

CRITERIA FOR THE DEVELOPMENT OF A MORE HUMANE ACTG

This document is intended to provide recommendations for processes that will facilitate accountability, accessibility, and accrual. Some of the recommendations are specific to New York, some will have a broader application. These are recommendations to the NIAID, the ACTG, and specific ACTUs. It is now in your hands to take action.

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with the
Women's Action Committee

ACT UP/NY

Two major healthcare issues people with HIV(PWHIVs) face are access to treatments and the quality of services and treatments accessed. Experimental therapies can play an important role in the treatment of HIV related illness, therefore it is imperative that access be equal for all populations.

"...the Executive Committee participates with the AIDS Program in establishing scientific priorities for the ACTG and ensuring equal access for all patient populations."

Attachment B, Standard Operating Procedures for AIDS Clinical Trial Group Committees 9.17.89

Motives

The reason the ACTG exists is to identify, test, and recommend for approval treatments that can reduce the devastation that HIV is wreaking upon certain communities in this country. Humanity need not be at odds with good science. If the ultimate goal of the ACTG is to reduce HIV related suffering, then that goal must be realized at every step of the process and not just projected onto some nebulous future date when a "cure" or vaccine is discovered.

In NYC the majority of women with HIV live at or below the poverty level. Socioeconomic factors play an important role in the differing survival rates for women and men with HIV. We live in a society with a two tier healthcare delivery system. This system has never answered the needs of poor women, of all colors, and their children. This same population of women are the ones being hardest hit by the HIV epidemic.

It is therefore necessary for the ACTG, which is more lavishly funded than many state's AIDS programs, to provide trial participants with certain amenities to remove barriers to accrual for disadvantaged populations. The faster the trials accrue, the more quickly they can produce results that can be translated into treatment options for all PWHIVs.

Obstacles to Trial Enrollment

A trial cannot be completed until it has started. It cannot start to produce statistically significant results until it has accrued statistically significant numbers of people. It cannot accrue statistically significant numbers of people until people with HIV and their care providers know it exists and until eligibility criteria are designed to allow enrollment.

The lack of accrual in ACTG trials is appalling. The current pace of accrual is interminably slow and absolutely unacceptable. The National AIDS Program Office has finally awakened to this reality and will take ability to accrue into account when renegotiating ACTU contracts in 1991.

There are many barriers to rapid accrual in ACTG trials. There are many steps that can be taken to radically alter the pace of accrual and make the ACTUs more accessible to the affected communities. Herewith are some identified barriers and recommendations for change.

Outreach

1. Referral Lists. ACTUs must develop networks of care providers and clinicians who are willing to refer patients to ACTU trials. These networks can be subdivided by state; all the physicians in the state on the list should receive trial and experimental treatment information from their local ACTUs immediately upon

the opening of a new trial at the site or when a new treatment becomes available. Comprehensive lists can be created in part through contacting the local state department of health's AIDS surveillance unit and obtaining lists of every physician who has ever reported a case of AIDS. Physicians interested in participating in the network can be further subdivided into physicians willing to refer patients, physicians willing to have patients referred to them (especially patients on Medicaid and the uninsured) and physicians willing to do both. Thus the network can provide the ACTU with patients and the ACTU can provide people with HIV with physicians in a mutually beneficial arrangement.

2. Outreach to Clinicians. Many community physicians do not have the time to take from their busy practices to keep up with the latest experimental therapeutic advancements in the treatment of HIV related illness. ACTUs must conduct forums on experimental AIDS drugs and the trials being conducted at the hospital site. ACTUs must also sponsor and conduct forums for local clinicians on issues of importance in patient care, state of the art treatment advances, and access to experimental therapies.

3. Outreach to Communities and PWHIVs. ACTUs must reach out to community based AIDS and service organizations whose clientele includes large numbers of PWHIVs. It is especially important to provide information on clinical trials to organizations such as community health clinics, public hospital clinics, methadone and other drug treatment centers, and community family planning clinics. ACTUs must also provide information to the patients at the above facilities in a manner appropriate to varying cultures, languages, and education levels.

