AIDS Education and Training Center
National Multicultural Center
HOWARD UNIVERSITY COLLEGE OF MEDICINE

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AETC-NMC NETWORK e-NEWS

Your Connection to Ensuring Cultural Competence in HIV Focused Healthcare

CULTURAL COMPETENCE:
The Burden of Disabilities and HIV/AIDS among Minority Populations

According to the Centers for Disease Control and Prevention (CDC), it is estimated that 20% of adults in the U.S., or 1 in 5 individuals, have some degree of disability. Moreover, based on CDC's surveillance data, a significant portion of people with HIV/AIDS and disabilities are from the various racial and ethnic groups of this country.

HIV/AIDS has been identified in virtually every racial and ethnic population, every age group, every socioeconomic group, and in every state in the United States.

Moreover, studies by the CDC's National Prevention Information Network reveal that individuals with disabilities are assumed to be at little or no risk for HIV infection, and thus have not typically been included in HIV/AIDS prevention and outreach efforts.

Another commonly assumed myth is that persons with disabilities are not sexually active, do not use intravenous drugs or alcohol, and are at low-risk for abuse or violence. But research shows that individuals with disabilities are just as equal or at increased risk of acquiring HIV/AIDS as the general population.

Persons with disabilities are just as likely as their able body peers to be sexually active and to use drugs and alcohol;

Homosexuality and bisexuality appear to occur at the same rate among individuals with and without disabilities; and

Persons with disabilities are more likely than persons without disabilities to be victims of violence or rape. Further, they are less likely to obtain police intervention, legal protection, or prophylactic care.

The lack of culturally and linguistically appropriate HIV/AIDS education, prevention, and treatment services for persons with disabilities

The existing health care system is not sufficiently responsive to the cultural and linguistic needs of persons with disabilities and HIV/AIDS. As a result, access to education, prevention, screening, diagnosis, treatment, and services for disabled individuals with HIV/AIDS and other sexually transmitted diseases are quite limited. Some of these limitations are as follows:

Health promotion and prevention materials are written at high reading levels for persons with disabilities and HIV/AIDS. According to the Center of Disease Control National Prevention Information Network and the World Bank Organization, the global literacy rate for adults with disabilities is as low as 3%. For racial and ethnic groups, low literacy rates compound their ability to understand and comprehend health prevention messages and approaches.

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Please visit our website (**www.aetcnmc.org**) for more information about our work and to register for upcoming Cultural Competency Training in HIV Management.

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CULTURAL COMPETENCE:
The Burden of Disabilities and HIV/AIDS among Minority Populations (*continued*)

Additionally, health promotion and prevention materials are not written in a culturally and linguistically appropriate manner to reach the targeted audience.

- Medical forms for persons with disabilities and HIV/AIDS are often inaccessible to racially and ethnically diverse individuals (e.g., Braille or interactive technology, translation of medical forms for non-English speakers).
- The lack of sufficient minority health professionals to meet the health care needs of racially and ethnically diverse individuals with disabilities and HIV/AIDS continue be a workforce barrier.
- Effective communication may be compromised as a result of limited availability of interpreters for persons who are deaf or hard of hearing, and for non-English speakers.
- Transportation and locality of clinics complicate access to specialized treatment for persons with disabilities and HIV/AIDS.

Howard University's AIDS Education and Training Center-National Multicultural Center (AETC-NMC) recognizes the burden that disabilities and HIV/AIDS has among minority populations and in society as well. Developing the cultural competencies skills of Clinicians and other health practitioners to provide quality care to persons with disabilities and HIV/AIDS is one of the Center's top priorities. Resources developed by the AETC-NMC include a webcast on ***Cultural Competence: Strengthening the Clinician's Role in Delivering Quality HIV Care to People with Disabilities***. The speakers of this training discuss the implications of Americans with Disabilities Act for providing clinical care, define disability in the context of HIV, describe prevalence and clinical management of HIV for people living with pre-existing disabilities and HIV, and discuss strategies for providing culturally competent care to people living with HIV and visual, hearing, mobility, speech/language, cognitive, and/or emotional disabilities. Visit **www.aetcnmc.org** to view the webcast and other related resources.



