Women with AIDS in the United States are daily confronted with the critical issue of health maintenance. This often involves using public transportation to travel from one side of town to another while ill in attempts to access medical and social services which may include receiving prophylaxis treatments, attending emotional support groups, fighting for entry into drug trials, seeking safe and affordable housing, and getting through the red tape to qualify for subsidized medical services.

From the health care professional’s perspective, women with HIV must make their health, their nutrition, and their medical appointments their top priority. Yet for most women, HIV is not unlike any other illness or personal need — it is secondary to the needs of the rest of the family, particularly if the woman has a child or partner with HIV.

In addition to their myriad responsibilities and health care needs, the majority of women with HIV are, like other women of reproductive age, also confronted with contraceptive and HIV prevention needs. Women with HIV have a desperate and immediate need for practical and emotional support to afford them their right to make informed decisions about their own reproduction, including the right to terminate or carry a pregnancy to term.

This article focuses on the family planning issues confronting women with HIV and specifically highlights two critical areas of concern: contraceptive options and pregnancy counseling.

In the first decade of AIDS, public health policy for HIV positive women was centered primarily on reducing the incidence of perinatal AIDS and, at times, to a lesser degree attempted to allow women to make informed decisions about their reproductive options. One consistent component of early intervention and HIV prevention campaigns has been to encourage HIV testing for pregnant women who are at-risk for HIV. The benefits of HIV testing and counseling in the family planning or AIA program setting are well documented. Knowledge of HIV status is extremely advantageous for the health maintenance of the HIV positive woman and for the monitoring of her pregnancy should she choose to take it to term.

Nevertheless, it has often been true that the motivation for promoting the HIV testing of pregnant women and subsequent counseling of HIV positive women was the erroneous assumption that knowledge of serostatus would inevitably result in a decision to terminate the pregnancy and thus lead to a significant reduction in the incidence of perinatal AIDS (Kurth and Hutchison, 1990).

Just as many health care professionals have found it difficult to understand why a woman with AIDS would miss a medical appointment when she is feeling ill, some have been surprised that HIV testing has not produced the ‘desired’ result (i.e., therapeutic abortion), and that large numbers of women carry their pregnancies to term despite their knowledge of their HIV positive status. “This reality calls current public policy into question on both ethical and pragmatic levels. This policy alone is not sufficient to reduce the incidence of perinatal AIDS. Furthermore, it is a policy that views women — or encourages women to view themselves — predominantly as vectors of disease; thus, this policy runs the risk of ignoring both the rights and the very real needs of women with HIV” (Kurth and Hutchison, 1990).

Any attempt to give voice to women with HIV and their reproductive concerns must consider how women perceive themselves in the context of reproduction in general and of reproduction specifically for a woman with HIV. Research has shown that motherhood plays a central role in the lives of many women and for some constitutes the primary source of self-expression and self-esteem. “The complications of HIV for a woman’s reproductive capacities can pose an enormous yet not always overtly recognizable burden on her life” (Kurth and Hutchison, 1990).
threat to her own sense of self” (Kurth and Hutchison, 1990).

Nearly 80 percent of women with HIV disease are in their childbearing years and more than half of these women have children under the age of 18. “Women with HIV disease frequently experience profound grief over the losses of health, of body image, of childbearing potential, and of their own sexuality, which is often equated with beauty, social value and desirability” (Stuntzer-Gibson, 1991).

The status conferred by reproductive capability and its association with each woman’s perception of herself as a reproducer and mother is shaped by psychology, culture, class, ethnicity, education and other socio-cultural and economic factors. For some women, pregnancy and motherhood can right the wrongs of the past, provide a reason to go on living, represent the possibility of an idealized archetypal family, and often times serve as the central source of pride and identity (Kurth and Hutchison, 1990).

