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Facts and Myths of AIDS and Native American Women

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INTRODUCTION

The standing of women in traditional Native societies varied from tribe to tribe. In many tribes women held positions of political, social, military, and spiritual leadership. They had the right to choose marriage partners, divorce, own land and property, as well as take critical roles in trade, home life, acculturation, assimilation, and political activism. In sum, Native women have been found to have egalitarian roles within their societies. The role of Native women today remains vital in a variety of tribal communities with recent studies emphasizing that they are essential in forming the "very core of indigenous resistance to genocide and colonization" and in transmission of culture.[1] The most important role of Native women, however, has been and continues to be that of mother. To bear and/or care for Native children is a position of honor and value throughout Native North America. Hence, the health and well-being of Native women is essential.

Although elements of traditional standing are found in the lives of many modern Native women, times have changed. Like other women in the United States, Native women today have less economic, social, and political power than men. They are a silent and marginalized group often relegated to dependency upon male partners. And as women of color, Native women have a lower economic, educational, and social status. Their position in society impacts every facet of their lives, particularly their health.

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This essay explores the facts and myths of AIDS among Native American women and discusses these women's vulnerabilities to the disease and steps being taken in the area of prevention. Since there is very little information on Native women and HIV/AIDS, I rely on research on Native women in South Dakota as well as general research on women and AIDS.

WORLDWIDE AND US AIDS STATISTICS

One of the most dangerous health problems for poor women around the world is HIV/AIDS. It is estimated that worldwide over 30 million people have been infected with HIV since the beginning of the epidemic in the early 1980s, and women account for more than 40 percent of adults infected.[2] The majority of the reported cases are among poor women. This statistic places a new face on the disease: a woman's face.

HIV/AIDS was identified in women early in the epidemic, but it was virtually ignored. When AIDS was first recognized among young gay men the disease was also identified in a woman. Shortly thereafter, other cases were reported that included women who injected drugs, hemophiliacs, and poor people who did not share the same risk factors as young gay men.[3] Yet AIDS continued, particularly in the United States, to be labeled as a gay man's disease or, from a Native American perspective, a *white* gay man's disease. This misunderstanding and misinformation about HIV/AIDS, coupled with current news coverage that the number of reported AIDS cases is decreasing, has led many to believe that AIDS is no longer a problem—particularly not a woman's problem.

Contrary to the popular understanding of HIV/AIDS and its impact, statistics demonstrate that infection is growing rapidly among women. In the United States the proportion of AIDS cases that are adult/adolescent women has increased from 7 percent of the annual total in 1985 to 22.9 percent in 1998.[4] Although infection among women has grown steadily, it was not until 1995 that The First National Scientific Meeting on HIV Infection in Adult and Adolescent Women was held in Washington, D.C.[5] At the conference the main theme was that women have been silenced through coverage of the epidemic and given a "seriously short shrift in AIDS research and treatment."[6] The participants noted that women were increasingly dying from AIDS and called for action.

While the number of women diagnosed with AIDS in the United States is steadily increasing, women are not affected equally. Of all the reported AIDS cases among women in 1998, African-Americans represented 56.7 percent (64,345), Whites 22.1 percent (25,104), Hispanics 20.1 percent (22,879), Asian/Pacific Islander .5 percent (585), and Native Americans .2 percent (232).[7] Clearly, the statistics are alarming with certain ethnic women representing large percentages of their respective ethnic group: African-Americans 25.6 percent, Hispanics 18.3 percent, Native Americans 16.7 percent, Asian/Pacific Islanders 11.8 percent, and Whites 8.3 percent.[8]

NATIVE AMERICAN WOMEN'S VULNERABILITY TO AIDS

Because the total number of Native AIDS cases is low, the threat to Native women has not been acknowledged until recently. Tribal communities are becoming more aware of the increase of HIV/AIDS among Native women as indicated in their participation in several conferences, including Empowerment: A Strategy for HIV/AIDS Preventions and Access to Care Among Women of Color and The Native Women and Wellness Conference.[9] Both conferences specifically addressed the wellness of Native women. Another indicator of concern over the rise of AIDS among Native women can be found in a recent article in the *Navajo Times* entitled "WARNING! 3 pregnant Native Women test HIV positive." The article notes that "AIDS has no boundaries" and that previous studies on the Navajo Reservation demonstrated that in the past ten years only two women were diagnosed with HIV but recent statistics show that "in the past six months three pregnant Native American Women in the Navajo Area of Indian Health Services have tested positive for HIV."[10] As with other minority women, Native women are vulnerable to acquiring HIV infection because of biological, economic, and social factors.