Voices from the Field Interview

Dr. Paul Nathenson



1. Briefly describe your current work in the field of cultural competency and HIV. (Whom do you serve? What services do you provide? What impact do you perceive? Length of service)

I have been a registered nurse since 1982 and have spent the past 25 years working in the field of medical rehabilitation. I currently work at Madonna Rehabilitation Hospital in Lincoln, Nebraska where we specialize in spinal cord injury, traumatic brain injury, and pediatric rehabilitation, as well as comprehensive general rehabilitation. Services are provided by an interdisciplinary team inclusive of nursing, physical therapy, occupational therapy, speech-language services, neuropsychology, and nutrition therapy. The services are augmented by driver re-training programs, therapeutic recreation programs, and assistive technology. Our facility has vast resources including advanced technology such as a Lokomat, a robotic device used for neuro muscular re-education. Due to the breadth of our specialized rehabilitation services we provide care to persons with complex medical and rehabilitative from 32 states. This has a significant impact for there are only a handful of facilities that provide this level of specialized rehabilitation programs and services. After 12 years at Madonna I developed an acquired disability secondary to surgery for a brain tumor. I spent 6 weeks in inpatient rehabilitation and more than a year as an outpatient to re-learn how to walk again. This provides me a unique perspective on disability and rehabilitative care.

2. What cultural factors affect clinical care management for your client population?

The primary cultural factors are working with persons with a variety of impairments including visual, hearing, mobility, emotional, psychiatric, and cognitive. These impairments are often complicated by medical co-morbidities, financial hardship, and socioeconomic issues. Additional cultural factors include persons with English as a second language or persons who do not speak English where interpreter services are utilized. Some cultural factors are related to health practices and beliefs which are assessed and accommodated. In many cases housing is provided at reduced cost or no cost so that families from out of state can be near their loved ones.

3. *What do you believe are the key cultural health issues in the population(s) you serve?*

In working with people with disabilities some common health concerns include incontinence of bowel and bladder, bowel and bladder program management and re-education, skin and wound management, fall prevention, and provision of highly specialized services including assistive technology and augmentative services for persons with paralysis, speech impairment, hearing impairment, swallowing problems or other health related or functional complications.

4. *Which culturally competent practices facilitate providing quality HIV care to your clients?*

Universal precautions are used at all times with all patients, so even when HIV diagnosis is known the person served with HIV is not treated differently than any other patient. Universal precautions start with hand washing and use of gown, gloves, and other protective gear when there is exposure to blood a/or body fluids. All persons served are treated with dignity and respect.

5. *What are some of the most important lessons you have learned about what alienates or pushes your client population away from care? Can you describe some situations that taught you these lessons?*

Lack of hope is the most critical barrier to overcome. For example, we had a couple from out of state that came to us with a young child severely disabled secondary to a case of shaken baby syndrome that occurred at a day care center. The mother was grateful for the treatment plan to work on the child's functional blindness, inability to articulate speech, and impaired developmental process for crawling walking and mobility development. The quote from the mother was not just her appreciation of her child' progress in rehabilitation but the culture of hope to replace as she said, "the litany of cant's and won'ts, and probably nots."

6. *How do we, as HIV providers continue to learn and be open to the cultural group(s) you serve while responding quickly and appropriately should a situation arise?*

Cultural competency is a critical strategy in closing the disparities gap in health care. Health care providers and health educators can come together and talk about health concerns without cultural differences hindering the conversation, but enhancing it. When we create health care services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients we can help bring about positive health outcomes for persons with HIV and disability. We must also be mindful that cultural competence is a developmental process that evolves over time. Therefore we must be vigilant in our efforts to overcome personal bias and work towards learning about the health beliefs and values of persons in various cultures that are different from our own. As we travel this continuum we move through the phases of tolerance to acceptance to true appreciation of the differences we see in others.

7. *If you could give a new clinician who wants to serve your client population one piece of advice, what would it be?*

Always be sure to introduce yourself and explain your role and tasks with person. Ask the person how they would like to be addressed, until you have permission address formally, Mr. Smith, Mrs. Smith, and Ms. Smith. Consider the patient the expert on his/her condition. If the client is in a wheelchair try to be seated or crouch down to be on eye level with person.

If you are in a health care facility you will be using universal precautions, remember to provide an explanation that universal precautions are used with all patients. The reason is that any patient may have an infectious process for example, hepatitis C, tuberculosis, MRSA, VRE, other resistant organisms. This means you will use gloves, also mask, goggles depending on assessed exposure to body fluids. Most importantly, always show respect to others.

