

HRSA Care ACTION

PROVIDING HIV/AIDS CARE IN A CHANGING ENVIRONMENT

Mitigating Health Disparities Through Cultural Competence

“Rosa,” who recently came to New York from Puerto Rico, goes to her local clinic and is relieved to find that the clinic provides an interpreter, because her English is poor. She explains to the doctor that she has fatiga, but she is perplexed when she is counseled to “get a little more sleep” to deal with her illness. Fortunately, she persists in describing her ailment, and discovers that the interpreter, who is from Spain, has been translating fatiga as “tired”—in Puerto Rico, however, the word fatiga is used to describe wheezing from asthma.

The recent Institute of Medicine report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* states that “racial and ethnic minorities tend to receive a lower quality of health care than nonminorities, even when access-related factors, such as patients’ insurance status and income,” are taken into account.¹ The report cites studies finding that African Americans and Hispanics are less likely than whites “to receive appropriate cardiac medication, undergo coronary artery bypass surgery, and receive hemodialysis and kidney transplantation” and are more likely than whites “to receive a lower quality of basic clinical services, such as intensive care.”²

According to *Healthy People 2010*, “current information about the biologic and genetic characteristics of African

Americans, Hispanics, American Indians, Alaska Natives, Asians, Native Hawaiians, and Pacific Islanders does not explain the health disparities experienced by these groups compared with the white, non-Hispanic population in the United States. These disparities are believed to be the result of the complex interaction among genetic variations, environmental factors, and specific health behaviors.”³ The report lists some troubling findings. Among them:

Although Asians and Pacific Islanders (A/PIs) tend to be one of the healthiest populations in the United States, different groups within this population vary widely on health indicators. For example, women of Vietnamese origin have cervical cancer rates nearly five times that of white women.

The infant mortality rate of American Indians and Alaska Natives is almost double that of whites, and the infant death rate among African Americans is more than twice as high as that of whites.

Compared with whites, Hispanics living in the United States are almost twice as likely to die from diabetes, and they have higher rates of high blood pressure and obesity.

In light of the research on health disparities among different minority groups, it is not surprising that a recent survey by the Commonwealth Fund found that African Americans, Asian Americans, and Hispanics “are more likely than

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The Bridges Project, New York, NY

The Bridges Project at the Asian and Pacific Islander Coalition on HIV/AIDS received funding through the CAREAct's Special Projects of National Significance (SPNS) program in 1996 to address the problems of Asians and Pacific Islanders (A/PIs) living with HIV/AIDS in the New York City metropolitan area. The project gives special attention to those who have limited or no English proficiency and who have difficulty accessing HIV services.

A/PIs are the fastest growing racial group in New York City. Despite their growing presence, A/PIs have difficulty accessing HIV-related services. Cultural attitudes and experiences, coupled with a fragmented and daunting health care delivery system, can make accessing culturally and linguistically appropriate care difficult. As a result, A/PIs living with HIV disease enter care at a later stage of disease than any other racial or ethnic group in New York City.

The Bridges Project improves access to care by integrating medical and social services for people living with HIV disease. Connections with comprehensive service sites and a referral services network comprising 80 individual bilingual providers have been created. The project also offers comprehensive case management services. The project increases levels of cultural competency and HIV sensitivity among providers through training.

Peer advocates are an important component of the program; they are recruited through word of mouth and advertisements in appropriate newspapers and receive training about HIV disease and related issues, such as homophobia. To bridge language barriers, bilingual peer advocates interpret between providers and patients. At this point, coalition staff and peer advocates have the capacity to handle approximately 15 different languages or dialects.

According to John Chin, a consultant to the coalition, the Bridges Program faces many challenges: "The providers [in our training program] wanted concrete rules for working with A/PIs. There are so many different languages and cultures that it was difficult. Part of the training was about how to work with a lay interpreter, such as where to sit and to talk directly to the patient and not to the interpreter."

whites to experience difficulty communicating with their physician, to feel that they are treated with disrespect when receiving health care, to experience barriers to access to care such as lack of insurance or not having a regular doctor, and to feel they would receive better care if they were of a different race or ethnicity."⁴ The survey found that 27 percent of Asian Americans experience communication difficulties such as "not understanding the doctor, not feeling the doctor listened to them, or [having] questions for the doctor [that they] did not ask." Fewer than half of the Hispanics surveyed (45 percent), but 59 percent of whites, reported that they found it easy to understand information from their providers.

