention among South Africans with visual impairments: a key informant study." *Journal of Visual Impairment and Blindness*. 2006; 100: 111–115.
- McGillivray, J. A. "Level of Knowledge and Risk of Contracting HIV/AIDS Amongst Young Adults with Mild/Moderate Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities*. 1999;12: 113–126.
- Ibid.
- US Department of Justice. [https://www.ncjrs.gov/ovc\\_archives/factsheets/disable.htm](https://www.ncjrs.gov/ovc_archives/factsheets/disable.htm)
- Cournos F, McKinnon K. "HIV seroprevalence among people with severe mental illness in the United States: A critical review." *Clinical Psychology Review*. 1997;17:259–269.
- Rosenberg SD, Goodman LA, Osher FC, Swartz MS, Essock SM, Butterfield MI, Constantine NT, Wolford GL, Salyers MP. "Prevalence of HIV, hepatitis B and hepatitis C in people with severe mental illness." *American Journal of Public Health*. 2001;91:31–37.
- Walkup JT, Akincigil A, Amin S, Hoover D, Siegel M, Crystal S. "Prevalence of diagnosed HIV disease among Medicaid beneficiaries with schizophrenia in U.S. metropolitan areas." *Journal of Nervous and Mental Disease*. 2010;198:682–686.
- Rosenberg SD, Trumbetta SL, Mueser KT, Goodman LA, Osher FC, Vidaver RM, et al. "Determinants of risk behavior for human immunodeficiency virus/acquired immunodeficiency syndrome in people with severe mental illness." *Comprehensive Psychiatry*. 2001;42(4): 263–271.
- Grassi L, Pavanati M, Cardelli R, Ferri S and Peron L. "HIV-risk behaviour and knowledge about HIV/AIDS among patients with schizophrenia." *Psychological Medicine*. 1999; 29: 171–179.
- Higgins A, Barker P and Begley CM. "Sexual health education for people with mental health problems: what can we learn from the literature?" *Journal of Psychiatric and Mental Health Nursing*. 2006;13: 687–697.
- Rohleder P. "Educators' ambivalence and managing anxiety in providing sex education for people with learning disabilities." *Psychodynamic Practice*, 2010; 16(2):165–182.