In their study about women with HIV and their reproductive decision-making processes, Ann Kurth and Margaret Hutchison suggest that “a woman’s affective response to her pregnancy may occur for reasons unrelated to class, race, education and other socioeconomic parameters.” Nevertheless, counselors need to be aware of impediments to care that are based on issues of class access and they must also strive for sensitivity when working with clients not of their own culture. Moreover, “it behooves health systems without staff from the culture of the client population to provide educational sessions that equip staff with greater awareness of the cultural beliefs of the client groups.” Further, Kurth and Hutchison caution us to be wary of the “relatively enlightened view that women of lower socioeconomic status should be given special consideration in terms of their childbearing needs because it retains a hidden assumption that more privileged women would not ‘act that way’ – i.e., take ‘unacceptable risks.’ However subtle, this kind of thinking reinforces an insidious sense of ‘us’ and ‘them’ that must be overcome” (Kurth and Hutchison, 1990).

Transmission of HIV from the mother to the fetus in-utero or during the birthing process is currently estimated at 30 percent (Centers for Disease Control, 1993). Perception of risk is relative to each individual’s life experience. For a woman living in poverty in an urban center where violence, crime and drug addiction are 100 percent present each day, a 70 percent probability of giving birth to a healthy baby seems to present exceptionally good odds.

Decision-making factors for pregnant HIV-infected women are complex. One

### CONTRACEPTIVE OPTIONS

**Abstinence, Massage, Masturbation** — best known method of birth control and of HIV prevention.

**Latex Condoms (rubbers)** — thin latex barrier that fits on a man’s penis. Should put condom on penis before ejaculation or pre-cum. For best protection, should be used along with lubrication, especially spermicides with nonoxynol-9 (such as foam), in case of breakage. Most effective barrier to HIV.

**Diaphragms and Cervical Caps** — latex rubber “cups”. You put spermicidal foam or cream inside the cup, then place it in the vagina in front of the opening of the uterus (womb) to prevent men’s ejaculate (which includes sperm) from entering into the uterus. May be partially protective against HIV.

**Contraceptive Sponges** — cuplike sponge that is put into the vagina before sexual intercourse. Wet before inserting to activate the foam inside the sponge. May be partially protective against HIV.

**Spermicides (Contraceptive Foam, Cream, Jelly, Suppositories, and Film)** — can be put directly into the vagina usually with an applicator (like a tampon applicator). May also be put inside diaphragms and cervical caps. Most have Nonoxynol-9 (an ingredient that helps to prevent HIV transmission). May be partially protective against HIV.

**Withdrawal and Douching** — mostly unreliable as a method of birth control. May be partially protective against HIV.

**Oral Contraceptives, “The Pill”** — are tablets containing female hormones. When taken daily they prevent the woman’s ovary from maturing and releasing an egg each month. No clear evidence of HIV protection. May affect disease progression.

**Norplant** — tiny rods surgically placed under the skin of a woman’s arm. These rods gradually release hormones (like the pill) into the woman’s body. Lasts for up to five years. Rods must be surgically removed when done. No clear evidence of HIV protection. May affect disease progression.

**Rhythm (Calendar Method)** — abstinence from sexual intercourse right before and during ovulation (when an egg is released). No protection against HIV infection.

**Sterilization** — permanent method for women and men who do not want more children. In women, the tubes leading to the egg-producing sacs (ovaries) are cut, pinched or burned shut to prevent sperm and egg from uniting. In men, the tubes (called vas deferens) that carry sperm to the penis are cut or blocked. Men still ejaculate fluid (“cum”) without sperm after sterilization so condom use is still recommended after sterilization to prevent HIV and other STD’s. No known protection against HIV infection.

**IUD** — device inserted in the uterus (womb). It prevents the egg from being planted and growing inside the uterus. This method is discouraged for HIV-infected women or women at risk of infection because of the risk of pelvic inflammatory disease (PID).
research study suggests that when pregnancy occurs, each woman has a unique psychological reaction called a psychoreproductive response to her pregnancy. The psychoreproductive response is composed of both HIV and non-HIV factors including the woman’s reproductive history, life context, current and past family dynamics, sense of reproductive self, and adaptation to the diagnosis of infection with HIV.

Social expectations of women are great and may prove paradoxical for pregnant women with HIV. Women often bear the full responsibility for decision-making during pregnancy. A woman might feel guilt or rejection associated with choosing to abort a pregnancy or guilt for passing HIV to her infant - a double bind at best. Health professionals and counselors can best support women by providing non-directive, non-judgmental counseling. All options counseling of pregnant women includes both information about carrying the pregnancy to term, abortion and contraceptive options for the future. For a woman with HIV, it also includes the effect of pregnancy on her health and risks of transmitting HIV to the fetus in utero or at birth.