These findings and others like them are not news to people concerned with the care of individuals living with HIV disease. Study after study has demonstrated unequal access to care and poorer health outcomes among certain segments of the HIV-positive population. For example, analysis of data from the HIV Cost and Services Utilization Study revealed that compared with nonminorities, women and African Americans with HIV disease who are receiving care are less likely to receive antiretroviral therapy, protease inhibitors, and prophylaxis for pneumocystis pneumonia. These disparities remained even after adjusting for gender, age, education, and insurance coverage.⁵ Follow up in 1997 revealed improvements, but African Americans and Hispanics were still only about half as likely as whites to participate in HIV clinical trials or to get experimental

medicines. Other minorities were also less likely than whites to get experimental treatment.⁶

Disparities in access to quality care extend beyond race and gender to segments of the population that are often marginalized. For example, HIV-infected injection drug users are less likely to receive antiretroviral therapy than non-drug users are.⁷ It follows that disparities in access to quality HIV care are related to disparities in survival, which have been reflected in AIDS mortality data for some time.⁸

Eliminating disparities in health outcomes is a challenge. No single solution will remedy the problem because the problem has no single cause. The many barriers separating individuals from quality care include lack of health information; comorbidity involving other serious health problems, such as addiction and mental illness; attitudes about accessing health care; the shortage of health care providers; and poverty. Cultural competency is also a factor.

Cultural differences between providers and patients affect the provider-patient relationship.⁹ How patients feel about the quality of that relationship is directly linked to patient satisfaction, adherence, and subsequent health outcomes."^{10,11,12} It has also been shown to influence whether patients continue to see a physician or even remain enrolled in a health care plan. If the cultural differences between patients and providers are not

recognized, explored, and reflected in the medical encounter, patient health outcomes may suffer.^{13,14,15,16,17}

Bridging cultural differences presents a challenge, however. One problem that both patients and providers bring to their interaction is that of biases, many of which are rooted in culture. For example, some patients may be uncomfortable dealing with providers of the opposite sex because of the gender roles prescribed in their culture. Some providers may be uncomfortable providing care to sexual minorities; likewise, some patients may be reluctant to go to providers who are sexual minorities. Culturally rooted biases of all kinds—whether they involve attitudes toward population groups or opinions about the utility of complementary and alternative therapies—can inhibit clear communication between the patient and provider and may lead to adverse health outcomes.

An elderly Native American woman is being assessed for pneumonia in a clinic. The physician orders x-rays of her lungs. He holds them up to her so she can see them. To the doctor, they are just another diagnostic tool, but

to the patient, they are an affront: In her culture, it is taboo to have pictures taken.

Culture and Health

Culture can be thought of as an integrated pattern of learned beliefs and behaviors that are shared among a group of people. Beliefs and behaviors include styles of communication, ways of interacting, views on roles and relationships, values, practices, and customs.^{18,19} Culture shapes how we explain and value our world; it is the lens through which we give our world meaning.²⁰

Many people may think of culture primarily in terms of their culture of origin—the environment and belief systems within which they were raised. Beyond cultures of origin, people are influenced by the many group cultures to which they belong. These can include kinship networks; ethnic, gender, or sexual orientation identity groups; religious affiliations; social classes; geographic regions; occupation; and disability.²¹ These variables influence us in many ways

Fenway Community Health, Boston, MA

Fenway Community Health was founded by community activists in 1971 in the Fenway neighborhood of Boston. Today it offers comprehensive integrated services with an emphasis on caring for lesbian, gay, bisexual, and transgender (GLBT) populations. Fenway has developed cultural competency standards for treating sexual minorities and has created programs to educate both providers and community members about specific GLBT health concerns. Fenway is one of only nine GLBT-specific Community Health Centers in the United States.

