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**SIECUS TAKES LEADERSHIP ROLE
IN FIGHTING HIV-POSITIVE NAMES REPORTING**

Mac Edwards

The fear, the apprehension, the shame. They *never* go away. Even when you think they do.

They hit me in the face again this past week—nearly 15 years after I made the agonizing decision to be tested for the HIV virus—as I read and re-read articles indicating the U.S. Centers for Disease Control and Prevention (CDC) would probably soon require the reporting of the names of HIV-positive people in the United States.

“No!” I thought to myself. “They wouldn’t.” If such a “list” had existed in the mid-1980s, I know I would have decided *not* to take the test and would have lived to this day without knowing if my body harbored the HIV virus. It’s bad enough to have to accept the possibility that you have the virus and that you might get AIDS. It’s intolerable to think that your name will be published on an “official list” somewhere.

Luckily, I tested negative. I thank God every day. Since then, I have made a pact to learn as much as I can to protect myself from HIV and AIDS...and to help other people do the same. That’s one of the reasons I am at SIECUS. And one of the reasons I am so proud to tell you that SIECUS is taking a leadership role to fight name reporting.

SIECUS’s Board of Directors has just approved an addition to the *SIECUS Position Statement on HIV/AIDS* that reflects the need to protect the privacy and civil rights of HIV-positive individuals by opposing names reporting. (See page 3.) In addition, this issue of the *SIECUS Report* includes a *Special Report*, “‘Names’ Versus ‘Unique Identifiers’: The ‘How’ of HIV Case Reporting” that explains why using a “unique identifier” system, instead of names reporting, will still accomplish the CDC’s objectives without jeopardizing the privacy and civil rights of thousands of Americans.

OUTREACH INITIATIVE

I am also proud to say that SIECUS is taking a leadership role through its Outreach Initiative to provide health care professionals and educators nationwide with the training, materials, and technical support that they will need to reach

underserved communities and communities of color with comprehensive sexuality education programs.

When SIECUS staff started this program two years ago, we knew that there was very little published information. Since then, we have met people who are making a difference, and we are proud to publish, and share with you, information about the programs with which they are involved.

First, Dr. Theresa Okwumabua, Dr. Jebose Okwumabua, and Theresa Elliott tell us in “Let the Circle Be Unbroken” about an innovative program in Memphis, TN., that is helping African-American youth learn about important sexuality issues through socialization processes frequently observed in African cultures.

Second, Dr. Ineke Cunningham, director of the HIV/AIDS Research and Education Center at the University of Puerto Rico, shares with us in “An Innovative HIV/AIDS Research and Education Program in Puerto Rico” the important work that she and her colleagues are undertaking to provide culturally competent prevention programs to young people on the island.

We know this *SIECUS Report* is just a small initial step in the Outreach Initiative. We hope that the total work of this Initiative will eventually lead to strong comprehensive sexuality education programs for all people.

MORE INFORMATION

Also included in this *SIECUS Report* is a *Fact Sheet on Teenage Pregnancy* with relevant information for those involved in Outreach programs. There is no question that teen pregnancies have a tremendous impact on both society and the affected young people. We all must work together toward realistic solutions to this serious national problem.

SIECUS staff has also written an indepth review of a new curriculum, *Managing Pressures Before Marriage*, that is an abstinence-only adaptation of the popular and effective *Postponing Sexual Involvement*. The review’s conclusions are both interesting and surprising.

Finally, this issue includes information about a variety of new programs and publications on outreach efforts throughout the nation.

“If such a ‘list’ had existed..., I know I would have decided not to take the test.”

SPECIAL REPORT "NAMES" VERSUS "UNIQUE IDENTIFIERS": THE "HOW" OF HIV CASE REPORTING

Anna Forbes, M.S.S., Consultant
Ardmore, PA

Item: On July 1, 1993, the grand jury in Virginia indicted two sex workers for attempted murder because they were allegedly having unprotected sexual intercourse. Commonwealth Attorney Cassandra Burns ordered the women's arrests after obtaining their HIV records from local Health Department files by subpoena. The charges were subsequently dropped after witnesses against the women perjured themselves.^{1,2}

Item: In 1991, Illinois passed a law requiring its state Department of Health to identify HIV-positive health care workers by cross matching the state AIDS registry against health care licensure records. The law then directed the Department to contact patients and disclose to them the HIV status of workers found in both registries.³ Due to intense activist opposition, this legislation was funded at one dollar and, therefore, never implemented.

These are just two examples of what Kelly Scott, a person with AIDS and a member of the Washington State Governor's Advisory Council on AIDS, calls secondary uses of name-linked HIV data, nonpublic health uses that can include obtaining HIV test records for criminal prosecution, medical licensing, child custody and adoption decisions. "There seems to be no way to protect against secondary uses," says Scott, "especially when they are legislatively or Congressionally mandated."⁴

Since 1985, the CDC has required as a condition of funding that states collect the names of people with CDC-

defined AIDS and report them (after replacing the names with Soundex unique identifier codes) to the CDC's AIDS Registry. No national registry of people with HIV yet exists but that may soon change. National pressure is escalating to require that every state in the country adopt name-based HIV case reporting.

To date, 30 states have established name-based HIV case registries. These 30 states, however, are home to only 24 percent of Americans with AIDS.⁵ Most of the remaining 76 percent (and, by extension, an estimated three quarters of Americans with HIV infection but not AIDS) live in one of the "high incidence" states and territories that have, so far, refused to do name-based HIV reporting. These are California, Georgia, Illinois, Maryland, New York, Pennsylvania, Puerto Rico, and Texas. What happens to the privacy of this 76 percent with HIV depends, in large part, on how the current debate over HIV case reporting is resolved. The debate centers not so much on whether such reporting should be done but on how.

THE CASE FOR NAME-BASED REPORTING

Citing dramatic medical breakthroughs in HIV treatment, public health authorities—including the American Medical Association (AMA), the Council of State and Territorial Epidemiologists (CSTE), the Association of State and Territorial Health Officials (ASTHO), and the *New England Journal of Medicine* are now urging all states to collect the

SIECUS HIV/AIDS POSITION STATEMENT AMENDED TO REFLECT OPPOSITION TO NAME REPORTING

The *SIECUS Position Statement on HIV/AIDS* was amended to reflect opposition to name-reporting of HIV-positive individuals. It now reads (with changes in bold type):

HIV/AIDS is a major public health concern. Strong government, private, and joint support should be maintained for research and programs on prevention and treatment; for medical and social services for people with HIV/AIDS, their families, and other caregivers; and for the continued development and delivery of straightforward, accurate, age-appropriate prevention information for all people. HIV testing should be done only with informed consent.

HIV infection case reporting should be done only using unique or coded identifiers that insure privacy and confidentiality of the individual. The United States ban on prohibiting entry to people with HIV/AIDS should be lifted.

names of people testing HIV-positive.

Some of these entities have supported the concept of mandatory name reporting of people with HIV for years. But their public advocacy for it moved into high gear last year as the epidemiological impact of the new triple combination therapies for HIV treatment became evident. This medical breakthrough, commonly known as HAART (**H**ighly **A**ctive **A**nti**R**etroviral **T**herapy), has caused the first decline in the number of annual AIDS deaths in the history of the epidemic.⁶

In the era of HAART, state AIDS registries are becoming less and less representative of the full scope of the HIV epidemic. With HIV infection rates still climbing, HIV case reporting may be the most effective way to compile an accurate, fully representative epidemiological picture of the epidemic. This picture should then guide national and local prevention strategies, services planning, and the targeted allocation of funding.⁷

Both proponents and opponents of name-based reporting agree on the need for HIV case reporting, and on the collecting of nonidentifying demographic information on a case-by-case basis.⁸ To maintain accuracy, cases must be labeled with some form of consistently reproducible identifier so that duplicate reports can be eliminated. Without such labeling, people tested more than once would be recorded in the registry as separate cases each time they are tested, thus skewing the data.

Name reporting proponents believe that names are the logical label to use for this purpose. The Council of State and Territorial Epidemiologists (CSTE) adopted a position statement at its 1997 annual meeting that called for name-based HIV case reporting, and that explicitly recommended that "unique identifiers not be used for HIV surveillance activities as evaluation of such systems have not shown a level of completeness comparable to name-based systems."⁹

Proponents of name reporting see it as an integral part of what has been called the "traditional" array of disease control strategies: routine testing (at the physician's discretion, with or without the knowledge/consent of the individual being tested) and name-based reporting followed by contact tracing.¹⁰ The AMA first called for classification of HIV infection as a sexually transmitted disease (to make it subject to these standard STD prevention policies) in 1990.¹¹

In September 1997, the *New England Journal of Medicine* endorsed name-based HIV case reporting as part of a four-pronged approach consisting of "a national standard for HIV reporting, greater access to effective medication, improved access to physicians experienced in treating the disease, and protection of patients from violations of privacy and discrimination."¹²

Although epidemiologists tend to favor name reporting for its efficiency, representativeness, and the high quality of data it produces,¹³ these are not the most frequently cited reasons for the push to implement HIV name reporting nationwide. Most supporters cite two primary reasons for collecting names:

- to enable public health departments to follow up with people, ensuring their connection to early medical interventions, and
- to facilitate partner notification—the practice of contacting the sexual and drug using partners of people testing HIV-positive to offer them testing and treatment.¹⁴

Ronald Bayer, for example, is a strong supporter of partner notification (also known as contact tracing). A professor at Columbia University's School of Public Health, Dr. Bayer coined the term "HIV Exceptionalism" in 1991 to describe the point of view that opposes the application of such traditional public health measures to HIV.¹⁵ "I think we can do much better epidemiological surveillance by doing blinded seroprevalence studies than by HIV name reporting," he said in a recent interview, adding that the primary value of name reporting is that it facilitates health department outreach to possibly infected partners.¹⁶

Advocacy for name reporting has taken its strongest form in legislation introduced by U.S. Representative Tom Coburn (R-OK) in March, 1997. Dubbed the "HIV Prevention Act of 1997," Coburn's bill proposes (among other things) the creation of a national name-based HIV registry and a compulsory program of partner notification. It also authorizes health professionals to make HIV testing a condition of treatment for their patients. The bill, cosponsored to date by 105 members of the U.S. House of Representatives, would withhold Medicaid funds from states that fail to comply with its provisions.¹⁷ A companion bill (S.503) was introduced in the U.S. Senate by U.S. Senator Don Nickles (R-OK).