It is important to prepare women for the barriers that might exist to obtaining a safe and legal abortion. Service barriers that result from misinformation should be reduced by greater counselor awareness of medical evidence that abortion is safer than childbirth for both HIV-infected and non-infected women (Stuntzner-Gibson, 1991). Women who choose to abort a pregnancy also face the challenge of finding a clinic willing to provide abortions to HIV-positive women. "Bias against HIV-positive women in abortion clinics in New York has been documented as clearly affecting women’s reproductive decisions" (Kelly, 1992). Poor women are often denied access to abortion due to the high cost of the procedure in states where no public funds are available for abortions.

For HIV-positive women who do not choose to have an abortion, approximately 30 percent will have infants who are HIV-infected. All infants are born with their mother’s antibodies to help protect them from illness, so all infants born to HIV-positive mothers will themselves test HIV antibody positive. In the past, parents faced 15 to 18 months of uncertainty while they waited to see if their infants were HIV-infected. The Food and Drug Administration has recently approved an HIV test which identifies the HIV virus and can identify if the HIV antibody positive infant is actually infected with the HIV virus. Because early intervention is key to health maintenance of HIV-affected infants, it is critical that HIV status be determined as soon as possible. HIV-positive infants, like adults with HIV, need a great deal of medical care and HIV positive mothers find themselves spending many hours each month getting medical advice and treatment for their infants.

In addition to concern for her baby, a woman with HIV faces issues of her own mortality and illness. For all of us, not only those who are HIV-positive, the ability to reproduce is a powerful hedge against mortality. It is not uncommon for a mother to plan for placement options for her child in the event of the mother's own serious illness or death. Some of our AIA programs, including Bienvenidos, CANDII, Maryland Department of Human Services, Mother’s Project, PACT, Project First Love and the Society for Seamen’s Children, provide special support services for mothers with HIV. A woman with AIDS each day confronts, grieves and lives with personal separation and loss. Even before a woman acquires an opportunistic infection that makes her very ill, she may suffer a negative change in her body image and societal role as a woman. The complex emotional, relationship and sexuality issues confronted by all women, at times, present an insurmountable challenge for women with AIDS.

Women with HIV who choose to become pregnant or to carry a pregnancy to term face increasing legal, medical and social pressures (Stuntzer-Gibson, 1991). A willingness and ability to directly and sensitively address these issues is critical for service providers to establish a good, helping relationship with their clients. The stigmatization often associated with these issues can sometimes make it dif-
Many health and social service providers are apprehensive about HIV risk assessment because it addresses such sensitive issues as drug use, sexuality, and life-threatening health conditions. In order to discuss these concerns more effectively, we must examine our own attitudes and attempt to overcome our own insecurities and biases.

Risk assessment can be opened with a discussion of general behaviors that are risky to our health. In fact, it is worthwhile to assess our own health risk behaviors, for example, eating junk food, not getting enough exercise, smoking cigarettes, drinking alcohol, not using seatbelts, or having sex without a condom. When we ask ourselves why we continue to engage in these behaviors despite the fact of known health risks, our responses usually include: I like it; It feels good; Everyone else is doing it; It's a habit that's hard to break; I don't have time to change; Only a little won't hurt me; It hasn't hurt me yet; I'll stop tomorrow. Considering our own health risk behaviors and barriers to change can help us to appreciate our own clients' difficulties in reducing their HIV risk behaviors. The following information is based on HIV, Children and Families: A Curriculum for Training Social Service and Health Professionals which was produced by the Child Welfare and AIDS Project at the University of California, Berkeley and the Center for Health Training. The curriculum is can be ordered from the AIA Resource Center.

Who Should Get an HIV Risk Assessment and Why?

HIV risk assessment should be a routine part of intake for every family served by a health and social services agency. There are three important reasons for doing HIV risk assessments with all clients: (1) Substance use and AIDS are increasingly prevalent problems in our child welfare population; (2) Assessment of substance use and HIV risk factors (e.g., parents' drug use, parents' health status, child's health status) is already part of the standard assessment to determine parents' ability to care for the child and the type of placement that may be needed; (3) Early identification of clients' substance use and/or HIV infection at intake can be crucial to referral of adults and children for preventive and possibly life-saving treatment.