4. Inreach. ACTUs must provide educational material to all hospital staff in the medical center. They must also provide this information to all staff who could come into contact with PWHIVs in their affiliated satellite hospitals. Educational material would include information about the clinical trials process, rationale for drugs under study at the site, summary of the inclusion/exclusion criteria, and any benefits to patient care that the trial can provide. Included with this should be the phone number of a contact person who can answer, at length, any questions clinicians may have.

5. Sensitivity. Lack of sensitivity to people with AIDS, especially low income or drug using PWAs, on the part of researchers can be a strong disincentive to trial enrollment. Trial sites should provide (or contract with an outside agency to provide) sensitivity training on addictophobia, homophobia, sexism, and racism to ACTG staff.

6. Drug Treatment Programs. ACTUs should be able to provide substance abusing PWHIVs with referrals to drug/alcohol abuse treatment facilities. ACTUs must coordinate with the drug treatment facilities in their immediate vicinity to provide mutual referrals.

7. ER Staff. Special effort should be made to insure emergency medical personnel are apprised of trials being run at the site, especially trials of treatments for opportunistic infections.

8. Billing matters. Trial participation must be 100% free. Some sites charge patients for procedures associated with the administration of the drug, such as hospitalization. This is particularly a problem for trial participants who are both Medicaid-ineligible and uninsured. If the ACTG cannot pay for costs associated with trial participation, then programs must be worked out with the drug's pharmaceutical sponsor, such as writing a budget into the protocol for trial associated medical costs. Alternately, the Health Care Financing Administration (HCFA), and NIAID could create grants to pay for trial associated medical care that is not covered by the protocol.

Location

The ACTUs were initially set up in private teaching hospitals, many affiliated with universities. These were the hospitals best equipped to handle the rigors of clinical research. However, these are not the hospitals that serve most women with HIV, nor are they the hospitals that serve the poor, minorities, and the majority of IVDUs with HIV related disease.

NYC as an example of a discriminatory system:

Distribution of women diagnosed with AIDS in NYC 1.12.90--NYC Department of Health AIDS Surveillance Update.

Manhattan	915	28%
Brooklyn	1,015	31%
Bronx	780	24%
Queens	409	12.5%
Staten Island	61	2%
Other	83	2.5%
Total	3,263	100%

Distribution of Pediatric AIDS cases in NYC 1.12.90--NYC DOH

Manhattan	119	21%
Brooklyn	180	32%
Bronx	172	30%
Queens	59	10%
Staten Island	14	2%
Other	27	5%
Total	571	100%

Distribution of ACTUs, Their Affiliates, and Pediatric ACTUs in NYC 3.90.

Manhattan	St. Luke's Roosevelt Cornell Mt. Sinai-Adult and Ped. Beth Israel (affiliate) New York University Medical Center (NYU) Bellevue-Adult and Ped. (affiliate) Manhattan V.A. (affiliate) Harlem Hospital-Ped. Memorial Sloan Kettering Cancer Center (MSKCC)
Brooklyn	None
Bronx	Albert Einstein-Adult and Ped. Montefiore Bronx Municipal North Central Bronx Bronx V. A. Medical Center (Mt. Sinai affiliate) Elmhurst (Mt. Sinai affiliate)
Queens	
Staten Island	None

NYC has 31% (3,263--1.12.90--NYC DOH) of the nation's reported female AIDS diagnoses.(10,611--12.89 CDC HIV/AIDS Surveillance)

NYC has 29% (571--NYC DOH) of the nation's reported pediatric AIDS diagnoses.(1,995--CDC)

NYC has 20%(10/49) of the nation's total ACTUs. NYC has 17% of the nation's Adult ACTUs and 27% of the nation's Pediatric ACTUs.

Brooklyn, NY has 9.5% of the nation's female AIDS diagnoses and 31% of NY's female AIDS diagnoses (1,015/10,611 and 1,015/3,263, respectively). Brooklyn, NY has 9% of the nation's pediatric AIDS diagnoses and 32% of NYC's pediatric AIDS diagnoses (180/1,995 and 180/571, respectively).
Brooklyn, NY has 0% of the nation's ACTUs.

The NIAID must immediately delegate and fund an ACTU in Brooklyn, NY. Downstate (SUNY Health Science Center) Hospital, a state teaching hospital, is affiliated with King's County Hospital, a municipal inner-city hospital. They are located across the street from one another in Brooklyn, NY. Downstate has experience in doing clinical research. King's County has an outpatient AIDS Clinic with over 450 patients and an inpatient AIDS ward that serves 100. NIAID should undertake negotiations with King's County/Downstate to create an ACTU in Brooklyn.