Although it has not taken a position on the Coburn bill, the CDC announced at a national meeting last May that it intends to move to states as expeditiously as possible in adopting HIV case surveillance. In a January 8, 1998, "Dear Colleague" letter to state and community-based organizational grantees, Dr. Helene Gayle, of the CDC, announced that new CDC HIV Case Surveillance guidelines are scheduled for release early this year. The CDC has also announced its willingness to put money into "resolving barriers" that states may have to the adoption of HIV case surveillance. CDC Deputy Branch Chief Joe Posid stated at last May's meeting that \$5 million was added to CDC's surveillance budget in 1991 to help a number of states adopt name-based HIV reporting. Hypothetically, he added, another \$15 million could be added now to help the

remaining states make the transition.¹⁸

In 1991, New Jersey became the first high incidence state to adopt name reporting. According to a 1993 report issued by the AIDS Action Council, New Jersey simultaneously received a CDC grant of \$450,000 for a computer surveillance program¹⁹—evidence of the persuasiveness of this form of CDC assistance.

THE CASE AGAINST NAME-BASED REPORTING

Such national organizations as SIECUS, the National Association of People with AIDS (NAPWA), the National Minority AIDS Council, the AIDS Action Council, the American Civil Liberties Union (ACLU), the Gay and Lesbian Medical Association, and the National Lesbian and Gay Health Association (NGHA) publicly oppose name-based HIV case reporting. Although they recognize the need for better HIV case data, these entities question the wisdom of using a name-based system.

They dispute, for example, the argument that state health departments need to collect names for follow-up to help people get into early medical care. This contention appears to be disproved by the CDC-funded MESH (Multi-state Evaluation of Surveillance of HIV) study, a massive eight-state survey carried out by the University of California's Center for AIDS Prevention Studies. Between 1995–97, the MESH researchers questioned over 2,500 people on a range of issues relating to name reporting.

Although the data are embargoed pending publication in early 1998, MESH highlights were presented orally by Principle Investigator Dennis Osmond, M.D., at the CDC's National Consultation on the Future of HIV/AIDS Surveillance in May 1997.²⁰ The data point to three important conclusions:

- people with HIV got into care just as rapidly after being tested at anonymous test sites (where names aren't used) as they did after testing positive at confidential sites (where names are required).
- HIV positive anonymous test site patrons supplied the same number of partner names on average as confidential test site patrons did.
- Most of the people surveyed didn't know what their state's policy was regarding name-based HIV reporting. But 19 percent—almost one in five—identified name reporting as a reason *not* to get HIV testing.

Advocates also note that the argument that collecting names will help get people into care is specious because adequate treatment simply is not universally accessible in the United States. The ACLU's position paper on HIV Surveillance states that, "Presently, there is no system to ensure that people with HIV receive potentially life-saving

treatments. The barriers to proper health care—poverty and lack of funding—will not in any way be addressed by adopting name reporting."²¹

Health care data confirm this reality. By early 1997, only 25 percent of Americans with CDC-defined AIDS were on any kind of protease inhibitor therapy.²² The federal AIDS Drug Assistance Programs (ADAP) provided medication to somewhere between 14 and 28 percent of the low income people with HIV who qualified for such assistance in 1996.²³ And, although the Clinton Administration may support an expansion of Medicaid to guarantee medical care for HIV-positive people without AIDS diagnoses, it has not yet asked Congress to take this step. Hundreds of thousands of Americans with HIV are still not getting adequate, early medical care, and no correlation has been shown between state adoption of name-based HIV reporting and enhancement of the state's ability to assure such care to its residents.

The second justification cited by its proponents—that name reporting facilitates partner notification efforts—is also contradicted by the available data. Activists point to the second MESH conclusion as evidence of the fact that partner name elicitation and, therefore, partner notification can be done effectively without name reporting of the "index patient" (the individual testing positive).

Coercive attempts to elicit partner names from the index patient are largely self-defeating because it is easy for patients to deny having any recent contacts or to lie about the identities of those contacts.

Advocates' concerns are triggered, however, by the fact that the Ryan White CARE Act was amended during reauthorization in 1996 to require that states, as a condition of funding, "make a good faith effort" to notify the spouses of people testing positive. What is to stop a state from cross matching its HIV registry (if name-based) against the state marriage license registry, obtaining the names of spouses of HIV-positive people and then contacting those individuals without the consent of the individual testing positive? Citing a 1995 study in which up to one third of the HIV-positive women resisted partner notification for fear of domestic violence, emotional abuse or abandonment, K. H. Rothenberg and S.J. Pasky emphasize that "health officials must reaffirm their commitment to partner notification that is both voluntary and confidential."²⁴ Cross-matching registries is far from voluntary for the people thus identified and the possibility of spousal notification efforts proceeding without the prior consent of the patients presents a very real threat to the safety of people testing HIV-positive.

Noting that partner notification is a prevention (not a surveillance) activity and that CDC-funded HIV Prevention Community Planning Groups are charged with determining how such mandates are implemented locally, the position statement on HIV Surveillance of the National Association

of People with AIDS (NAPWA) emphasizes that “data collected under this system must remain decoupled from partner notification and contact tracing.”²⁵ By contrast, the Coburn legislation (H.R. 1062) proposes linking the two.

In addition to refuting arguments in support of name-based reporting, advocates cite two major arguments against it that it triggers testing avoidance and that, as noted by Kelly Scott above, name-based registries can be used to violate or endanger the privacy of people with HIV.

The MESH data, as shown, indicate that almost one fifth (19 percent) of the surveyed population see name-based reporting as a reason to avoid HIV testing. Given that about half of the 650,000 to 900,000 people estimated to be HIV-positive in the United States do not know their serostatus,²⁶ anything that reduces public interest in testing to this degree has a potentially negative public health impact.

The ACLU report summarizes nine studies that, like the MESH data, document the link between name-based reporting and testing avoidance.²⁷ In one California study, 60 percent of the individuals surveyed indicated that they would avoid HIV testing altogether if getting tested meant risking name-reporting.²⁸ The ACLU report also points out that “the deterrent effect of name reporting is most pronounced in the very populations with the greatest need for preventive intervention: gay and bisexual men, people of color, intravenous drug users, and sex workers.”²⁹

The National Minority AIDS Council (NMAC) concurs. Since testing avoidance and lack of trust in medical institutions are particularly prevalent in communities of color, NMAC actively opposes government pressure to force states to adopt name reporting policies that will exacerbate these problems.³⁰

With regard to secondary uses of HIV registries, advocates recognize two areas of risk. The first is illegal violations by individuals and the second is breaches authorized by local, state, or national governmental entities. The first area is best exemplified by the highly publicized 1996 incident in St. Petersburg, FL, in which a computer disc containing 4,000 AIDS registry names was illegally obtained and sent to two local newspapers.³¹

This type of leak is certainly not without precedent. In 1987, two computers containing 60 AIDS registry names were stolen from the state Health Department in Sacramento, CA.³² There are numerous incidents, documented and undocumented, of smaller leaks by health care workers, police, and others with access to name-based lists.³³

More dangerous than these, however, are the legislatively or judicially mandated breaches such as those cited at the beginning of this article. Because they hold the potential for violating the privacy of thousands of HIV-positive individuals at a time (as in the case of the Illinois health care worker legislation), these are the source of greatest concern to AIDS and

privacy advocates. State confidentiality laws designed to prevent privacy violations are clearly only as strong as the will of the various state legislatures and courts to uphold them.

Under sufficient public pressure—such as that precipitated by the case of Nushawn Williams, a Jamestown, NY, man accused of knowingly transmitting HIV through unprotected sexual relations with dozens of young women—state interests in protecting privacy tend to be set aside in favor of the generic state STD control laws and newer HIV criminalization laws that, when invoked, can be used to violate the privacy of people known or presumed to present a “clear and imminent danger” to the public health.^{34,35} Availability at the state level of name-based registries simply facilitates governmental access to HIV status information.