HIGHER RATES OF INFECTED MALE PARTNERS

The growing number of infected males increases the odds that a female will have an infected partner. One factor that makes women today more vulnerable to HIV infection is the large number of men who have AIDS. In the United States there are more men (592,552) than women (118,789) who have AIDS.[11] In addition, HIV infection cases reported through June 1999 from thirty-three areas with confidential reporting demonstrate that males have twice as many infections (82,657) than females (31,293).[12] In contrast to the general perception of AIDS being a man's disease, HIV is considered by some scholars as a "biologically sexist" disease because women are biologically more susceptible.[13] The virus is more concentrated in seminal fluids than in vaginal secretions and some studies show that HIV is anywhere from two to twenty times more efficiently transmitted from men to women.[14] Heterosexual transmission of AIDS to women has risen from 13 percent of women with AIDS in 1983 to 39 percent in 1998.[15] Most alarming is the fact that the number of women infected by heterosexual contact has increased 243 percent from 1994 to 1998.[16]

BIOLOGICAL VULNERABILITY

Women are also susceptible to infection because HIV enters the bloodstream easily through the lining of the vagina and cervix.[17] Some researchers argue that "vaginal dryness" is an additional risk factor for some menopausal women, as well as the thinning of vaginal walls, which makes them more susceptible to tearing and subsequently to HIV infection.[18] It has been noted that research in the area of menopausal women and HIV/AIDS is lacking and the scant biomedical information on older women indicates that the disease may

progress quicker due to delayed diagnosis and/or immune suppression as a function of age. It is also suggested that older infected menopausal women have more difficulties and that there is a possibility that "hormone replacement therapy may contribute to HIV risk through the immunodepressive effects of estrogen and progesterone."[19]

SEXUALLY TRANSMITTED DISEASES

Women's vulnerability increases further if they had or have a sexually transmitted disease (STD). The presence of STDs not only signifies high-risk behavior (unprotected sexual intercourse) but also can assist in the transmission of HIV. STDs allow entry for HIV through open sores or microscopic breaks in affected tissue.[20] It has been reported that when a person is infected with an STD, "he/she is two to five times more likely to become infected with HIV."[21] The risk will vary depending upon the particular STD. For example, ulcerative STDs have the greatest risk because they affect the integrity of the vaginal protective barrier, creating an open portal of entry for HIV infection, and host the immune cells that HIV may infect.[22]

The relationship between HIV/AIDS and STDs place Native people in grave danger because Native communities have high STD rates. In South Dakota, where Natives are 6.7 percent of the population they represent 40.2 percent of the state's gonorrhea cases.[23] They have the highest gonorrhea percentage of any race in the state. A study of thirteen states revealed that gonorrhea and syphilis rates among Native people were twice that of non-Natives.[24] Chlamydia trachomatis, which has passed gonorrhea as the most common sexually transmitted disease in the United States with an estimated 4 million infections a year, is also a problem among the Native population.[25] The Indian Health Service (IHS) is engaging in a campaign to stop the spread of chlamydia because Native communities have "the highest documented rates of chlamydia in the U.S."[26] A study in Alaska found that rates for rural Inupiat women compared to the local non-Native population were ten times higher.[27] It is easy to see why the IHS feels that the "prevention of STDs may be one of the most effective means to prevent HIV/AIDS."[28] The IHS statements are encouraging and echo calls for action by Native organizations. For several years the Native American Women's Health Education Resource Center has been calling for aggressive efforts to stem the STD rates in an effort to slow HIV transmission.[29] In addition, many women are exposed to complications of undiagnosed or untreated STDs—70 to 80 percent of STDs go unnoticed because individuals do not show any symptoms.[30] STDs such as chlamydia, gonorrhea, and primary syphilis may be asymptomatic, particularly in women. A screening of female patients in IHS facilities during routine pap smears found that 59 percent of chlamydia infected women had no symptoms.[31] STDs, like AIDS, tend to be diseases of poverty because they are intensified by conditions of economic hardship whereby women do not have the money or time to get tested, leaving their STDs or HIV infections untreated.