Fenway collaborated with the Gay, Lesbian, Bisexual, and Transgender (GLBT) Health Access Project to improve access to health and social services for GLBT individuals and their families. Funded by the Massachusetts Department of Public Health, the GLBT Health Access Project was developed to

eliminate barriers to health care and prevention services for the GLBT community;
increase community awareness of GLBT health issues; and
promote appropriate health norms for GLBT people.

Working with providers and consumers from across the community, the Health Access Project developed the *Community Standards of Practice for Provision of Quality Health Care Services for Gay, Lesbian, Bisexual, and Transgender Clients* (<http://www.glbthealth.org>). The *Community Standards* provide a set of core principles and quality indicators that cover administrative practices and service delivery components, such as personnel policies, clients' rights, intake and assessment procedures, confidentiality, and community outreach and involvement. Agencies can use the standards to assess their existing practices and address potential barriers to care for GLBT clients.

In discussing the Health Access Project's training program, Rhonda Linde, Ph.D., Fenway's coordinator of mental health training and research, says: "It helped them [the agencies] understand their own attitudes and beliefs and the steps they can take as practitioners to address potential barriers."

Regarding GLBT health care, Dr. Linde stated, "Whether it be anecdotal information, information from clients, or actual research, [GLBT] and questioning people's fear of facing prejudice, discrimination, or ignorance from health care providers makes them more hesitant to seek out health care services. Once they access services, they may withhold key information because they are afraid to 'come out,' [but doing so] may have serious consequences to their emotional and physical well-being. Our goal is to educate agencies and providers so that they can provide welcoming and encouraging, competent care."

and are reflected in what we think about health care and the people who provide it.

Culture influences how people receive health education messages, perceptions about HIV risk, acceptability of risk-reduction strategies, negotiation of safer sex practices, and health-seeking behavior. For example, HIV prevention messages targeted to American adolescents are most effective when they are explicit and direct, but the same frank language will not work for all groups.

Consider the influence of *marianismo* among some Hispanic women. The cultural aspects of *marianismo* make women subservient to men, and women often feel powerless to act without the consent of the men in their life. *Marianismo* can perpetuate stereotypical expectations of virginity and lack of sexual desire among many Hispanic women. Consequently, the idea of discussing their sexual practices and preferences with a clinic worker may intimidate some women so much that they will avoid seeking HIV information and testing.

At the onset of the AIDS epidemic, negative stereotypes about homosexuality were sometimes manifested in provider attitudes. Some providers were uncomfortable treating men who have sex with men. Conversely, patients feared discussing their sexual behavior with their providers. Stories of the partners of dying men being prohibited from visiting intensive care wards were common. Cultural differences on both sides of the provider-patient relationship led to alienation from the medical system of people with HIV disease and feelings that providers were not sensitive to their patients' needs.

The idea that disease is caused by organisms that are invisible to the naked eye (i.e., "germs") may be a given for many people in the United States, but the idea is not necessarily understood and accepted in all cultures. In some Caribbean countries, for example, HIV disease is seen as a curse, and people known to have the disease are often ostracized. In many societies, traditional healing practices—which can include everything from prayers to herbal remedies to animal sacrifice—exist alongside, or instead of, traditional clinical medicine. Immigrants bring these practices and beliefs with them when they come to the United States, and even among second-generation families, the traditions may continue. Moreover, many people, regardless of culture of origin, have a generally poor understanding of disease causation, progression, and appropriate therapies, and spiritual, religious, and moral beliefs may play a role in their understanding of HIV and related matters. Providers must assess patients' knowledge and belief systems and tailor their communication appropriately in order to develop trust as well as provide high-quality care.

In the context of the HIV epidemic, motivating people to seek care is an important part of slowing the spread of HIV infection. Getting people into care and helping them stay in

care over time requires sensitivity to cultural factors—or cultural competence.

"Hector" is originally from El Salvador and only speaks Spanish. He goes to his health clinic to see a physician for HIV care. The physician needs a translator in order to treat Hector, so he calls in the Spanish-speaking receptionist to help. Hector is taken by surprise: The receptionist is related to his boss at work. Now, he fears that she will tell his boss that he is HIV positive and that word will spread through out the small Latino community in his town. He leaves the clinic upset and afraid.