The federal government has attempted to address this problem by writing “Assurances of Confidentiality” into the Public Health Services Act. Section 308(d) of the Act assures that surveillance data supplied to the CDC cannot be used without consent for any purpose other than that for which it was supplied and that identifying epidemiological information cannot be published or released without consent of those so identified.³⁶ Unfortunately, this assurance has been interpreted to date as applying to federal, not state, public health entities. We do not yet know whether it is possible to use this legislation to block “secondary uses” of state health department registries.³⁷

UNIQUE IDENTIFIERS

To meet the need for case-by-case epidemiological data without risking privacy endangerment or testing avoidance, many advocates support the option of HIV case reporting by unique identifier rather than name. Unique identifiers (UI's) are number or letter-number codes that correspond to an individual person, thing, or location. They are used every day in the form of Social Security numbers, phone numbers, ZIP codes, product serial numbers, and motor vehicle registration numbers.

An enormous array of UI systems currently exist, from the simple systems designed to entertain children (the Captain Midnight Decoder Ring is one example),³⁸ to complex computerized encryption systems used by intelligence agencies.

UIs are already being used for HIV case reporting in Maryland and Texas and abroad in Australia, Belgium, Denmark, and the United Kingdom. Maryland's system, the only one successfully implemented for HIV case reporting in the United States to date, produces a UI by combining the last four digits of the individual's Social Security number with date of birth and codes indicating race/ethnicity and gender. The HIV testing provider puts these data elements into UI code form (a task that takes, on average, less than 90 seconds) and attaches the UI to the blood sample before sending it to

the laboratory. The laboratories then report the UIs of those testing positive to the state Health Department.³⁹

Encryption options have also been proposed in connection with HIV case reporting because they offer a higher level of security than unencrypted systems. This is especially true for UIs in which a private data element or key (an unchanging piece of personal information not found in public records) is combined with the standard, public data elements such as name, birthdate, gender, and race.⁴⁰ One example of a highly secure, private key UI is Client Key, a system developed for client-level reporting of CARE Act funded services and field tested in ten AIDS services provider sites throughout Pennsylvania in 1992–93.⁴¹

The most closely scrutinized of the UI systems available for HIV case reporting are those used by Maryland and Texas. Both states set up the three-year UI trials after receiving one-time CDC evaluation grants of \$600,000. Neither state allocated funds to support the project.

At the national CDC meeting in May, Dr. Sharon Melville of the Texas Health Department reported that barriers to the successful implementation of the Texas UI system included lack of “buy-in” by local health departments, lack of supplemental state funding, and lack of provider awareness of the reporting requirements. These and other problems resulted in incomplete reporting that compromised the system’s utility. Out of the 20,000 UI codes reported over three years, only 9,899 were complete (although Melville noted that completeness rose from 39 percent in the first six months to 77 percent in the last six months, indicating a steady improvement over time). The Texas Health Department, however, is not satisfied with the effectiveness of its UI system and is considering switching to name-based HIV case reporting.⁴²

Dr. Liza Solomon of the Maryland Health Department, on the other hand, presented a very different outcome at the May meeting. Solomon describes the Maryland UI system as “still immature” and still plagued by incomplete reporting. Over 71 percent of the 18,245 UIs reported by laboratories over the last three years were complete, however, and the rate of completeness had risen steadily every year.⁴³ Dr. Solomon attributes this improvement to progress on a learning curve among providers.⁴⁴ The Maryland system, overall, is accomplishing its major objectives.

Critics of the Maryland system raise two major objections. The first problem is that hospitals and private providers (who provide two thirds of the HIV tests in this country⁴⁵) are accustomed to using names and may never comply fully with UIs. The second is that UIs are generally viewed as too expensive in comparison to name-based reporting.

Maryland reports that rates of compliance with UI

reporting requirements vary among providers. The state-funded HIV counseling and testing sites in Maryland, for example, have a much better track record of collecting the data elements and arranging them into complete UIs than hospitals and private providers do. By Year Three, 97 percent of all UIs submitted by test sites were complete. But this disparity in compliance is not so great as to cripple the system since the overall rate of reporting completeness rose from 65 percent in Year One to 84 percent in Year Three for all data elements except Social Security number. In retrospect, Dr. Solomon believes that it may have been unwise to select part of the Social Security number as a required data element since many people either don’t know it or are reluctant to disclose it. Using another data element in UI design might well result in an even higher level of reporting completeness.⁴⁶

It must also be noted that name-based reporting does not achieve total completeness. Names are omitted, duplicated, or erroneously included in name-based registries for a wide variety of reasons. Chief among these is the prevalent use of pseudonyms by people seeking HIV testing. States with name-based HIV registries are estimated to be achieving only 80 to 90 percent completeness in HIV case reporting.⁴⁷

The real costs of HIV case reporting—whether by names or by UIs—is another important consideration. The Maryland system costs about \$100,000 annually to operate and is handling approximately 7,500 reports annually.⁴⁸ By contrast, the New York State AIDS Institute administrators report that, when New York adopted name-based reporting of low CD4 test results in 1996, they had to add two fulltime program research specialists and two fulltime public health representatives to handle follow-up, as well as a one-quarter time technical support for computer maintenance and improvement. These staff handle 14,400 low CD4 reports per year.⁴⁹ Since the combined salaries for these staff (with benefits) can be assumed to total at least \$200,000 per year, the per-report costs of the two systems are roughly comparable.

The experiences of Maryland and Texas in creating and implementing UI-based HIV case reporting systems has been highly instructive. Since much has been learned about their strengths and weaknesses, there is now a pressing need to learn more about other UI systems and their relative capabilities.

Some states, California and Massachusetts for example, are convening working groups to study this issue. Such groups should include people with HIV/AIDS, Health Department personnel, testing providers, and UI experts so that workable, well-informed compromises can be made.

Once convened, these working groups, at minimum, should ask themselves the following questions when considering UI systems:

- What data elements don't change over time and are supplied without objection?
- Is the system user-friendly enough that providers will comply if required to use it?
- What is affordable? HIV case reporting costs money—whether names or UIs are used.
- What is the highest level of affordable confidentiality? Computer encrypted UIs may offer some privacy advantage but may not be as inexpensive to create. The possibility of using one centralized, call-activated computer that providers access via touch-tone phone, however, should enable states to consider computerized encryption without having to assure that every HIV testing provider has computer access on site.

The answers to these questions should provide working groups with basic parameters for their deliberations. Given these parameters, experts in the construction and implementation of UI systems can then advise groups on practical UI alternatives.

CONCLUSION

UI-based HIV case reporting addresses the twin goals of collecting accurate epidemiological data without triggering HIV testing avoidance and without placing the privacy of people living with HIV at risk.

NAPWA's policy statement on the subject is fairly characteristic of most of the advocacy community's response to UIs: they "guardedly support" HIV case reporting and only if done "using unique or coded identifiers that insure the privacy and confidentiality of the individual."⁵⁰

Pressure on states to adopt some form of HIV case reporting is generated in part by the deadline of the Ryan White CARE Act reauthorization in 2001. Persuading members of Congress that AIDS was an emergency requiring federal relief was easier in 1990, when the CARE Act was originally passed, than in 1996 when it was first reauthorized. By 2001, AIDS case statistics will very likely suggest a waning epidemic. But HIV case data, particularly if collected in high incidence states, will show the opposite. Strong HIV case data, aggregated and processed by the time the next CARE Act reauthorization battle gears up in the year 2000, would be of substantial value.

As deliberations on this incendiary issue proceed state by state, it is worth noting that the CDC's funding decisions reflect a clear, albeit tacit, message about where they stand. Every year for the last three years, the CDC has made unexpended money available to states for HIV surveillance. Every year Maryland has applied for some of that money to supplement its shoestring UI system budget. Every year Maryland's application has been turned down.

In an August 6, 1997, conference call with state AIDS

directors, the CDC announced that it would be dividing the 1997 unexpended money among Florida, Puerto Rico, New Mexico and Texas⁵¹—all locales that have either just adopted or are about to adopt name-based HIV case reporting.

Whether name-based reporting opponents, whose advocacy runs counter to the CDC's de facto position, will be able to move the undecided, high-incidence states toward UI options depends entirely on what level of pressure they are able to mobilize. Absent a powerful, broad-based, grassroots demand for non-name alternatives, it is very likely that being listed by name in a state HIV registry will be one of the realities of life for virtually all Americans living with HIV in the year 2000.

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SEATTLE'S CENTER FOR HEALTH TRAINING EXPLORES NEEDS OF EDUCATORS OF COLOR

The Center for Health Training in Seattle, WA, which has long provided training for sexuality educators in the Northwest United States, has designed a four- or five-day training program that will emphasize the professional responsibility of sexuality educators who are people of color.

Training session themes will include "Exploring Workplace Issues," "The Role of Sexuality and HIV Educators in Organizations and Communities and with Clients," "Exploring the Connection Between Spirituality and Sexuality," "Strategies for Working with Diverse Communities," "Controversial Issues and Topics Relating to Communities of Color" (including adolescent parenting), "Developing Individual and Team Plans of Action," and "Developing Professional Standards or Ethics."

The program's goals are to provide community and school-based educators with the opportunity to: (1) broaden their recognition and understanding of the complexities of racial and ethnic experiences, (2) acquire skills for dealing with the barriers faced in many tasks (such as working as a "minority" in a "majority" organiza-

tion or dealing with unknown factors of institutional racism or bias), and (3) develop a set of professional standards or ethics.