HIGH POVERTY RATES

To many AIDS scholars and researchers, poverty is one of the leading cofactors in the advance of the global AIDS pandemic. This fact is especially alarming for women since 70 percent of the world's poor are women, placing them at high risk.[32] In the United States, HIV has moved freely through impoverished communities. It has been found that the HIV virus disproportionately affects women "from poor and minority populations in more affluent countries, and [who] come from a background of poor physical and mental health, malnutrition, and inadequate health care."[33] Complaints have been made in the United States that collecting data on women and AIDS by ethnicity rather than by socioeconomic status distorts the fact that "the majority of women with AIDS in the U.S. are poor" and at extreme risk.[34] Employment status for Native women placed them in a potential high-risk category, showing that economic conditions must be taken into consideration in the fight against HIV/AIDS.

In the United States the percentage of unemployment for females age sixteen and above is 6.2 percent; for Native women it is 13.4 percent.[35] The low economic status for Native women thus places them in a potential high-risk category because poverty prevents or inhibits people from obtaining health education, accessing good health care, and obtaining proper medical treatment, all of which assist in the prevention and treatment of AIDS. A physician and AIDS activist, Paul Farmer, has found "that some women are, from the outset, at high risk of HIV infection, while other women are shielded from risk."[36] He defines women "whose social [and economic] status denies them access to the fruits of scientific and social advances" a result of "structural violence," meaning that the women are made vulnerable to HIV/AIDS through the social processes that shape the dynamics of HIV transmission.[37]

With poverty comes a host of other factors, such as poor health, poor diet, and threatening related diseases, making Native people more vulnerable to HIV infection. Diabetes, a leading cause of morbidity and premature mortality in Native populations, weakens the immune systems, hastening the progression of HIV to AIDS. The disease is widespread among tribal people. In the Aberdeen area of South Dakota, IHS statistics indicate that Native people with diabetes are "13 times more likely to require kidney dialysis, 6.5 times more likely to have lower extremities amputated, and half of those with diabetes will get diabetic eye disease that leads to blindness."[38] Again the factor is relevant to women and HIV/AIDS because a 1998 study reported that the majority of the 63,400 Native diabetics who received care from the Indian Health Services in 1996 were women.[39]

Since poverty is closely related to health and disease it is also a factor in determining the length of survival after contracting AIDS. Studies report that once Native women develop AIDS they have a shorter survival time than men following the trend indicated in survival studies suggesting that women, in general, are more likely to die earlier than men once diagnosed with AIDS.[40] AIDS-related deaths, in general, dropped 26 percent between 1995 and 1996.[41] For Native people between January 1996 and June 1996 AIDS deaths dropped by 32 percent compared to January 1995 and June 1995. The

decrease was more substantial among Native people than any other ethnic group and many credit the decline to an increase in access to health care and improved treatment options accessed through Native American HIV case management programs. However, while Natives as a group experienced a decrease, women saw an increase in AIDS-related deaths of 3 percent.[42] There are several possible reasons for the rise in AIDS death among Native women. It has been found in survival studies that gender inequality (social and economic) may lead to the differences in survival rates.[43]

FEMALE-HEADED HOUSEHOLDS

Researchers are not in complete agreement over whether women die earlier because of biological or socioeconomic factors. Some researcher feel that survival differences may be biological while other studies suggest that survival differences have more to do with inadequate medical care rather than biological differences. Women tend to seek medical attention later than men, when their symptoms are already advanced, and then they usually receive lower quality of health care. This is especially true for women who are heads of households and primary caretakers in families.[44] According to the government census in 1997, 27 percent of the nation's American Indian family households were maintained by a woman with no husband present.[45]