What Is Cultural Competence?

The literature provides many definitions of cultural competence. In 2001, the Office of Minority Health (OMH) of the U.S. Department of Health and Human Services published the *National Standards for Culturally and Linguistically Appropriate Services in Health Care* (available online at <http://www.omhrc.gov/CLAS>), known as the CLAS Standards, which defines cultural competence as

a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. "Competence" implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.²²

Culturally competent individuals and organizations are able to use their knowledge of the health-related beliefs and practices of clients to improve the quality of care they provide. Cultural competency is more than cultural sensitivity or awareness, however. Providers must possess knowledge of and respect for different cultural perspectives as well as skills that are used effectively in cross-cultural situations.^{23,24,25} From an organizational perspective, cultural competency refers to an ongoing commitment or institutionalization of appropriate practice and policies for diverse groups.²⁶

Evidence of an agency's cultural competence may include signs and notices that are in the languages spoken by the consumers, whether it is English, Spanish, or Creole. It may be the agency's providers know that when using a translator, they should make eye contact with the patient, not the translator. It includes not relying on family members—often children—to translate, and instead using translators who have training in health sciences, not the

AIDS Services Center, Anniston, AL

Located in northeast Alabama, the Anniston AIDS Services Center serves a primarily rural, 14-county area. The center was started in 1991 with CARE Act Title III funding; it has expanded to provide care in five satellite clinics throughout the 14 counties.

In a recent interview, Barbara Hanna, M.D., the director of the center, described the changes that the organization has made as the racial and ethnic makeup of its clients has shifted: "There is a large African American population in rural Alabama. . . . We have worked hard to hire a staff that is diverse and reflects the population." Today, approximately half the staff is either African American or Hispanic.

One of the reasons center personnel need to reflect the community, according to Dr. Hanna, is that the clinic is "very close to Tuskegee. It's the only medical study that everyone in the community is aware of. Whenever patients are asked to sign consent forms, the staff is asked, 'What are you going to be doing to me? What am I signing?' The community has all heard of it, and it makes them mistrustful. . . . It's a barrier that they have to step over to enter care."

In addition, says Dr. Hanna, "there is a small enclave of men from Mexico who live year round in the area and work in the textile mills, [and] there are migrants, mostly Puerto Rican, who work in the poultry industry. Plus, a number of Guatemalans have moved into the area and have never heard of HIV. Many of them have never seen physicians." To meet their needs, a Hispanic case manager is on staff.

To better serve the changing population in the area, all staff received cultural competency training. Presenters were brought onsite, and staff members participated in a series of HRSA-sponsored trainings and attended a mandatory 12-week series of Spanish classes. Dr. Hanna added that the AIDS Services Center has addressed its organizational culture, including issues of homophobia, staff members' fear of contracting HIV, and "how to get along with new staff members who were coming in."

first available administrative staff person. It means finding out whether a patient has consulted traditional healers and is taking herbal medications that could interfere with the effectiveness of prescribed drugs.

"Jennifer," who is 16 years old, goes to her family physician because her period has stopped. As the physician is taking her medical history, Jennifer tells her that she is "not sexually active." During the physical examination, the physician notes signs of pregnancy. Upon further discussion, it becomes clear that Jennifer believes premarital sex is a grievous sin and that she is simultaneously in denial about her sexual behavior and terrified that her family or fellow church members will find out. The physician, who is not especially religious, can provide medical advice but has no idea how to reach Jennifer on the emotional or spiritual level, although she can provide referrals. Both patient and doctor end the encounter unsatisfied.