The program is being developed by a national committee consisting of Maxine Bryant, Alfonso Carlon, Brenda Hanson, JoAnn Henderson, and Dennis Torres. They anticipate producing the training as a national event next year.

The Center for Health Training is a private, non-profit organization that has provided a wide range of services to health and human service agencies and client populations for more than 20 years to community educators, clinicians, and public health agency staff.

For more information: Center for Health Training, 400 Tower Building, 1809 Seventh Avenue, Seattle, WA 98101-1313. Phone: 206/447-9538.

—Joan Helmich and April Pace
Center for Health Training,
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SIECUS DEVELOPS OUTREACH INITIATIVE

Felix E. Gardon
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New York, NY

SIECUS has found that many health care professionals and educators serving underserved and low-income communities lack the training opportunities, materials, and technical support to provide comprehensive sexuality education programs. SIECUS's Outreach Initiative is designed to help correct this situation by:

- developing collaborative relationships with national organizations serving these communities;
- conducting workshops and trainings on sexuality education at their annual meetings;
- holding regional symposia for them and their constituents on sexuality education;
- providing technical assistance to communities developing comprehensive sexuality education programs; and
- publishing new—or adapting existing—related resources.

Much of Initiative's work during the past year has focused on developing relationships with key national organizations, and subsequently disseminating information.

Specifically, staff has worked with more than a dozen national organizations serving communities of color—including the American Red Cross; Balm in Gilead; the Latino Health Institute; the National Association for Former Foster Children; the National Coalition of Gay, Lesbian, and Transgendered Youth; the National Asian Women's Health Organization; and the National Native American AIDS Prevention Center.

The past year was also highlighted by three meetings:

- **The Rio Piedras (Puerto Rico) Symposium** focused on culturally competent sexuality education, model sexuality education, and HIV-prevention programs in Puerto Rican communities as well as strategies for handling controversies about sexuality education. Participants came from all over the island and included representatives from government agencies, community-based organizations and schools working with low-income youth.
- **The Vicksburg (Mississippi) Symposium** focused on the challenges facing underserved youth in the Southeast United States and specifically covered model sexuality education and youth development programs as well as

the need for comprehensive sexuality education. Participants came from Alabama, North Carolina, Tennessee, and Louisiana.

- **The Philadelphia Symposium** focused on creating support for sexuality education programs, understanding how to develop culturally competent programs, and learning how to evaluate curricula. Participants came from Delaware, New Jersey, New York, and Pennsylvania.

The Outreach Initiative has also provided technical assistance and information to more than 50 communities in such areas as Brooklyn, NY; Oakland, CA; Miami, FL; Cambridge, MA; Baltimore, MD; Jackson, MI; Atlantic City, NJ; Philadelphia, PA; and Aguadilla, PR.

For example, the Initiative assisted Mujer 2000, a community-based organization in New York's South Bronx,

with a project to address women's sexuality; it worked with the South Jersey AIDS Alliance, a community group in Atlantic City, NJ, to design an after-school program for minority youth struggling with issues of sexual orientation; and it worked with Plain Talk, a Seattle-area teen pregnancy-, STD-, and HIV-prevention program, to provide information to parents and other community members about the program's impact.

The Initiative has also published information which these groups can use in their

work. Highlights include a Fact Sheet on *Sexuality Education and Underserved Youth in Communities of Color*, an *Annotated Bibliography on Culturally Competent Sexuality Education Resources*, and Latino/a adaptations of such SIECUS publications as the *Guidelines for Comprehensive Sexuality Education*, *Talking About Sex*, *How to Talk to Your Children About AIDS*, and *Oh No! What Do I Do Now?*

CONCLUSION

SIECUS feels that the accomplishments of the past year are a small but significant step in its goal to help to provide comprehensive sexuality programs to all Americans.

(For more information on SIECUS's Outreach Initiative, contact Felix Gardon at SIECUS, 130 W. 42nd Street, Suite 350, New York, NY 10036-7802. Phone: 212/819-9770, extension 311.

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—Editor)

*The Outreach Initiative
will bring comprehensive
sexuality education
to underserved
and low-income
communities.*

" LET THE CIRCLE BE UNBROKEN "
HELPS AFRICAN-AMERICANS
PREVENT TEEN PREGNANCY

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The high rate of adolescent pregnancy among African-American adolescents and the detrimental consequences of premature parenting make it imperative that strategies be developed to address these problems.¹

In reality, a number of programs and strategies have been developed and are being implemented in various sites across the United States. Very few of these, however, have sufficient evaluation components to provide meaningful data about their success.² Even fewer have published results on the efficacy of their intervention or provided data on the impact of the program on actual sexual behavior. Furthermore, many of the strategies appear to circumvent the impact of race, gender, and socioeconomic class on adolescent pregnancy outcomes.³

This oversight is tragic given that an early adolescent pregnancy often predicts the beginning of a rapid succession of unwanted births and that such repeat pregnancies have adverse consequences for the infant's health as well as for the mother's developmental, educational, and occupational well-being.⁴

Failure to consider the impact of these factors in the implementation of prevention efforts could be harmful, especially if it contributes to biased assumptions and programs that fail to meet the needs of the targeted group.⁵

**TRANSLATING CONCEPTS
INTO A PROGRAM**

Over the past 20 years, the African-American community has witnessed several attempts to provide prevention programs and services for many of its problems. Noting the apparent ineffectiveness of many of these approaches, some scholars and practitioners have argued that prevention services to African-American communities are doomed to failure when they do not recognize or build on the cultural integrity of that community.⁶

For example, the continued high rate of adolescent

pregnancy among African-Americans, despite extensive intervention and prevention efforts, brings to the forefront the issue of cultural consistency as a key ingredient in providing prevention programs. However, even with the call for cultural consistency in program development, there remains the question of pragmatically translating the theoretical discussions of culture into programmatic activities.

The "Let the Circle Be Unbroken: Rites of Passage" program represents an attempt to pragmatically translate the theoretical underpinnings of an Afrocentric conceptual model into a prevention program. It involves an adaptation of socialization processes frequently observed in African cultures, which openly acknowledge the necessity of formally assisting adolescents in the transition or passage from childhood into adulthood.

This socialization process, commonly referred to as "rites of passage," is generally a cultural experience which requires that ideology, education, training, and culture be taught prior to an activity or celebration marking the successful transition from one stage of development (adolescence) to another (adulthood). For example, young people in many African societies are involved

in initiation and training experiences that can extend from a few days or weeks to several years. More often than not, the training is conducted by elders in the society and includes a period of total separation from one's family and community during which the young person lives alone or together (communally) with others who are also in training. The young person's return from the separation—back to her family or community—signifies the successful completion of a developmental process and the earning of the respect of the community for having done so.⁷ Frequently, new responsibilities and privileges are given to the youth at this time.

Following these basic premises, the "Rites of Passage"

*This program is
an adaptation
of socialization
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in African cultures.*

program is designed to teach adolescents the knowledge and skills necessary to become responsible members of their community as well as spiritually mature adults. Specifically, it is designed to help young people build self-esteem; enhance self-image; develop leadership skills, cultural awareness and appreciation; and make healthy, productive, and self-affirming life choices.

Proponents of the program believe that young people who achieve these goals will not become involved in health- and life-compromising behaviors such as becoming sexually active too early and becoming parents prematurely.

HISTORICAL OVERVIEW

The "Rites of Passage" program began in 1991 as a pilot project of the Memphis (TN) City Schools Adolescent Parenting Program. It initially targeted only pregnant and parenting adolescents and was offered as an after-school program at the Comprehensive Pupil Services Educational Center (CPSEC), home to the system's special program for pregnant and parenting students.

Although participants did show some skill and behavior improvements, attendance was low. Furthermore, administrators of the program quickly realized that efforts were seriously needed to *prevent* young girls from becoming pregnant and parents. The program was, therefore, implemented during the next school term at two junior high schools.

Using research regarding predictors of adolescent pregnancy, program administrators targeted young girls from families where a sibling and/or parent were teen mothers as well as young girls who were considered *at risk* for a premature pregnancy by school officials because of their association with a teenage mother or their lack of involvement in school activities. Attendance at these school sessions increased dramatically. The program administrators learned early on that many of the targeted young girls had a history of academic difficulties. They determined that they needed to target youth earlier than junior high if they were to truly delay premature sexual involvement and parenting. They began offering programs for fifth and sixth graders during the second half of the school year.

Although the program administrators continued to sponsor some secondary prevention programs for pregnant and parenting adolescents, their focus has been on primary prevention since 1994. The majority of the programs target youth between 10 and 14 years of age who are considered high risk for teenage pregnancy and other problem behaviors.

Most of the programs are offered in schools during the regular school day. There are, however, several community-based programs that are offered after school or on weekends. They are offered in both rural and urban settings. Although youth from other ethnic backgrounds are

involved in some programs, most of the participants are African-Americans.

PROGRAM IMPLEMENTATION

The typical "Rites of Passage" program runs from six to nine months and is implemented in three phases.

The orientation phase. During this phase (usually six to eight weeks), the program administrators set the tone by conducting two orientation sessions: one for those participating in the program and one for those conducting the program.