The difficulties that women who are heads of households encounter are enormous. As primary caregivers many women must place their needs and concerns after the needs of their children and family. A recent study found that one-third of HIV patients forgo medical care because they cannot afford the time or money.[46] They spend their money on basics—food and shelter—rather than themselves. Native women, like poor women in general, have others dependent upon them for their basic needs. This is illustrated through the narrative of Nan, an HIV positive 46-year-old Shawnee/Delaware woman with seven children, who explains that her number one need is to "make my bills meet at the end of each month and make sure my children are taken care of."[47] A woman who is HIV positive or has AIDS, and is the head of the household is placed in an even more trying situation with burdens of illness, emotional exhaustion, and the emotional needs of their own children. A recent study of HIV and family structure and the parenting challenges of HIV-infected mothers found that disclosure of their status to their children and planning for their children's future were the two critical issues facing them.[48] The burdens placed on HIV/AIDS positive women increase if there is a child in the family who also has HIV/AIDS. They not only fear losing their own life but also that of their child.[49] It is estimated that between 1992 and 2002 between 93,000 and 112,000 uninfected children will be born to infected women.[50] The stress under which "single-status" women are placed can be daunting, overwhelming, and can lead to other medical conditions.

Another problem poor women encounter is obtaining adequate care. Author Martha Ward has noted how poor women tend to receive inadequate health care, in part because "service providers have a continuing orientation to middle-class values."[51] Native women speak about the lack of compassion that

health workers have for them and complain that they are not viewed as "individuals."[52] Another factor closely tied to receiving adequate care is relative isolation. One HIV-infected Native woman spoke of the hardship of getting "to places that know about HIV." She stated that since she lives "on a very limited income" she has "to be very careful about her budget and try to make sure that she has enough money set aside for gas to get her to her doctor's appointment," which is seventy miles away.[53] Infected women who live in Indian country may have to travel as far as 300 miles one way to a health clinic.[54] One Native woman described how she traveled on foot to a main road when her rural road was impassable and then hitchhiked to her doctor appointments.[55]

RELATIONSHIP WITH PARTNERS

Low Rates of Condom Use

Powerlessness of Native women is another factor that affects potential HIV/AIDS infection and is related to poverty. For example, poverty contributes to women's dependence and lack of power in the family, particularly if the partner is the one who "brings home the bread." This limits the ability of women to insist on monogamous relationships or condom use, which is of great importance in preventing the spread of HIV among women, particularly since HIV transmission through heterosexual contact is on the rise. Sadly, studies show that less than 20 percent of high school and college women who are sexually active use condoms, clearly indicating that new strategies are needed to prevent the spread of HIV.[56] Empowerment and effective communication are critical in providing women with the tools for condom negotiation. Condom use has been found to be a complex issue in sexual relationships, and is tied to poverty, self-esteem, the preservation of good relationships with their children's father, abuse prevention, rejection, and abandonment.[57]

Domestic Violence

Poverty is also a factor that keeps women in violent and abusive situations. It has been shown that violent-crime rates are highest for those whose annual income is less that $7,500.[58] Studies have also shown that women who live in violent circumstances are too scared to demand that their abusive partners wear a condom. Women in the United States confront violence regularly. Statistics show that in their lifetime, 50 percent of women will be battered, with one out of three being physically abused repeatedly every year and that every seventy-eight hours a women will be forcibly raped.[59]

The statistics for Native women are equally frightening. Although Native Americans comprise .6 percent of the US population, 1.4 percent of victims of violence are Natives. Between 1992 and 1996 the percent of rape/sexual assault against Native people was 5.6 compared to the US average of 4.3 percent.[60] The violent crime rate against Native females was found to be ninety-eight per 1,000 females, the highest among all female ethnic categories.[61] In South Dakota, where Native women are a very small portion of the state

population, they constitute 50 percent of the domestic violence shelter population.[62] A study of sixty-eight Native American women in New York City revealed that 44 percent of them reported a lifetime trauma that included domestic violence plus physical or sexual assault.[63] In an interview, Kashka, a Native Alaskan HIV positive woman, related that after her husband had sex with an HIV positive male in the village she was afraid to ask him to wear a condom or to refuse sex because it would make him "angry and violent." Furthermore, she knew she would have little support from other women because she felt that in her village it is wrong to refuse to have sex with your husband.[64] A history of childhood violence and living with adult-age violence not only makes negotiating safe sex extremely difficult, but also produces what some clinicians call posttraumatic stress disorder in women.[65] Exposure to trauma and abuse among non-Native women has been associated with sexual risk behaviors and many HIV positive women have reported a history of abuse.[66] It is likely that the abuse and trauma that Native women have and are enduring will also contribute to their high-risk HIV behaviors. The violence against Native women in the United States has become so severe that the federal government has recently published a Request for Proposals (1999) for studies on violence against Native women.