How Do I Do an HIV Risk Assessment?

The first step to conducting an HIV risk assessment is to recognize our own barriers. It is a myth that HIV risk assessment can be done only by medical personnel. Frequently, we find ourselves reluctant to initiate discussions on sensitive issues because we feel the pressure of time constraints. Sometimes, we assume that clients will refuse to discuss or be

NEW HIV DEFINITION

Effective January 1, 1993, the Centers for Disease Control redefined the AIDS definition to include HIV infection and any one of the following:

- CD4 count below 200 or less than 14 percent total white blood cell count;
- Pulmonary tuberculosis;
- Recurrent pneumonia;
- Invasive cervical cancer.

This new definition will include more women and therefore may provide increased access to entitlement benefits. For more information, contact the National AIDS Hotline at 1-800-283-AIDS.
truthful about sensitive issues. More often than not, this assumption is based on our own personal prejudices, fears, and/or discomfort in discussing HIV and AIDS, substance use, and issues of sexuality with clients whose lifestyles and values are different from our own. After recognizing our own personal issues on HIV risk assessment, we need to collect accurate, up-to-date and culturally sensitive information about HIV to educate ourselves and share with our clients.

Tips for Administering the HIV Risk Assessment

- Incorporate into standard child abuse assessment for all clients.
- Explain to the client that questions about HIV risk are asked to determine that child's health needs.
- Respect the client's privacy and confidentiality. HIV risk interviews should always be done in a private place and with the client alone unless the client gives express permission to have someone else present.
- Assure the client that HIV risk or HIV-positive test results do not necessitate out-of-home placement.
- Present a neutral, accepting, non-judgmental attitude. Avoid value judgments that are conveyed via words, body language, voice inflections, and reactions.
- Use standardized assessment tools to assist and guide the risk assessment.

What Should I Do if My Client is at High Risk for HIV?

If your assessment indicates that your client is at high risk for HIV, the first order of business is to identify the behavior that is putting your client at risk, express concern, and briefly educate your client about reducing risks. This discussion should allow for the client to raise questions and concerns. Encourage HIV testing for adults, adolescents and children at risk so that they can get the health care they may need. Refer parents and children for HIV testing and the health and social services that they need.

For more information on standardized HIV risk assessment, contact your local health department or the AIA Resource Center.

—Victoria Sanford, M.A.
The Yale Mothers Project provides comprehensive services to pregnant or recently delivered women who are currently using cocaine and includes services to HIV-infected mothers and their children within its array of available resources. The project attempts to maintain children with their biologic families and assist mothers to reduce or cease substance use through integrated health, mental health, educational and home based, family support services. Both infant care and early childhood programs for older siblings are provided at the central facility; an early stimulation component also provides service at home. The project utilizes its own van to transport mothers and children to services as needed. The project also includes a component that provides specialized support services to biologic and foster families of HIV positive children to enable the children to have continuity of caretaking when there is a need for placement in foster care.

The AIA Resource Center asked Dr. Brian Forsyth, associate professor of pediatrics and the Child Study Center at Yale University, to share some of the experiences of the Mothers Project in their efforts to provide HIV services to clients. Here are some excerpts from a recent conversation with him:

**Why Drug-using Women are at Risk for HIV Infection**

First of all, we need to recognize that drug use, and not just IV-drug use, is a risk factor for HIV infection. We cannot assume that a woman is risk-free simply because she is not using drugs intravenously. Drug use put women at risk for HIV infection because of the need they have for drugs which can place them in the vulnerable situation of exchanging sex for drugs or sex for money. Another factor is the inattention to safe sex practices when under the influence of drugs or alcohol. The prevalence rate for HIV infection is likely to be higher for drug-using women than it is in the general population because, more often than not, these women are involved in a social crowd of drug users which includes drug-using sexual partners. Thus, these women are at particularly high risk even if they are not using IV-drugs.