The first session involves potential participants, their parents, school teachers and administrators, members of the Advisory Committee (the Council of Elders), and other interested community members.

Potential participants are sent an invitation that contains information on the program's rationale, schedule, activities, requirements, and expected outcomes. They are also sent a consent form that participants and their parents are required to sign and return. They are then invited to attend a Parent/Participant Orientation Meeting and are provided contact information if they have any questions or concerns.

The second orientation session involves a special two-day training session for program facilitators. This includes presentations about the "rites of passage" theoretical basis, the "how-to's" of establishing and maintaining a program, learning and teaching techniques, and a program evaluation. The program facilitators are asked to examine their beliefs and assumptions about the African-American youth with whom they will work and the role that adults should play in their development. This must include an honest examination of their views on African-American culture and history.

Facilitators are also asked to embrace the program rationale, training methods, and curriculum materials. They are, in fact, coached in the use of a wide range of learning and teaching techniques, including brainstorming, role-playing, audiovisuals, guest speakers, cultural outings, and other structured activities. They are also given strategies for addressing problems such as apathy, poor attendance, and group conflict.

Similar in-service trainings are also provided for teachers and other school officials.

The passage phase. This phase (four to six months) includes initiation activities, weekly sessions, and periodic workshops/meetings with parents, families, and others involved in the program's implementation.

Participants first attend several meetings where they take part in activities to introduce themselves to each other to build a sense of group identity and unity. Facilitators must, at this time, review with the participants the program's purpose, participation requirements, and group rules.

One of the hallmarks of the passage phase is the initia-

AREAS OF STUDY: "RITES OF PASSAGE"

The subjects that are covered in the "Rites of Passage" program are described briefly below.

Knowing Africa

increases awareness of global Africa, her geography, people, culture, beliefs, community, and family.

Knowing Self and Others

introduces participants, adult facilitators, leaders, and elders to the "Rites of Passage" program as a means of socializing youth for adult roles and responsibilities.

Family History

encourages appreciation of the African-American family, including its role and function from a cultural and historical perspective.

The History of African People

increases basic understanding of the history and accomplishments of people of African descent.

Family Life Education

increases knowledge and awareness about family life matters, including human sexuality and how one's sexuality relates to responsibility, values, and respect for self and others.

Spirituality: The Journey Within

increases understanding and awareness of the importance of spirituality to well being.

Taking Care of Self and Etiquette

promotes understanding of the importance of total wellness, including physical, emotional, and spiritual well being and enhances understanding of socially acceptable (appropriate and inappropriate) behaviors.

Housekeeping and Finances

increases understanding of the overall management of a household, including financial planning, money management, and homemaker skills (cleaning, grocery shopping, cooking, sewing, and mending).

Values Clarification and Goal Setting

develops awareness of the traditional value system that guided African people, and explores and begins to clarify

individual values and encourages behavior, including life goals, that is consistent with values.

Conflict Resolution and Violence Prevention

increases awareness and understanding of violence, including the kinds of violence that are destroying African-American communities and people as well as the cause and consequences of violence. It also illustrates that violence is preventable and that there are alternatives to violence.

Creativity

increases basic understanding of the contribution of people of African descent to the creative arts as well as knowledge and appreciation of the creative arts, particularly those related to the history and culture of African people.X

Life Management: Time, School, Work, and Leisure

develops skills to appropriately manage one's life in regard to time spent at school, work, and at leisure.

HIV/AIDS and Other

Life-Threatening Conditions

increases knowledge and awareness about sexually transmitted diseases and other health conditions (high blood pressure, homicide) that threaten the longevity of people of African descent.

Communication

increases awareness of the importance of communication skills.

Assertiveness and Leadership

increases awareness of the qualities of leadership, including those qualities shown by famous and/or high profile African-Americans, as well as the importance of assertiveness and leadership to one's growth and development.

Career Development

exposes participants to a variety of career options and the requirements for each career.

tion or induction ceremony where participants publicly acknowledge their willingness to participate in and complete the "rites of passage" training. Their intention is then acknowledged by the "elders of the community" in the form of "pinning" female participants with a pin consisting of three beads (red, black, and green) strung on a safety pin and "hooding" male participants with a necklace strung with the same red, black, and green beads. The colored

beads symbolize (1) the blood shed by African people in their struggle for freedom (red), (2) the people of Africa (black), and (3) the land (green), respectively. Participants are encouraged to wear the pin to all program activities and are told that they will exchange the pin/necklace for something more valuable at the conclusion of the activities.

During the induction ceremony, the facilitator acknowledges his or her willingness to serve as group leader and his

or her intention to fulfill all responsibilities. This includes making a commitment to: (1) attend monthly training sessions; (2) work with school and community representatives; (3) maintain records of group processes and activities; (4) read at least two books (one by or about people of African descent and one about "Rites of Passage" training; and (5) memorize the group pledge, the *Nguzo Saba* (the Seven Principles) and the *Black National Anthem* ("Lift Every Voice and Sing"). The facilitators are also "pinned" or "hooded" during the induction ceremony.

Another hallmark of the passage phase are the weekly group sessions. These sessions are usually conducted during the regular school day for school-based programs and as an after-school or Saturday activity for community-based programs. Each session, which lasts approximately 60 to 90 minutes, is designed to prepare participants to assume adult roles and responsibilities. Particular emphasis is placed on providing participants with the knowledge and skills to resist negative influences (media, peers) and health- and life-compromising behaviors (becoming sexually active too early).

The program also offers educational remediation and enrichment activities, including supervised homework and tutoring sessions; projects that build on skills and ideas learned during the school day through non-traditional ways (e.g., recording an oral history of senior citizens), and programs that expose youth to new skills, ideas, and experiences. Sports, recreational, and leisure activities are also incorporated into some programs. These include team sports, exercise classes, theater, and dance. These activities are intended to provide variety and fun. Although field trips (for example, tours of black-owned businesses and the National Civil Rights Museum in Memphis) were initially scheduled simply to expose the participants to their heritage and culture and to reinforce material presented during group sessions, they have also provided opportunities for the participants to engage in meaningful activities together. Some of these activities are conducted outside the weekly group sessions and often on weekends.

The culminating phase. During this phase (four to six weeks), which represents the final stage of the program, participants prepare for an overnight retreat and a closing ceremony.

As part of the overnight retreat, participants are given a challenging task which they must complete alone or with other young people in the group. The completion of this task, coupled with the successful completion of other program requirements, is evidence that the young person has taken the program seriously and has made significant strides toward assuming adult roles and responsibilities.

THE CURRICULUM

One of the first tasks in offering the "Rites of Passage" program was to locate curriculum resources that were culturally

and developmentally appropriate for African-American youth. Program administrators also attempted to identify material that addressed factors frequently associated with risky sexual behavior.

A search of the literature and discussions with practitioners across the country resulted in a paucity of material. In fact, this search convinced program administrators that they needed to develop their own curriculum consistent with the theoretical underpinnings of Afrocentric theories and explanations of unintended pregnancy among adolescents. They, therefore, sought to apply concepts, strategies, and techniques outlined in papers and books on Africentric theory by authors like Nathan and Julia Hare,⁸ J. A. Sofola,⁹ and Nsenga Warfield-Coppock¹⁰ into a comprehensive, user-friendly curriculum.

Within this framework, the "Rites of Passage" curriculum was developed. It is organized into 16 major areas or units of study. Each unit contains lessons and activities that address issues relevant to the education as well as the physical and religious/spiritual responsibilities of African-American adulthood. (See page 14.)

PROGRAM LEADERSHIP

The two leadership groups for the "Rites of Passage" programs are the Council of Elders and the group facilitators.

As in traditional African societies, the Council of Elders plays an important role in the education and socialization of program participants. They assist in:

- determining the need for a program in a certain area or site
- designing the program
- presenting the program to school boards and community organizations
- reviewing educational materials, and
- hearing and responding to program concerns.

Because the responsibility of guiding and directing youth is critical to the efficacy of the program, the selection of a Council of Elders is not taken lightly. Some adults, though willing to serve, may not be qualified. In fact, this responsibility is earned in most African societies by those who have already been initiated into adulthood, who are involved in the community, and who have shown a great deal of wisdom and understanding.

Members of the Council of Elders tend to be highly respected within their community and have tremendous leadership responsibility. They are usually older individuals who are also considered spiritual leaders. An Elder has generally demonstrated some degree of personal accomplishment (or success), is knowledgeable, and has an appreciation for the history, culture, and achievement of the community.

The selection of a facilitator is equally important. In

fact, the success or failure of programs often depend on facilitators. They should possess all of the characteristics of an Elder and also should:

- believe in the importance of educating and socializing youth for adult roles and responsibilities
- know about African and African-American culture, history, and achievements
- have enthusiasm about working with youth
- have good communication and group facilitation skills
- understand how to comfortably use teaching techniques in working with youth
- understand the needs and concerns of children and/or adolescents
- have experience with children and/or adolescents
- understand how to use the “Rites of Passage” program
- demonstrate a willingness to work with parents to foster their involvement in the program.

Two men are selected for the leadership role in male programs, and two women are selected for female programs. Both are usually the same ethnic composition as the majority of the group. This helps create an immediate rapport between facilitators and participants. Coeducational sessions with male and female coleaders are sometimes scheduled to help foster and model healthy, respectful relationships between genders.