Lesbians and AIDS

One aspect of Native women and HIV/AIDS that has been almost completely ignored is HIV/AIDS among lesbians. For example, there is very little work on violence against lesbians, which is not only a fact of life in the United States, but is also, according to some studies, on the rise.[67] Consequently, the studies on violence against lesbian Native women are virtually nonexistent.[68] There is a general idea that lesbians are immune from HIV/AIDS. This idea has been, in part, perpetuated by medial researchers and clinicians, the lack of national research, by physicians who publicly declare that "lesbians don't have much sex," and by the belief that HIV transmission from female-to-female is considered minimal.[69] The Center for Disease Control (CDC) has actively chosen not to use a transmission category of women who have sex with women because they view it as low risk. This action silences lesbians in the AIDS debate because CDC data assists in determining funding, hence excluding them from resources.[70]

It is critical that lesbians find a voice in the AIDS debate to keep themselves and their partners safe, and to assist in creating much-needed research and developing organizations that address the needs of lesbians. The story of Tara, a California Native lesbian and AIDS activist who was diagnosed with AIDS in 1989 details the difficulties she encountered when she was told of her diagnosis because there were no organizations for women with HIV/AIDS, and absolutely no services for lesbians. Tara's message in the late 1980s, stating that "none of us [lesbians] are just safe by virtue of our sexual identification or anything else," is still true today.[71] And many lesbians have come to realize that lesbianism is not a condom.

The assumption that lesbianism is a prevention against HIV/AIDS gives the false message that lesbians have nothing to fear. The myth that the risk to lesbians is minimal does not take into consideration that lesbian sexual activities can be diverse and include bisexuality, sex work, and the use of sex toys that can potentially create tears through which the HIV virus may enter.[72] Studies of female-to-female transmission are critical for lesbians to adequately assess their risks and vulnerabilities to HIV.

Vulnerability for lesbians comes from the same sources as other women, as well as from discrimination and the gay lifestyle. Two surveys found that "the lesbian community is underserved, underdocumented, and at greater risk than heterosexual women for a variety of health problems," because lesbians access health care less often.[73] Lesbians do not access health care for a variety of reasons. Some report that they receive poor treatment because of their sexual orientation. In many instances they do not trust health services to provide them with adequate or quality care. Other studies have reported that lesbians not only have high rates of breast cancer, but they are also more likely to smoke, be obese, and undergo a tremendous amount of stress due to discrimination by society and health care personnel.[74] In addition, the coming out process is very difficult for many Native lesbians and some do so by immersing themselves in the white gay party scene, placing them at further risk.[75]

LACK OF TRUST IN HEALTH CARE PROVIDERS

The issue of trust is also critical for effective HIV/AIDS prevention and care for Native American women. The history of distrust that Native people have for the government and health providers prohibits many women from seeking diagnosis, assistance, and medical attention. The distrust is due to a legacy of a history of deliberate introduction of diseases, as well as sterilization abuses among Native women. Native American women were at least two times more likely to be surgically sterilized than other women of color and many were sterilized without informed consent.[76]

For many Native people mistrust is combined with a lack of confidence in the Indian Health Service. One problem is the issue of confidentiality in small tight-knit Native communities where everybody knows everybody. Native women have described how they would "not even take brochures, fliers, or any HIV specific information for fear someone from the community might see it and guess about their HIV status."[77] There are others, however, who disagree with the idea that confidentiality is in fact a problem. Gloria Bellymule, a Cheyenne RN and case manager, for instance, thinks that the confidentiality issue is "a lot of phobia, due to the close-knit nature of Native communities."[78]

Another problem is the lack of confidence that the IHS will provide appropriate and quality care. Cordelia Thomas, a forty-eight-year-old rural Oklahoma Native woman with AIDS complained that her health facility was ignorant about HIV/AIDS and that "it's hard for people in the rural areas to access help, get to places that know about HIV."[79] She further noted her disappointment in IHS because they have not prioritized HIV.