People with HIV in Brooklyn need access to experimental therapies.

Transportation

Trial sites must cover study participants' transportation costs, including bus, subway, ambulette, and cab fare. Trial sites are not currently located in areas easily accessible to a significant proportion of women with HIV or the majority of poor persons with HIV, except by extensive travel.

Childcare

In NYC 50-80% of women with diagnosed, reported AIDS have children. They have an average of 1.6-2.6 children each. Variations are dependent upon neighborhood (Lower East Side, Bronx, etc.). For women with HIV the lack of childcare is a serious impediment to enrollment in ACTG trials. This barrier should be addressed in two ways:

1. On site childcare. The provision of free on site childcare will make a site incomparably more accessible to mothers with HIV. This childcare facility should be medically equipped to care for children with HIV and could work with the hospital's pediatric psychiatric program to provide these children with other support services. Ideally this childcare facility would also be able to provide childcare services for the researchers' children.
2. Payment for off-site childcare. Each site could contract with an outside agency located in the immediate hospital vicinity to provide free, quality childcare to mothers participating in protocols. Women could leave their children at this site before their study visit. Additionally, each site should offer the option of providing money to a parent to pay for a babysitter or friend to care for her children in the home or to pick up her children from school.

Combined Maternal/Pediatric ACTUs

Women must be able to access experimental treatments at the same site as their children. Pediatric ACTUs must be coordinated with the adult ACTUs; areas with high incidences of HIV related illness among children are areas with high incidences of HIV related illness among women. Women must no longer have to choose between providing for their own health and the health of their child.

ACTUs with female enrollment figures that reflect the proportion of women with HIV utilizing medical care in the area are usually coordinated with heterosexual or vertical transmission studies. It would be useful for NIAID to coordinate its trials program with research efforts into the transmission and natural history of HIV

infection. In this way NIAID could be providing access to experimental treatments to large cohorts of HIV infected people.

Community Advisory Boards

All ACTUs must have community advisory boards. ACTUs need to have input from the affected communities. Community boards would function to increase enrollment, community input into trial design, patient/researcher communication, and community input into site research priorities. Satellite sites may be located in different communities and have different patient populations and operational difficulties and should therefore each have their own community advisory board. This board should include at least one participant from every trial being conducted at the site, with an effort made to include a wide demographic mix. It should also include community physicians, physicians involved in the day to day patient care of trial participants, patient advocates and AIDS activists. Members of community advisory boards should attend the ACTG core committee meetings. According to Martin Hirsch of Harvard ACTU, the community advisory board at his site has already become an integral part of the research process.

Within the AIDS affected communities, however, a much greater diversity of opinion and expertise exists than could ever be represented on a community advisory board. To most efficiently utilize this expertise ACTUs must hold periodic community forums wherein people not involved in research at the trial site can speak to the ACTU researchers and provide researchers with community research priorities and empiric information about drugs that are commonly being taken in the community. AIDS research must be accountable to the affected communities and the affected communities must be able to contribute more than their bodies to the AIDS research effort.

Support Groups

Trial sites should sponsor support groups for people in trials. These would serve to provide a space for persons on an experimental regimen to compare notes and provide each other with helpful information on how to manage and integrate experimental therapies (some of which have complicated or painful modes of administration) into their daily lives. There must also be a commitment on the part of ACTUs to providing informational forums for trial participants on all the latest information about the drug they are taking, as well as providing trial participants with a copy of the complete protocol that they are being studied under, and preliminary data from the trial as it becomes available.

Trial Design

None of the above recommendations are enough without a serious rethinking of protocol design and eligibility. At one point in December of 1989, MSKCC had screened 150 patients for the three ddl trials and only found three that were eligible for the trials. Even if the number of people applying for enrollment in trials increases due to outreach efforts, it will do no good until entry criteria are made more realistic, until every arm of the trial contains a real treatment option, and until the ACTG makes an effort to design trials to test treatments for the medical conditions that PWHIVs are actually in.