It may not always be possible to have facilitators of the same ethnic composition of the group. For example, agencies interested in offering a “Rites of Passage” program may have staff from other ethnic groups. In these situations, the agencies are encouraged to seek ethnic minority volunteers to serve as facilitators, or, at the very least, to serve in visible program roles (elders, mentors, guest speakers, recreation leaders).

STAFF TRAINING

As noted earlier, all program staff are required to attend a two-day training that is offered during the initial orientation phase of the program. They are also required to attend monthly one-hour training sessions to review progress, to discuss the focus of the lessons for the upcoming months, and to plan cultural outings/field trips and other activities.

EVALUATION

Given the increased emphasis on accountability by funders, administrators, and the general public, the “Rites of Passage” program evaluation is critical.

In evaluating the various programs, program staff utilize both process and outcome measures. They routinely obtain information about the participants’ education and school status (attendance rates, graduation rates, dropout rates, course/grade accomplishments, school suspensions), knowl-

edge regarding African-American history, and level of self-esteem. They may also collect data on pregnancy outcomes (infant birth status, birth weight, pregnancy status) and the participants’ intention to engage in specific behaviors (sexual relations, alcohol, drugs).

Preliminary data indicate students enrolled in the “Rites of Passage” program, as opposed to other programs, show more favorable graduation rates and tend to drop out of school less frequently. Favorable anecdotal reports by current and past program participants, parents, group facilitators, and community representatives reflect on the benefits of the program for a group of African-American girls referred to the program because they were not doing well academically and were at high risk for school dropout.

Officials at one Memphis city school reported that they had seen significant changes in program participants’ behavior and attitudes. According to the guidance counselor, “a lot of them have stopped using profanity, and they are showing more respect.” The principal of the school also observed positive results and recommended expansion of the program.

Program implementors are pleased with such program responses. They realize, however, that there is a need for more rigorous evaluation. Plans are underway to do so. In the meantime, they would like to share some of the lessons they have learned that will be useful to individuals considering implementing a similar program:

- Successful implementation of this type of program requires community support. It is extremely difficult for one person or one agency operating alone to successfully implement the program. Collaboration is essential.
- It is crucial that all parties involved in the project understand the theoretical underpinnings of the approach as well as the practical implementations of these tenets. Therefore, extensive training prior to the start of the program coupled with periodic training after the program is important for all project staff.
- Everyone involved in the program must have a common vision and commitment to goals. Everyone, working together, must make concerted efforts to reach the young people.
- Attrition, especially in school-based programs, is low and participants are eager to continue their involvement in the program beyond one year. Some thought should, therefore, be given, early on, to the continuation of programs beyond one year of funding.
- Careful documentation of the program process is important in order to determine how program activities were implemented and the nature of exposure to the program units on the part of individual participants.

The “Rites of Passage” curriculum is available for

\$80.00 (plus shipping and handling) by writing to Dr. Theresa Okwumabua, 286 N. Avalon, Memphis, TN 38112. Dr. Okwumabua is also available for program training and consultation.

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"OUTREACH" RESOURCES

Sexuality Education Across Cultures: Working with Differences

by Janice M. Irvine.

This book demonstrates how cultural differences can profoundly shape beliefs about what it means to be a man or a woman and how these differences shape an individual's sexual thoughts, feelings, and behaviors.

It includes information on: (1) different cultural approaches to sexual identity, (2) different meanings of risk among cultures, (3) understanding the diverse perspectives of sexual speech, (4) understanding sexuality in terms of an individual's social world, and (5) examples of ways to develop culturally appropriate education.

Order information: Jossey-Bass Publishers, 350 Sansome Street, San Francisco, CA 94104. Phone: 888/378-2537. Cost: \$30.95.

Cultural Diversity and Social Skills Instruction: Understanding Ethnic and Gender Differences

by Gwendolyn Cartledge.

Educators must learn to differentiate between social skill deficits that need to be changed and cultural differences that either need to be respected or to be changed according to specific social conditions.

This book explains the relationship of culture and social behavior and then specifically looks at Asian-Americans, African-Americans, Native-Americans, and Hispanic-Americans. There is also a section on the culture of gender.

Order information: Research Press, 2612 N. Mattis Avenue, Champaign, IL 61821. Phone: 800/519-2707. Cost: \$24.95.

AN INNOVATIVE HIV/AIDS RESEARCH AND EDUCATION PROGRAM IN PUERTO RICO

Ineke Cunningham, Ph.D.

Director, HIV/AIDS Research and Education Center
University of Puerto Rico
Río Piedras, PR

The HIV/AIDS Research and Education Center of the University of Puerto Rico was founded to promote research and to create programs to help prevent HIV infection through a decrease in risk practices. It has two specific goals: (1) to create research projects to ascertain the socio cultural factors in risk behavior, and (2) to develop innovative educational programs and techniques based on the research findings.

A CULTURAL BASIS

Prior to the founding of the Center, a series of knowledge, attitudes, and practices (KAP) surveys of students at the University of Puerto Rico were launched at the request of its president. Three separate surveys involving more than 7,000 students uncovered extremely useful information, including:

- **Puerto Rican teens have not effectively used contraception.** Ninety-five percent of the University students know that condoms can protect them from contracting HIV. Yet, only about one in ten report always using them. In addition, only three in ten men and one in ten women gave correct responses to all four questions about correct condom use. Since condoms are not always used, the number of sexual partners becomes an important risk factor. University of Puerto Rico men on the average report a mean of 6.1 lifetime partners; women report 2.5.¹
- **Many puerto rican heterosexual couples engage in anal intercourse.** Approximately 30 percent of the University women report having engaged in anal intercourse.² They cite the desire to please their partner and themselves. When asked who decides on this type of intercourse, nearly two-thirds of the women responded that their partners always made the decision while 30 percent of the men said that both partners decided. These data indicate a different perception of a specific practice by men and women.³
- **Puerto Ricans have rigid sexual norms and polarized gender roles.** Both old and new surveys show that there exists on the island a traditional expression of sexuality, rigid

*“A Center goal is...
to ascertain the
socio-cultural factors
in risk behavior.”*

sexual behavior norms, and polarized gender roles.

These findings, among others, indicate that meaningful HIV/AIDS interventions must be developed with a clear understanding of sexual behavior within the context of socially and culturally constructed meanings of social interactions.⁴ While people can learn from research in other societies, they must conduct research in their own society in order to:

- analyze the organization of sexual interactions, the cultural roles in sexual behavior, and the way men and women view their bodies
 - study the relationships between meaning and power in sexual experiences by gender
 - examine the contexts in which safe and unsafe sexual practices occur
 - understand male and female perceptions of risk for HIV and STDs
 - study verbal and nonverbal communication between couples;
 - identify styles of interventions and the factors and scenarios involved in them
- recognize appropriate sites where future interventions could be offered.

These are only some of the issues which the Center has begun to consider.

THE RESEARCH PROGRAM

The Center's original surveys did not provide sufficient insight into the reason why the University students, who are aware of the fact that their sexual behavior left them at risk for HIV infection, did not take preventive measures.

The Center has, therefore, embarked on a five-year project to relate contextual variables to the specific context of sexuality and gender roles in sexual negotiation and sexual practices in Puerto Rico. In the process, it plans to refine and test a conceptual model that explains the relationships between these elements, and to develop a curriculum for intervention that will enable young people to effectively negotiate safer sex practices.

Data from focus groups have provided interesting

insights. The project has found that Puerto Rican men and women see themselves, to some extent, as limited by their gender roles. They still subscribe to some of the more traditional concepts of gender roles and sexuality. For example, men still emphasize the physiological aspect of sexuality, whereas women emphasize feelings and emotions. Women still see themselves as sex objects who are not expected to talk about sexuality. Both men and women still acknowledged the importance of social taboos and prohibitions regarding sexuality.⁵

Study on masculine identity, male sexuality, and high-risk sexual practices. The project has also found that in Puerto Rico, as in other societies where the masculine ideology is dominant, a man is expected to be proud of his sexuality, to display it, and, above all, to demonstrate it. Unfortunately, sexual harassment and violence are often part of this orientation to conquer and control women.⁶ The Center is beginning to study the relationships between the dominant sexual culture, the construction of male identity, and the influence of these factors on the sexual practices of men who have sexual relations with women. This will help to explain how penetration, power, and pleasure are related to sexual practices with a high risk for HIV and STD infection.

Project about verbal and nonverbal communication between men and women. Another project, which is just beginning, involves the study of verbal and nonverbal communication between men and women. Are these messages congruent? To what extent do the sender and the receiver understand the same message? Do women understand the cues that men give? Do men understand those that women give? To which aspect, the verbal or the nonverbal, do sexual partners pay more attention? Are there gender differences? This type of research will help the Center create better interventions and modules for a curriculum for elementary, junior high, high school, and university students.

Project to study communication patterns between mothers and daughters in relation to HIV risk behavior. The Center is engaged in a pilot project with the Medical College of Wisconsin to study communication patterns between Puerto Rican mothers and daughters and their relationship to HIV-related sexual behavior. Given the importance of family, friends, and neighbors in influencing and reinforcing beliefs among Latinos,⁷ an eventual intervention to help mothers improve their communication skills with their daughters should result in safer sex practices.