HIV education and risk reduction, testing, provision of services to HIV-infected individuals and their families, and medical intervention are the key levels at which AIA programs can play a role in meeting the needs of their clients.

**Education and Risk Re-education**

At the Mothers Project, we are trying to not only educate, but also to change people’s behavior so that they are less likely to be exposed to HIV infection. First of all, to do this successfully, we all need to be able to talk about this infection being more prevalent among our clients than they themselves may realize.

It is important for clients to know that the virus goes more easily during sex from a man to a woman, than it does from a woman to a man. The woman is at much greater risk because of the ease with which she can become infected with HIV from one episode of sex.

In changing behaviors, there is also a need to talk about the effects of being under the influence of alcohol or drugs...
and to try to find a way to decrease the chances of exposure to such a situation. Within our programs we have to be able to talk about the issues of sex for drugs and sex for money. We must be able to discuss them openly and look for concrete ways for our clients to address these problems.

Testing

Every woman who has ever been at risk of exposure has a right to be tested. In New Haven, we know that one out of every 40 black women giving birth in the city is infected with HIV. It must be emphasized that HIV treatment therapies can make a difference and early therapy can make a real difference in the lives of HIV-positive women. Knowing that, it is the right of every woman to know her HIV status.

Counseling and testing do have real positive advantages. For example, if the woman turns out to be negative, then this is her chance to talk about and understand the issues. In essence, the power of the knowledge that she is alright now gives her the option to choose to stay healthy. It is a milestone for a woman to be at this stage. She can change her life.

If she is HIV-positive, there is no doubt that medical intervention at the right time can prevent someone from becoming seriously ill and can also prevent an early death. I would translate that to the children, as well. As example here is the median age of children getting pneumocystis pneumonia (PCP), is about six months. If we know that a mother is infected, then we can begin monitoring of the T-cells of the baby which enables us to put the baby on medicine at an early stage and prevent PCP early in life. Babies used to come in at six months of age and die from PCP. But now, with early diagnosis, we can maintain these children so that they are living at least a number of years and with a better quality of life. Obviously, this is very important to every mother, to every parent.

It is my belief that if we talk to a woman in a way that she can understand about the benefits of knowing her HIV status, then that woman will be less afraid and more able to accept HIV testing and subsequent appropriate care regardless of her status.

Provision of Services to HIV-Infected Individuals and Their Families

The social stigma associated with HIV disease has a tremendous impact on families and, in turn, the climate of secrecy it creates affects our working relationship with them in that we have to be able to ensure confidentiality. This stigma has important implications for the provision of services. To start with, we have a disease that is affecting, for a large part, poor people, minorities, and families already affected by substance abuse. Then, on top of that, we add the disease which is a death sentence. The HIV-infected individual feels ashamed, has a tremendous fear of others finding out about the disease, and, in the instance where they may have an infected child, feel guilty about passing the disease on to their child.

Normally, if someone were to have cancer, they would turn for support to their family members and friends. In this disease, the individual often tells no one. Sometimes, they do not tell their spouse, often not their parents, and very rarely do they tell their friends.

It is not uncommon for us to see a situation where a parent brings her child for health care, but does not herself seek health care because of the fear that someone she knows might see her. Yet, for us it is just as important that the mother stays healthy for herself and for her desire to look after her child and maintain her family. Programs need to provide support services for these families that would normally be provided by others. Programs also need to deal directly with the woman’s fears and sense of isolation by helping her turn to others for support.

The effect of secrecy has dramatic effects on both the infected individual and the uninfected members of the family. We already know that children who experience chronic illness among their siblings or parents have an increase in psychological problems. In this instance with AIDS, the children are often not told about it, although they know at some level that something serious is affecting their family. Secrecy can have as important an effect on the child’s behavior as knowledge of the illness itself. We very rarely have an instance where parents have explained things to their children. We find that we often must initiate a more appropriate approach for the mother to deal with these issues within her own family.

Medical Care

The health care of an infected child requires that a program offer comprehensive, coordinated, family-centered, community-based services. Early medical intervention can lengthen and improve the quality of a child’s life. However, it is useless to have clinicians sitting in clinics waiting for children to arrive to their appointments if for some reason the parent and child are unable to make the appointment. It is also useless and ineffective prescribing AZT for a child if for some reason that child is not given the medication prescribed. Comprehensive service for the parent and the child can go a long way toward ensuring that the needs of each are met.