***Paul Nathenson, ND, RN, CRRN**, HN-BC is the Vice President of Integrative Health and Community Services at Madonna Rehabilitation Hospital in Lincoln, Nebraska. He has served in the capacity of Vice President at Madonna for the past 19 years. Dr. Nathenson is currently a member of the board of directors of the Commission on Accreditation of Rehabilitation Facilities (CARF) where he served since 2009. In addition to his work at Madonna Dr. Nathenson is involved in a wellness and integrative health practice in Lincoln, Nebraska.*





Voices from the Field Interview

Dr. Barbara Johnston



1. ***Briefly describe your current work in the field of cultural competency and HIV***

I am the Associate Medical Director and physician in the Mount Sinai Comprehensive Health Program Downtown (MSCHP-Downtown), Manhattan, New York. I and many of the physicians and staff in our Center, have worked in HIV/AIDS since the early 80's. We take care of over 3500 patients; the majority of them African American and Latino. In our Downtown site 60% are gay or transgender. HIV primary care is provided by HIV Specialists, psychiatrists with experience in addiction, psychologists, nurses, social workers, a gynecologist and specialists dealing with the most important medical co-morbidities—Hepatitis C, neurologic, gastroenterologic and cardiac disease. We also stress sexual health and monitoring for STDs, and run a surveillance program for anal cancer, given our high risk population, particularly MSM. Because of this multidisciplinary team approach, we see the impact in direct outcome measures like high retention rates and viral suppression rates.

2. ***What cultural factors affect clinical care management for your client population?***

Many newly diagnosed young MSM as well as transgender male to female are coming into care. On the other end of the age spectrum, many patients are survivors 20-30 years, and beginning to experience diseases of aging. Forty percent of our population is Latino, many Spanish dominant.

3. ***What do you believe are the key cultural health issues in the population(s) you serve?***

For the youth population, issues relating to sex and sexuality, epidemics of sexually transmitted disease, as well as issues of substance use linked to increased risk behavior and decreased adherence. Also, issues of identity and mental health are included among these important factors. Specifically for the Latino population, language fluency and practices sensitive to cultural beliefs are also key cultural health issues.

4. ***Which culturally competent practices facilitate providing quality HIV care to the clients you serve?***

A commitment to see the patient the same day they test positive is important to patients and referring agencies. This is so because early engagement leads to better linkage and retention in care. Cultural competence as it relates to the youth population includes a dedicated Nurse Practitioner, Physician, and social worker to provide ways for them to connect, like text messaging and peer support groups led by the social worker. For the Latino population staff and physicians speak the language and are familiar with the culture, and a weekly group is headed by Latina social workers for Spanish speaking women with HIV. In addition, the staff members participate in forums led by an experienced physician, a transgender activist, and health care providers who treat patients with hormonal therapy in issues related to the transgender population. There are also monthly Consumer Advisory Board meetings to advise--on improvements in the practice, and greatly contributes to the culture by sponsoring community events, such as World AIDS Day, and forums inviting staff to discuss issues with patients. A recent showing of Oscar-award nominated film "Surviving a Plague" in the Center had significant archival footage shot by one of our patients.

5. ***What are some of the most important lessons you have learned about what alienates or pushes your client population away from care? Can you describe some situations that taught you these lessons?***

Patients are sometimes frustrated with long waiting times. We convened a Staff Performance Improvement Project to make substantive changes and have an all staff alert for patients waiting longer than optimal times in order to expedite their visit.

6. ***How do we, as HIV providers continue to learn and be open to the cultural group(s) you serve while responding quickly and appropriately should a situation arise?***

It is important to demonstrate a nonjudgmental attitude towards patients sexual behaviors, substance use, mental issues, while giving them the best education, and using interviewing techniques such as motivational interviewing to help alter behaviors which may be risky. It is helpful to use the patients' language to assess risks and to offer concrete approaches and resources for those with mental health or substance issues.

7. ***How do you propose to build bridges between various cultures in your community to further the HIV prevention efforts outlined in the National HIV/AIDS Strategy?***

We offer concrete services to prevent HIV. For example we have, for many years, provided PEP, post-exposure prophylaxis, assess risks, provide counseling, STD screening and treatment to further lower risks. STI testing was also incorporated into our HIV testing, realizing that patients were at high risk and this elevates their chance of acquiring HIV. Gay Men's Health Crisis, AIDS Service Center and others have partnered with us on test, link, and treat strategies to lower the high risks of transmission in early stages of HIV. In a new prevention grant GMHC, Sinai Uptown (the Jack Martin clinic) and Chelsea Downtown will enter into partnership to test, administer PEP as appropriate, and work with the person on further interventions to prevent future seroconversion.