THE CENTER'S EDUCATION PROGRAM

In an analysis of sexuality education and HIV/AIDS texts used in junior high and high schools on the island, the Center has found that most were written in the United States and translated into Spanish. These texts emphasize

reproduction and physiology with little regard for the cultural and social aspects of sexual relationships. The Center is working to correct this problem by developing programs that will help students both learn and talk about their sexuality from a more holistic perspective. A long-term goal is to provide sexuality education curricula from kindergarten through high school and beyond.

A sexuality, HIV/AIDS anthology. The Center has already published an anthology titled *Sexualidad y el VIH/SIDA: Módulos innovadores de enseñanza (Sexuality and HIV/AIDS: Innovative Education Modules)* that contains 26 units and two original short stories about sexuality and HIV/AIDS that instructors can incorporate into many different university courses.

Each unit contains (1) a summary of the content; (2) a list of instructional objectives or expected outcomes; (3) a list of questions for discussion; (4) a description of the instructional methodologies; (5) a list of suggested readings for students; (6) an essay that discusses the thematic content; (7) a list of classroom activities; and (8) an extensive bibliography for the professor

Examples of the modules include "The Social Aspects of Epidemics" (for history and biology courses); "Sexual Negotiation" (for a variety of courses); "How to Deal with the Death of a Loved One" (for psychology, counseling, and social work courses); "HIV/AIDS and the Puerto Rican Press" (for communication, sociology courses); "How to Become Men and Women by Watching TV Programs" (for psychology and communication courses), as well as original stories about safer sex and other topics related to sexual relations and love (for humanities courses).

Integrated sexuality curriculum for intermediate school students. The Center recently received funds to develop modules with Project SAMM of Case Western University that are based on an holistic perception of sexuality education for seventh graders. The Center will test the modules in two schools on the island.

CONCLUSION

The Center is approaching HIV/AIDS infection as a consequence of insufficient knowledge of sexuality and gender roles, and insufficient skills in interpersonal communication to adequately negotiate safer sexual practices.

The Center will continue to carry out research to build an holistic integrated sexuality education curriculum where young people can learn to talk about their sexual health, and, in the process, help prevent HIV infection and other sexually transmitted diseases and also promote an attitude of tolerance and understanding.

(Copies of the anthology Sexualidad y el VIH/SIDA: Módulos innovadores de enseñanza (Sexuality and HIV/AIDS: Innovative Education Modules) are available for \$22 (plus

\$4.50 regular shipping and handling or \$5.50 air mail) for the softbound edition and \$25 (plus \$8.50 regular shipping and handling or \$11.50 air mail) for the loose-leaf edition by writing to HIV/AIDS Research and Education Center, University of Puerto Rico, P. O. Box 23345, Río Piedras, PR 00931-3345.)

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FACTS SUPPORT NEED FOR PUERTO RICAN RESEARCH

The HIV/AIDS Research and Education Center of the University of Puerto Rico was founded in 1993 in response to a number and trends including:

- **A high rate of prevalence.**

Since 1981, over 21,000 Puerto Ricans have been diagnosed with AIDS.¹ In the United States, the District of Columbia and New York State are the only two areas with a higher prevalence rate.² In 1994, AIDS was the fourth cause of mortality in the general population and the leading cause of death from men 30 to 49 years old and for women 25 to 39 years old.³

- **An increase in heterosexual transmission.**

Intravenous drug use is the most frequent risk factor for AIDS among Puerto Ricans. Heterosexual intercourse is, however, increasing as a risk factor: up from 5.7 percent of reported cases in 1987 to 33.6 percent in 1996.⁴

- **Failure of information campaigns to change behaviors.**

In the most recent island-wide reproductive survey of Puerto Rican women 15 to 49 years old, the reported current use of condoms by their partners rose only from 4.4 percent to 6.5 percent between 1982 and 1996.⁵

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TEENAGE PREGNANCY

Teenage pregnancies in the United States have declined in recent years but they remain an endemic public health problem. Young women of color and young women of low income are disproportionately affected by teenage childbearing.

PREGNANCY RATES

- Teen pregnancy rates are much higher in the United States than in many other developed countries—twice as high as in England, Wales or Canada, and nine times as high as in the Netherlands or Japan.¹
- One in every 15 men fathers a child while he is a teenager.²
- The 1995 Youth Risk Behavior Surveillance reported that, nationwide, 6.9 percent of students reported that they had been pregnant or gotten someone pregnant.³
- Half of all initial adolescent pregnancies occur within the first six months following first intercourse, and 20 percent occur within the first month.⁴
- Estimates available for the early 1990s suggest that the pregnancy rate peaked in 1990 and 1991 at 115 pregnancies per 1,000 females 15 to 19 years old.⁵
- In 1992, 112 pregnancies occurred per 1,000 U.S. women 15 to 19 years old. Of these, 61 ended in births 36 in abortions, and 15 in miscarriages.⁶
- One in five African-American teenagers and one in six Latina teenagers become pregnant each year.⁷
- There is a direct relation between poverty level, education of parents, and pregnancy rates in communities of color. Young people who live in extreme poverty with parents who have low levels of education have higher rates of pregnancy than youths who live in better socioeconomic conditions.⁸

UNINTENDED PREGNANCY

- Among teenagers, 85 percent of pregnancies are unintended, accounting for 25 percent of all unintentional pregnancies annually.⁹
- Among teens 15 to 17 years old, 46 percent of those with incomes below the poverty level are at risk of unintended pregnancy, compared with about one third of teens with family incomes 2.5 times the poverty level or above.¹⁰

BIRTH RATES

- In October 1996, the U.S. Department of Health and Human Services released data showing an 8 percent drop in the teen birth rate from 1991 to 1995.¹¹
- The birthrate for teenagers 15 to 19 years old per 1,000 was 56.8 in 1995. This rate declined steadily from its recent high in 1991 (62.1) and earlier high in 1970 (68.3).¹²
- In 1995, the birthrate for teenagers 15 to 17 years old declined 4 percent, while the rate for teenagers 18 to 19 years old declined 3 percent.¹³
- Birthrates for second births for teenagers declined in 1995 by 4 to 9 percent.¹⁴
- In 1994, the teen birthrate dropped slightly among African-Americans, stayed the same among Caucasian teens, and rose slightly for Latinas. The birthrate for Latina and African-American teens is 108 per thousand females 15 to 19 years old compared to 40 births per thousand for Caucasian females 15 to 19 years old.¹⁵

ABORTION

- The abortion rate, which remained in the low forties per 1,000 females 15 to 19 years old throughout the 1980s, also declined in the early 1990s, from 40 abortions per 1,000 females 15 to 19 years old in 1990, to 38 in 1991 and 36 in 1992.¹⁶
- 35 percent of all pregnancies among women 19 years old and younger end in abortion.¹⁷
- Teenagers who have abortions most often cite their young age and low income as the reason why they decide to end their pregnancies.¹⁸
- 11 percent of abortions are obtained after 12 weeks of pregnancy; these later abortions are disproportionately obtained by adolescents. Among young women under 15 years old, 22 percent of all abortions are done in the second trimester compared to 9 percent to women over 20 years old.¹⁹

PREGNANCY RISKS AND OUTCOMES

- 94 percent of teens believe that if they were involved in a pregnancy they would stay in school; in actuality, 70 percent eventually complete high school.²⁰

- 51 percent of teens believe that if they were involved in a pregnancy they would marry the mother/father; in actuality, 81 percent of teenage births are to unmarried teens.²¹
- 26 percent of teens believe that they would need welfare to support a child; in actuality, 56 percent receive public assistance to cover the cost of delivery and 25 percent receive public assistance by their early twenties.²²
- 32 percent of teens say they would consider an abortion; in actuality, 50 percent of pregnancies to unmarried teens end in abortion.²³

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CALL FOR SUBMISSIONS

The *SIECUS Report* welcomes articles, reviews, or critical analyses from interested individuals. Detailed instructions for authors appear on page 29 of this issue. Upcoming issues of the *SIECUS Report* include:

Sexuality Education Worldwide

June/July 1998 issue.

Deadline for final copy: March 1, 1998

Sexuality and the Law

August/September 1998 issue.

Deadline for final copy: May 1, 1998

ABSTINENCE-ONLY GUIDELINES RESTRICT POSTPONING SEXUAL INVOLVEMENT ADAPTATION

Emily Lamstein
SIECUS Program Associate

Debra W. Haffner, M.P.H.
SIECUS President and CEO

A new adaptation of the popular *Postponing Sexual Involvement* comprehensive sexuality education curriculum (Emory/Grady Teen Services Program, Grady Memorial Hospital, Atlanta, GA) is strictly aligned to the seven restrictive provisions of the new federal "abstinence-only" education guidelines.¹ Titled *Managing Pressures Before Marriage*, the new adaptation says, among other things, that:

- abstinence from sexual activity outside marriage is the expected standard for all school age children;
- a mutually faithful monogamous relationship in the context of marriage is the expected standard of human sexual activity; and
- sexual activity outside the context of marriage is likely to have harmful psychological and physical effects.