Creating Cultural Competence

No universally effective approach to building cultural competency or creating a culturally competent workplace exists. The cultural competency literature is vast, and approaches to implementation tend to distinguish between

organizations and the providers in an organization. Some programs have focused on structural changes, such as training bilingual and bicultural providers, instituting interpreter services, and developing culturally and linguistically specific materials and health care resources.²⁷ In addition, the literature offers strong support for training providers to care for clients of different sociocultural backgrounds.²⁸ A recent study of HIV-positive sexual minority males found that care seeking, utilization of HIV antiretroviral therapy, and adherence were associated with culturally competent providers.²⁹

Cultural Competence and Quality of Care

Improved quality of care is the outcome measure that indicates whether implementing training programs, policies, and culturally or linguistically appropriate standards makes a difference. A new trend in the literature suggests that using cultural competency in a focused or strategic way can be a helpful adjunct to the quality improvement process. For example, if a program wants to analyze patterns of broken appointments, it might examine variables such as age, gender, or race/ethnicity. If the analysis reveals that adolescents have the highest rate of broken appointments, the program can target specific strategies to this group. Does the clinic need to have weekend hours, when teens can more easily slip away from home? Would providing

Arizona Border Health HIV/AIDS Care Project, Tucson, AZ

The influx of illegal drugs and impoverished migrants has significantly increased the presence of HIV risk factors in the Arizona-Mexico border region. Residents of the region face many barriers to care, ranging from lack of insurance to transportation difficulties to problems with maintaining confidentiality. Few physicians are both knowledgeable about HIV care and adept at working with the many cultural and linguistic differences in the region's population.

The Arizona Border Health HIV/AIDS Care Project (ABHAC), a CARE Act-funded collaboration of agencies, is developing and implementing early intervention and primary medical care services for people affected by HIV in the Arizona-Mexico border region. The project is conducting HIV training with health providers in a number of clinics and Community Health Centers within Arizona; project staff are working with the Arizona AIDS Education and Training Center to conduct the trainings.

Stephen Trujillo, project coordinator for ABHAC, recently described the program's efforts: "There are two aspects of cultural competency. One aspect is the organization's, and the other is the individual's. . . . We did assessments at the Community Health Centers and asked staff, 'What is your perception of the clinic's cultural competency, and what is your perception of yourself?' It was a surprise to find out that the nursing staff thought that the clinics were not delivering culturally competent care."

Trujillo further explained, "We discovered a cultural clash. . . . Providers who practice in rural Community Health Centers that serve minority populations tend to be from countries outside the United States. The patients of the Community Health Centers are from the culture of the community, predominantly Latino. The nurses and the ancillary staff are more likely to be from the culture of the community. They are more attuned to the nuances and perceptions of treatment of the consumers. Usually, the nursing staff and ancillary staff members are themselves members of that minority group."

One example of miscommunication that results from these cultural differences, says Trujillo, is that "Latinos may tend to wait to seek health care until they are very sick, or they may delay seeking care for economic reasons. This clashes with a physician who thinks that the patient is not attuned to their health. Also, physicians from another culture have a different philosophy of care that they learn in medical school in their country of origin."

Trujillo pointed out that providers should assess the patients' degree of acculturation. How long have they lived here? What traditional ways of medical care are they using? Have they used herbs or a curandero [traditional healer]? Providers also need to understand family dynamics in different cultures. For example, Trujillo said, "with recent immigrants who are monolingual Spanish speakers, the children learn English in school. Frequently, the parents rely on their children or a family member to do the interpreting, [but] the father is still the head of the household and must be treated with respect. The provider needs to make eye contact with the person who is ill."

free transportation or reminder calls from caseworkers help? Does the provider reflect a youth-sensitive approach to the clinic's client base?

Many guidelines and tools to help providers move toward higher levels of cultural competence have been developed at the Federal level.

Culturally and Linguistically Appropriate Services in Health Care (CLAS) Standards

OMH's CLAS Standards consist of 14 recommendations³⁰ that can provide a blueprint for health care providers who want to create culturally competent organizations. The CLAS Standards are helpful if race, ethnicity, or language is the focus of efforts to improve cultural competence. Standards of care for the lesbian, gay, bisexual, and transgendered community; substance users; women; or the

deaf are not as readily available, but a variety of publications offer guidance for care providers seeking to learn more about specific cultural groups. Many resources are available on the HIV/AIDS Bureau website at <http://hab.hrsa.gov/publications>.