INTRAVENOUS DRUG USE

By far the most critical cofactor placing women in danger is their behavior. For adult/adolescent women, the principal behavioral risk is intravenous drug use, the source of 42.8 percent of all reported female AIDS cases through December 1998. In the heterosexual exposure category, over 42.3 percent of cases resulted from sex with an intravenous drug user. Tragically, Native women have a higher percentage of intravenous drug use as a mode of transmission than any other race: Native American 47.1 percent, African-American 43.8 percent, White 42.4 percent, Hispanic 41.1 percent, and Asian/Pacific Islanders 17.2 percent.

Women who are intravenous drug users are at an extreme risk for contracting HIV because of their social circumstances. Paul Farmer, in his book *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence,* brilliantly discusses the connections among poverty, sex, money, and drug use. Farmer argues that drug users usually "hang" with other drug users and that females will spend time with male drug partners because of their perceived notion that they will be protected. This protection comes with a high price, however, because they increase their risk of HIV through sharing needles and having sex with men who may be infected with HIV.

Drug use and poverty are also tied to social behaviors that govern sex and money. It is fair to say that many drug users are in deep despair and struggling to survive. In this equation a woman who is exchanging sex for drugs or money has little power to negotiate condom use and, hence, places herself in severe danger for HIV infection. The drug-use lifestyle also places women at further risk through exposure to assault and rape. Studies have indicated that commercial female sex workers are in great danger from sexual violence by their male clients and intimate partners, whether they are drug users or not.[80]

Intravenous drug use among Native peoples is becoming more and more prevalent in urban, rural, and reservation communities. In South Dakota, for example, "at least a third of the AIDS cases in Native Americans are a result of injection drug use or having a partner that injects drugs."[81] Activist Carole LaFavor (Chippewa) believes that there is a lack of attention to Native American drug users due to the fact that many do not think Natives use drugs other than alcohol. This misunderstanding was further supported as recently as 1989 when researchers reported that there was a "low intravenous drug usage among Indians."[82]

LaFavor confronts the myth that Native people are not drug users in a video in which she discusses how she contracted HIV through intravenous drug use and how she used drugs with other Native people.[83] LaFavor's declaration that drug use is a problem is supported by John Bird, a consultant from Bozeman, Montana who publicly stated that "intravenous drug use is epidemic on some reservations."[84]

NATIVE AMERICAN WOMEN AIDS ACTIVISTS

Women have taken an active role in HIV/AIDS prevention. In hopes of protecting Native Americans and fulfilling her vision, Carole LaFavor has become

an AIDS activist. She is the editor of a newsletter for HIV positive Natives, *Positively Native*, and has participated in many Native American AIDS videos, including *American Indians Against HIV/AIDS Leadership Project: Presentation by Carole LaFavor, An Interruption in the Journey*, and *Her Giveaway: A Spiritual Journey with AIDS*. LaFavor is also a national AIDS activist who advocates the use of alternative medicine in conjunction with western medicine. She speaks at legislative hearings, and works for increased access to quality health care for Native peoples.[85] LaFavor is following her vision, talking to people about AIDS and helping prevent people from becoming infected.

With few resources, Native HIV/AIDS infected women Barbara Byron and Lisa Tiger join LaFavor in spreading the word about AIDS through videos. Byron's video, *I'm Not Afraid of Me*, is her personal story of being a young Native Alaskan woman who contracted the HIV virus through heterosexual contact, then passed the infection to her daughter. Lisa Tiger's (Muscogee Creek/Cherokee) video, *Lisa Tiger's Story*, discusses how she contracted HIV heterosexually at the age of twenty-seven, and how she considers it her duty to educate Native people about AIDS. In the video Tiger is shown in an open discussion with Native students from Haskell's Indian Junior College.[86]