—Victoria Sanford, M.A.

ANNOUNCEMENT

The National Association of People with AIDS is seeking People with AIDS and HIV positive people to participate in their national Speakers Bureau. For more information, please contact: Regina Sackrider at 202/898-0414.
Twenty years ago, the Federal government established the National Institute on Drug Abuse (NIDA) as the organization charged with combating drug abuse in the nation. Later in 1985, as the tragic interrelationship between drug use and HIV became apparent, substance abuse treatment staff, serving high-risk, drug using populations, were considered to be in an optimal position to stem the tide of AIDS. NIDA launched an initiative that aimed to prepare alcohol and drug treatment staff throughout the country to deliver AIDS prevention and intervention services to their clients. The mechanism for reaching this long-term goal was the formation of cadres of national and state HIV and substance abuse trainers to implement the training; the conduit was the state Alcohol and Drug Abuse agencies. An HIV and Substance Abuse curriculum was developed, piloted, and revised and, in 1988, a training agency was created by NIDA to further develop and manage this large scale training endeavor.

These days, The Center for HIV/Substance Abuse Training (The Center) is a project of Hi-Tech International and under the auspices of the newly established Center for Substance Abuse Treatment (CSAT) within the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. The Center updates the HIV/Substance Abuse curriculum, issues new courses, identifies, trains, and certifies a core consultant staff of master trainers, implements AIDS training at the request of state or regional substance abuse programs, provides technical assistance to states in developing AIDS training plans, develops the trainer certification program, and produces “Training Facts”, a training newsletter which features various issues and news from the field.

To insure current and ongoing, consistent, and quality-controlled AIDS training, an elaborate training of trainer (TOT) system was devised. The model consists of: 1) a national consultant pool of 70 trainers who deliver the train-the-trainer workshops to state trainers throughout the country; 2) state training coordinators, typically within state Alcohol and Drug Abuse agencies, who are responsible for replicating NIDA courses in their state; 3) statewide training needs assessments which are required before the delivery of NIDA-sponsored courses; 4) state training plans which outline training needs, resources and action plans; and, 5) groups of certified state trainers who are expected to provide training to alcohol and drug abuse workers and administrators according to the state AIDS training plans.

Trainers at the national, as well as state levels, are not certified as general trainers, but rather are certified to teach particular courses. The curriculum developed by The Center for HIV/Substance Abuse Training features twelve courses, ranging from one to two-and-a-half days. It includes: Prevention of HIV Disease Among Substance Abusers; Administrative Planning for Substance Abuse Treatment; A Training Program for Substance Abuse Counselors; Human Sexuality; Gay, Lesbian, & Bisexual Issues; Focus on Women; Risk Reduction Counseling; Antibody Test Counseling; Treatment Planning for the Client with HIV Disease; Dysfunctional Families; Supportive Groups and Buddies; Dying and Death; and Relapse Prevention. Some of these courses serve as prerequisites for others.

In addition to The Center’s curriculum, NIDA supports four other HIV and Substance Abuse training projects, who have also developed curricula. Advanced Resources Technologies, T. Head & Company, Transamerica, and Westover Consultants have respectively produced curricula on AIDS Prevention Among African Americans, Research for Practitioners, HIV Prevention Among Hispanic/Latina Women, and AIDS High Risk Adolescent Prevention. These courses range in length from 2 - 5 days. A catalog describing the curricula is available and the entire curricula can be purchased, in whole or in part, at cost.

Forty states are now participating to some degree in this training effort and twenty states have active state training teams. Most states convene from 5 to 15 group trainings a year targeting substance abuse treatment staff and many sponsor annual regional institutes. If Abandoned Infant Assistance or related programs are interested in inquiring about the opportunities that may exist for a staff representative to attend a state or local HIV/Substance Abuse training or to receive a copy of the curriculum catalog, you may call Jack Stein, MSW, co-director of The Center for HIV and Substance Abuse Training at (703) 998-0268, ext. 230.

—Jeanne Pietrzak, M.S.W.
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