8. ***If you could give a new clinician who wants to serve your client population one piece of advice, what would it be?***

Our population is interesting, diverse, sometimes challenging therefore it is always key to listen to the community and determine the need, then seek the right personnel and programs to meet them.

Barbara Johnston, MD *has been a physician in HIV/AIDS for thirty years and is Associate Medical Director at Mount Sinai Comprehensive Health Program Downtown in Manhattan. She has been involved for many years with the New York AIDS Institute Quality Advisory Committee and Medical Criteria Guidelines Committee.*

Tune-In or Join-In: It's Your Choice: (HIV and Cultural Competency-Focused Webinars/Webcasts/Events)

Upcoming AETC-NMC Webinars (Spring 2013)

- Cultural Competence: Strengthening the Clinician's Role in Delivering Quality HIV Care within API Communities (Burmese) – Spring 2013
- Cultural Competence: The Impact of Stigma on Patients with HIV/AIDS – Spring 2013

The following information is disseminated for informational purposes only and does not constitute an endorsement by the AETC-NMC:

APRIL 1–30, 2013

National Minority Health Month "Health Equity Can't Wait. Act Now in Your Community!"
http://minorityhealth.hhs.gov/actnow/

STD Awareness Month

http://www.cdc.gov/Features/STDAwareness/

APRIL 10, 2013

26th Anniversary HIV and AIDS on the Front Line Conference
UC Irvine
Irvine, CA
http://www.hivconference.org/

APRIL 13, 2013

Annual CCO HIV and Hepatitis C Symposium: Regional Workshop
New York Marriott Downtown
New York, NY
http://www.clinicaloptions.com/

APRIL 25–26, 2013

Health Disparities Research at the Intersection of Race, Ethnicity, and Disability: A National Conference
Washington, D.C.
www.ohsu.edu/projectintersect

APRIL 25–28, 2013

National Hispanic Medical Association 17th Annual Conference "Strategies to Build Patient-Centered Medical Homes, Curriculum and Research to Improve the Health of Hispanics"
Washington, D.C.
http://www.nhmamd.org/index.php/events/17th-annual-conference

MAY 1–31, 2013

National Hepatitis Awareness Month
http://www.cdc.gov/hepatitis/HepAwarenessMonth.htm

MAY 7–9, 2013

National Council of Urban Indian Health Leadership Conference
Arlington, VA
www.ncuih.org

MAY 17–18, 2013

National Transgender Health Summit
Oakland, CA
http://transhealth.ucsf.edu/trans?page=ev-summit2

MAY 17, 2013

23rd Annual HIV/AIDS Clinical Conference – Henrietta
RIT Inn & Conference Center
Henrietta, NY
http://transhealth.ucsf.edu/trans?page=ev-summit2

MAY 18, 2013

HIV Vaccine Awareness Day
http://www.niaid.nih.gov/news/events/hvad/Pages/default.aspx

MAY 19, 2013

National Asian & Pacific Islander HIV/AIDS Awareness Day
http://www.aids.gov/news-and-events/awareness-days/asian-pacific-islander/

Hepatitis Testing Day
http://www.cdc.gov/hepatitis/testingday/

AIDS Walk New York
http://www.aidswalk.net/newyork

JUNE 2–4, 2013

8th International Conference on HIV Treatment and Prevention Adherence
Eden Roc Renaissance Hotel
Miami, Florida, USA
http://www.iapac.org/

JUNE 6–8, 2013

2013 North American Refugee Health Conference
Toronto, Canada
http://www.researchraven.com/conference/2013/6/6/2013-northamerican-refugee-health-conference.aspx

JUNE 8, 2013

Caribbean American HIV/AIDS Awareness Day
http://aids.gov/news-and-events/awareness-days/caribbean-american/

JUNE 17-19, 2013

NIHB 2013 National Tribal Public Health Summit

Maps, Moccasins & Milestones: Our Journey to Wellness
Seminole Hard Rock Hotel and Casino
Hollywood, FL
http://www.nihb.org/communications/phs_2013.php

JULY 10–13, 2013

2013 American Association of Naturopathic Physicians Conference
Keystone, Colorado
http://www.naturopathic.org/content.asp?pl=10&sl=625&contentid=625

JULY 21, 2013

National Clinicians HIV/AIDS Testing and Awareness Day
http://www.theaidsinstitute.org/node/474



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