LaFavor, Byron, and Tiger have been driven to tell their personal stories because of their love and concern for their communities. Joining them in their fight against HIV/AIDS are other non-infected women who also have a desire to warn tribal peoples and communities. Native American female producers and/or directors, have used their talents to fight the spread of AIDS by creating culturally specific Native American videos. Sandra Osawa's (Makah) *AIDS and the Native American Family*, one of the first Native AIDS videos produced, presents the story of an urban Native man who gives AIDS to his pregnant Native wife before he dies. This story advocates strong family and community ties as a source of prevention and the use of spirituality for healing. Another woman, Mona Smith (Lakota), has worked independently and in conjunction with Native organizations on AIDS videos. Smith's videos, *Her Giveaway: A Spiritual Journey with AIDS* and *An Interruption in the Journey* are funded, in part, by the Native American Minnesota AIDS Project. These videos give support to Carole LaFavor's message about living with AIDS instead of dying from it by providing hope for the future.

Women are also working in other ways to address HIV/AIDS. Sharon Day (Chippewa), executive director of the Minnesota American Indian AIDS Task Force, serves a large group of urban Natives in the Minneapolis area. Under her directorship the Minnesota American Indian AIDS Task Force provides case management, outreach, technical assistance, peer education, a two-spirit risk reduction program, and publishes a monthly newsletter focusing on current AIDS-related issues. The task force also serves as a clearinghouse for educational materials from around the country.

The task force programs are all culturally specific, and some are geared especially toward the needs of HIV/AIDS-infected Native women. The needs of Native women include Native support groups and spiritual healing. The task force's talking circle for American Indian women is a good example of a way to address gender- and culture-specific needs. These talking circles

include traditional forms of counseling and provide transportation, child care, and meals to participants. In the talking circles, the women smudge, pray, and, at times, make Indian crafts as they discuss the impacts of HIV upon their lives and families.[87] Child care is critical since most Native women must take their children with them. The American Indian Community House HIV/AIDS project has recently added female talking circles as well as a group called Visiting Aunties, women who make home visits to help HIV/AIDS infected tribal members.[88]

NATIVE AMERICAN WOMEN'S HEALTH EDUCATION RESOURCE CENTER

The type of work that the Minnesota American Indian AIDS Task Force and American Indian Community House are involved with is carried out in a reservation setting by another organization comprised of women dedicated to Native women's health issues: the Native American Women's Health Education Resource Center. Both the Minnesota American Indian AIDS Task Force and this women's center are prime examples of self-determination for medical self-sufficiency among family and community members and are positive models for other communities. It is clear that women are taking control over their own medical treatment, prevention, disease intervention, and recovery and it is under these circumstances that they become models for others.

The women's center opened in 1988 and was the first organization located on a reservation to address the needs of Native women, as well as the first organization in South Dakota to provide AIDS education. Director Charon Asetoyer was honored in 1998 for ten years of dedicated leadership to this organization. The women's center's entire budget is $450,000 and they have fourteen full and part-time staff members. The center offers several programs including community organizing and leadership development, domestic violence prevention, child development, adult learning, cancer prevention, reproductive health, and scholarships for Native women. Their curriculum is holistic, incorporating HIV/AIDS prevention and treatment as an integral component of their programs.

Since there are so many factors placing Native women at risk, an effective curriculum must address not only the health and medical aspects of HIV but also other critical aspects of many Native women's lives, such as poverty and powerlessness. These are addressed by the women's center in their programs dealing with adult learning, domestic violence, and community and organization leadership. The women's center works against social forces that undermine women's capacity to adopt and sustain healthy lifestyles.

The development of self-esteem and personal power is critical in combating the spread of HIV/AIDS because of the stigma attached to the disease. The stigma for women is layered on top of perceptions of HIV/AIDS as a disease of immorality and deviance: a gay disease, a drug-user disease, and now a disease that "bad" women contract. This societal perspective of inferiority and immorality of Native women is not new, however. Historically they have always been represented in literature and art in a dualistic conception whose

roots are found in the patriarchal Victorian virgin-whore dichotomy. Hence, empowerment and the building of self-esteem is critical.