HIV/AIDS Bureau Efforts

Many programs funded through the Ryan White CARE Act are enrolled in HIVQUAL, a national project sponsored by the Ryan White Title III Program. The project is based on a model of quality improvement consultation that was developed in New York State, and its goal is to improve the quality of care delivered to people living with HIV. A software program developed through the project will analyze data for different subpopulation groups using variables including gender, race/ethnicity, exposure categories, age, viral load, CD4 count, and clinic site.

Providers can use the data for different groups to assess the quality of care patients are receiving, raise their awareness of differential treatment of people from various cultures, and take corrective action, if necessary. For more information on the HIVQUAL Project, visit the HRSA/HAB website at <http://hab.hrsa.gov/special/qualitycare.htm>.

Recent HRSA Initiatives

The Provider's Guide to Quality and Culture, a joint project of Management Sciences for Health and HRSA's Bureau of Primary Health Care, is an interactive, Web-based resource for health care professionals who want to provide high-quality, culturally appropriate care. The guide helps health care providers examine their own cultural beliefs, attitudes, and biases and learn more about how cultural differences may influence clinical outcomes. It also offers an exercise that is geared to helping organizations get started with their efforts to improve cultural competence (see box).

HRSA recently published *Cultural Competence Works*, a new tool to help health care professionals become more culturally and linguistically competent in delivering health care to individuals and families from diverse backgrounds. The document developed from a national competition sponsored by HRSA's Center for Health Services Financing and Managed Care, which identified HRSA-funded programs that respond creatively to the unique needs of a

diverse clientele. *Cultural Competence Works* profiles the practices used to provide culturally competent care and describes an approach to cultural competency that is based on the following eight principles:

1. Define culture broadly.
2. Value clients' cultural beliefs.
3. Recognize complexity in language interpretation.
4. Facilitate learning between providers and communities.
5. Involve the community in defining and addressing service needs.
6. Collaborate with other agencies.
7. Professionalize staff hiring and training.
8. Institutionalize cultural competence.

HRSA encourages providers to examine the strategies to see how they can be adapted to their own programs. *Cultural Competence Works* is available on the Web at <http://www.hrsa.gov/financeMC/ftp/cultural-competence.pdf> or through the HRSA Information Center at 1-888-ASK-HRSA.

In many ways, the issue of cultural competence reflects the enormous tension between what health care actually is in the United States versus what patients would like it to be. Providers of all kinds are generally trained according to a scientific, evidence-based model, which they seek to apply in

Assessing the Cultural Competence of Organizations

The Provider's Guide to Quality and Culture offers the following exercise to help organizations get started with their efforts to improve cultural competence:

Describe the culturally diverse populations your health care organization serves.

Describe the barriers to service delivery you have encountered in serving culturally diverse populations.

Discuss any challenges you have had working with the following groups:

- Providers and staff of culturally diverse backgrounds
- Patients and families of culturally diverse backgrounds
- Natural healers or complementary and alternative medicine healers.

Describe any cross-cultural success stories in the following areas, along with why they occurred:

- Clinical (i.e., situations involving patients, providers, natural helpers, and/or complementary/alternative medicine healers)
- Organizational (i.e., situations involving patients, providers, administrative personnel, or executives).

Describe any policies and procedures you have developed and strategies and resources you have used in serving culturally diverse populations.

Identify areas in which key stakeholders and constituency groups can collaborate to improve the delivery of services to culturally diverse populations.

Source: Culturally competent organizations. In: *The Provider's Guide to Quality and Culture* [MSH Electronic Resource Center Web site]. Quality and Culture Topic 11. Available at: <http://erc.msh.org>. p. 3.

practice. Yet patients often hope to find something very different. In addition, the skyrocketing health care costs often place limits on the time providers are able to spend with patients and can inhibit the development of good provider-patient relationships, even when everyone involved is of the same culture.

The growing awareness of cultural issues and their relation to both individual patient outcomes and population-based health disparities, however, is likely to motivate

providers to acquire new tools to enhance the quality of care, such as different approaches to communicating with patients or greater appreciation of the role of traditional medicine. Improved cultural competency on the part of providers and health care organizations—which has been given considerable attention in the CARE Act community—is an important and, perhaps, decisive component of any approach to mitigating disparities in health access and outcomes among minorities and other underserved populations.

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