DISMAY AT NEW VERSION

SIECUS staff were dismayed to review the new *Managing Pressures Before Marriage* curriculum because the changes turn the effective *Postponing Sexual Involvement* curriculum (which is abstinence-based and is designed to help young people delay sexual involvement until they are physically, cognitively, and emotionally mature) into one that explicitly promotes the restricted "abstinence-only" federal law (which say that marriage is the only acceptable context for sexual relationships).

In the process, the new *Managing Pressures Before Marriage* version risks alienating adolescents who are sexually active, who are children of single parents, and who may be gay, lesbian, or bisexual.

Managing Pressures Before Marriage also omits other critical information included in the original *Postponing Sexual Involvement* program. Specifically:

- HIV/AIDS is mentioned only briefly and is never defined or discussed;
- contraception and condoms are not discussed except to say that they are not 100 percent effective in preventing

pregnancy and sexually transmitted diseases (STDs);

- sexual orientation is never mentioned, and all the role plays and skits are heterosexual;
- the "Finding Help" section has been significantly changed. It had encouraged young people to seek more information from parents, libraries, physicians, and hotlines.

PSI WAS EFFECTIVE

First published in 1983 and still available, the original *Postponing Sexual Involvement* curriculum contains detailed, comprehensive information about reproduction, family planning, and sexually transmitted diseases.

It also has a proven track record. Phone interviews with 536 eighth grade students from the Grady Hospital's low-income population showed that only four percent of program participants began having sexual relations by the end of eighth grade as compared to 20 percent of nonparticipants. The program has also had a lasting effect. By the end of the ninth grade, just 24 percent of participants had begun having sexual relations as compared with 39 percent of nonparticipants.²

SIECUS was surprised to review this adaptation. We have long supported *Postponing Sexual Involvement* as a non-fear-based approach to helping adolescents delay sexual involvement. We know the authors and know they are experienced and concerned about the education and health needs of young people. We asked them to respond to this article. They chose not to. They did ask us to let *SIECUS Report* readers know that *Postponing Sexual Involvement*, in its original form, is still available.

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"The changes
turn the program
into one that
explicitly
promotes...
'abstinence-only.'"

MANAGING PRESSURES BEFORE MARRIAGE MIRRORS RESTRICTIVE FEDERAL GUIDELINES

The new *Managing Pressures Before Marriage* curriculum, based on the popular *Postponing Sexual Involvement* comprehensive sexuality education curriculum, mirrors the restrictive “abstinence-only” federal law.

The following are comparisons between the language in the the two curricula and the federal law. The comparisons demonstrate how the new curriculum reflects the the language in the abstinence-only law.

Federal Guidelines: (A) Programs must have as their exclusive purpose “teaching the social, psychological, and health gains to be realized by abstaining from sexual activity.”

- “[*Postponing Sexual Involvement*]...was developed to help young people learn skills to resist pressures to become sexually involved before they are ready for such involvement.” (page 3)
- “[*Managing Pressures Before Marriage*]...was developed to help young people learn skills to resist pressures to become sexually involved outside the context of marriage....It creates understanding of the social, psychological, and health gains to be realized by abstaining from sexual activity. (page 3)

“One of the main purposes of the *Managing Pressures Before Marriage Educational Series for Young Teens* is to affect peer norms, reinforcing those that support abstinence and converting others to an abstinent point of view, or at least neutralizing opposition to those who wish to abstain.” (page 3)

- “[*Managing Pressures Before Marriage*] is designed to help teens begin to define the social, psychological, or health gains to be realized by abstaining from sexual activity.” (pages 3, 15)

Federal Guidelines: (B) Programs must teach “abstinence from sexual activity outside marriage as the expected standard for all school age children.”

- “[*Postponing Sexual Involvement*]...was developed to help young people learn skills to resist pressures to become sexually involved before they are ready for such involvement.” (page 3)
- “[*Managing Pressures Before Marriage*]...was developed to help young people learn skills to resist pressures to become sexually involved outside the context of marriage....It creates understanding of the social, psychological, and health gains to be realized by abstaining from sexual activity.”(page 3)
- *Postponing Sexual Involvement* says: “Most of us reserve the

next two steps for those few special people for whom we have very special feelings. And in most people’s lifetimes, there are only a couple of special people with whom they would choose to share the bottom step.” (page 49)

- *Managing Pressures Before Marriage* says: “Leader points to have sex sign. ‘And in many people’s lifetimes, they will share the last level only with someone to whom they are married. Society feels it is in teens’ best interests to stop before this level because teens usually are not ready for marriage and all the responsibilities that go along with being a parent.” (page 78)

Federal Guidelines: (C) Programs must teach “that abstinence from sexual activity is the only certain way to avoid out-of-wedlock pregnancy, sexually transmitted diseases, and other associated health problems.”

- *Managing Pressures Before Marriage* says: “The preteens participating in this Series will also be able to:
 - Identify that abstinence from sexual activity is the only certain way to avoid out-of-wedlock pregnancy and sexually transmitted diseases and other health problems.” (page 5)

Federal Guidelines: (D) Programs must teach “that a mutually faithful monogamous relationship in context of marriage is the expected standard of human sexual activity.”

- *Managing Pressures Before Marriage* says: “The preteens participating in this Series will also be able to:
 - State that society expects school-age youth to wait until marriage before becoming sexually involved.
 - State that society expects that people who are married will be faithful to one another. (pages 5, 9, 11, and 45)
- *Managing Pressures Before Marriage* says: “As you know, our society feels it’s better for teens to wait until they are married. Although marriage may seem like a long way off to you now, it is clear that the consequences of a sexual relationship are much better handled within marriage. (page 12)
- *Managing Pressures Before Marriage* says: “Our society, and most other societies, expects that eventually all people will

mature and be able to make a commitment to one other person, marry them, and remain faithful to that person. Over time, that has proven to be in most people's best interest and in the best interests of society." (page 39)

Federal Guidelines: (E) Programs must teach "that sexual activity outside of the context of marriage is likely to have harmful psychological and physical effects."

The authors clearly had the most trouble repeating this assertion which is not based on any scientific evidence. They try to turn it into a statement that is defensible, at least to some extent.

- *Managing Pressures Before Marriage* says: "The preteens participating in this Series will also be able to:
 - Identify the risks associated with sexual involvement before marriage.
 - Name one harmful psychological or physical effect that could result from violating a commitment to have sex only within marriage. (pages 5, 69, and 116)
- *Postponing Sexual Involvement* says: "Pam could tell Larry how much she liked him, but that she is not ready for a relationship which involves sexual touching at this time." (page 87)
- *Managing Pressures Before Marriage* says: "Pam could tell Larry how much she liked him, but that she does not want to become sexually involved until she is married....Since Pam has chosen to wait until she is married before having sex, she needs to understand that violating her beliefs could have harmful psychological and physical effects. For example, she could feel guilty about what she has done. It could affect her belief in herself and her ability to control her actions. It could also lower her self esteem. If she got a sexually transmitted disease, it could lead to health problems, including not being able to have children later when she was married." (page 143)

Federal Guidelines: (F) Programs must teach "that bearing children out-of-wedlock is likely to have harmful consequences for the child, the child's parents, and society."

- *Managing Pressures Before Marriage* says: "The preteens participating in this Series will also be able to:
 - State one way that having children without benefit of marriage can harm the child, the parent, and society." (pages 5, 9, and 11)

"Our society feels it's better for teens to wait until they are married. Although marriage may seem like a long way off to you now, it is clear that the consequences of a sexual rela-

tionship are much better handled within marriage.

"For example, children are better off when they have two parents who are committed to each other and to the health and well-being of their children. Parents who have to raise a child by themselves are under a lot of pressure to try to be both a father and a mother to that child.

"Without the support of another parent, single parents can be easily overwhelmed by all the responsibilities of raising a child. It can leave them with little or no time and money for themselves and their personal needs. It can limit their ability to achieve personal goals other than being parents.

"Also, children born to a single parent have a greater likelihood of being poor and this can have harmful consequences for the children and for society." (page 12)

- *Managing Pressures Before Marriage* says: "Again, it is important to understand that beginning childrearing without the commitment of another partner in marriage is not what society expects because it can have negative consequences for both parent and child." (page 18)

Federal Guidelines: (G) Programs must teach "young people how to reject sexual advances and how alcohol and drug use increases vulnerability to sexual advances. Federal Guidelines (H) teaches "the importance of attaining self-sufficiency before engaging in sexual activity."

- "[*Postponing Sexual Involvement*]...was developed to help young people learn skills to resist pressures to become sexually involved before they are ready for such involvement." (page 3)
- "[*Managing Pressures Before Marriage*]...was developed to help young people learn skills to resist pressures to become sexually involved outside the context of marriage....It creates understanding of the social, psychological, and health gains to be realized by abstaining from sexual activity....They are helped to understand that it is in their best interests to wait before having sex, allowing themselves time to become self-sufficient, mature, and ready for marriage." (page 3)
- *Managing Pressures Before Marriage* says: "Avoid situations that might lead to sexual involvement before marriage." (page 5)
- *Managing Pressures Before Marriage* says: "To reinforce the importance of being independent and self-sufficient before marriage and sexual involvement." (pages 9, 25)

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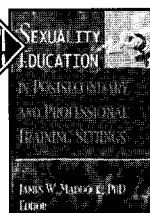


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