One of the most critical aspects of HIV/AIDS is how it affects others, including community, parents, siblings, sexual partners, and children. The women's center attempts to address these concerns and holds workshops for many groups, including high school students, spiritual leaders, and families. Various programs instruct trainers, provide pre- and post-HIV-test counseling, and assist with problem solving for people with AIDS and their families. The women's center's family work is critical because women with HIV/AIDS are greatly concerned about their children's needs. Pregnant HIV/AIDS women worry about passing the disease to their babies, the psychological well-being of their kids, and the discrimination they may face. Many Native women have stressed that at diagnosis they were mainly concerned about their children and how their disease would impact them. They also stressed how important it was to get things in order to make sure that someone was there to take care of their children when they were no longer around.

Good education is one of the keys to successful support for those with HIV/AIDS. The women's center sponsors a peer counselor program that trains high school students to talk about AIDS with their peers. Knowing the importance of how AIDS information is disseminated in a Native setting, the women's center wisely calls upon and trains Native spiritual leaders, women, and youth. The women's center is staffed with women dedicated to empowering and saving the lives of women and other members of their community.

In addition to addressing women-specific issues, the women's center, for a time, extended their AIDS work to include Sun Dance participants.[89] The Sun Dance is primarily a ritual of self-sacrifice. An individual, making a vow to the Great Spirit, will pledge to fast, pray, and dance for several days for the well-being of the people. This very sacred and profound ceremony is conducted by many Plains Indians and has been practiced since time immemorial. It is mainly conducted to provide health, prosperity, and healing for Native communities. For the Lakota people the Sun Dance is one of their seven sacred rites given to them by White Buffalo Calf Woman and taught to a holy man in a vision. Some Sun Dance ceremonies include the piercing of the chest or back and skin offerings as a sacrifice given to the Great Spirit for the well-being of the people. These activities have the risk for infection. The women's center worked with the spiritual leaders, those who were pierced, and those who made skin offerings. The center educated them about AIDS, recommended specific Sun Dance precautions, and distributed more than 10,000 scalpels to Sun Dancers and other Sun Dance participants. The budget of $25,000 for this special project came from the Indian Health Service. This budget barely paid for staff, phone, and travel and as of Summer 1998 the budget was cut entirely and placed in the hands of the Indian Health Service.[90]

The women center's work includes teaching tribal adults and children through the media and they have developed several AIDS videos. The video, *It Can Happen to Anybody*, presents the story of two AIDS-infected Natives, male and female, who talk about the reactions of their families and communities to their diagnosis. They discuss how they were discriminated against by their com-

munity, church, and other tribal members. Their situation reinforces the tribal health officials' concerns that Native people are not exempt from HIV/AIDS. The center's other video, *Mom & Sons Series*, is a cartoon with three sections directed toward three age groups. The sections can be viewed together or individually. Section I, "What is AIDS?," for grades kindergarten through five, is presented in simple language. This section shows a young Indian child, Sam, asking his mother about AIDS because his friend John has the disease. His mother responds by telling Sam what AIDS stands for and some of the ways it is not transmitted, such as "by sharing a Popsicle." In Section II, "Is John Going to Die?," directed at grades four though seven, the story of Sam and John continues but the children are older and the language more complex. In this section, Sam not only asks his mother more questions about AIDS, but he also visits John in the hospital where he speaks to John and his doctor about having AIDS. This section contains more details about AIDS and its physical consequences. Made for an older audience, grades six through twelve, Section III, "How Do People Get AIDS?" shows John and his mother having a more in-depth conversation about the causes of AIDS and how people can protect themselves. Native musical, cultural, and visual textures are prominent throughout both of the center's videos.[91]

There are many more Native women working to empower, heal, and protect themselves and their communities. These women, as well as those I have named, should be honored. Faced with the alarming and daunting task of saving their own lives and the lives that make up their communities, these women are attacking AIDS through education, prevention, and care with dedication, hard work, creativity, and love. By examining their work, scholars, researchers, health officials, AIDS activists, and Native AIDS organizations will gain invaluable insights into the ways Native women are positively impacting the health of themselves and their communities. The acts of these women, on behalf of those affected by HIV/AIDS, ensures that Native women will be neither silent nor invisible in the epidemic, overturning the dangerous belief that AIDS is only a man's disease.

Through their dedication and storytelling, Native women are able to articulate the long-standing concerns of Native women and influence the development of AIDS/HIV resources, identify and address a variety of women's health concerns, and work on community building and empowerment to ensure the survival of women, men, and children.

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