Exclusion criteria must be both medically and scientifically justifiable. Exclusion of a particular group is not appropriate unless the rationale is based on medical necessity. If there is a medical reason (such as hemophiliac's different blood parameters) then the trial must be designed with an arm specifically for this population or a parallel trial for this population.

Women

Women must be included in clinical trials of potential AIDS therapeutics from day 1 of Phase 1 human safety and toxicity testing. It is poor science to exclude half of the species (if not the infected population) because of liability concerns and concerns for a theoretical fetus.

It would be unacceptably poor science to do animal carcinogenicity studies on only male mice, yet this low standard of scientific inquiry is accepted as the norm in human clinical research.

The goal of Phase 1 testing is to determine the toxicities of an agent and the correct hypothesis for Phase 2 testing. To exclude women from early drug testing is to test an agent incompletely and inefficiently. If an agent causes a different or more severe toxicity in women it is more beneficial to women with HIV to find this out during Phase 1, rather than only during Phase 4 post-marketing studies or through anecdotes traded amongst overworked doctors practicing in inner-city AIDS Clinics.

Philip Pizzo has shown that ZDV plasma level correlates with development of neutropenia. (Remarks of Carl Peck @ 7th ACTG meeting 10.6.89) During the FDA Anti-Viral Advisory Committee meeting on AZT, 2.3.90, Peck observed that, "the average plasma level on a fixed dose will be about 50% higher" for women than for men. Burroughs Wellcome's representatives at the meeting affirmed that plasma levels that average 20-30% higher than men's have been documented in women. Do women on ZDV have a higher rate of neutropenia? Do women with HIV related disease become ZDV intolerant more frequently than men? Do women on ZDV develop more or different toxicities more frequently than men? What are the human cancer risks? Why are these questions still unanswered three years after the drug's FDA approval?

Anecdotal reports describe women developing amenorrhea upon initiation of ZDV. Female rats and mice develop malignant and benign vaginal neoplasms when given high doses of ZDV. Burroughs Wellcome's Dear Doctor letter of 12.5.89 by and large dismissed the carcinogenicity results as sex and site specific. At the FDA Anti-Viral Advisory Committee meeting, 2.3.90, Kenneth Ayers, DVM and Burroughs' senior toxicologist hypothesized that because the tumors were site specific there is a "possibility that chronic local contact with high urine zidovudine has a role in tumor formation."

Jerry Collins, PhD and FDA Clinical Pharmacologist countered, "Regarding the possibility... that vaginal tumors were produced as a result of high urinary concentrations of AZT, I have a few problems accepting this concept. My own calculations would suggest that urinary concentrations are perhaps five times greater in mice than in humans and that is a fairly minor difference."

Burroughs Wellcome asserted that doses given to mice were 50 times human doses, and those given to rats were up to 386 times the human dose. Dr. Collins maintained that the average AZT exposures to mice were closer to 0.5 to 3 times the human exposure.

Women with HIV need to know what the true risks associated with ZDV therapy are, especially if women are to begin taking ZDV earlier in the course of HIV disease as is now being recommended.

Women and Drug Use

Research priorities are not decided solely by desire for fame and funding; they are also decided by how highly different groups of people are valued in our society. By this, the second decade of the epidemic, it should be overly apparent to even the most dim-witted that bias determines response. It is inexcusable that substance abusers are still excluded across the board from AIDS drug trials.

Researchers argue that IVDUs are a difficult population to study because drug use is not conducive to good health and active drug use by trial participants may make it impossible to read the data, yet nationally 52% of women with reported AIDS diagnoses contracted HIV through IV drug use. (CDC-12.89) It is never an argument to design trials that do not take into account who the eventual patient population for the drug will be. It is necessary to research what drug interactions occur when persons combine drugs such as ZDV with heroin or crack as they are certainly doing in the real world of AIDS among substance abusers. A pharmacokinetic and long term safety study of ZDV in drug users must be conducted.

A study of this type would require an unprecedented level of cooperation, understanding, and trust between researchers and PWHIVs. (A level of understanding the ACTG has obviously not reached considering that ACTG 126-- "Impediments to Initial and Continued IVDU Enrollment in ACTG Clinical Trials"-- has been deferred.--NIAID AIDS Division Protocol Overview, 2.16.90)

Recently anecdotal reports have surfaced that aerosolized pentamidine and crack are a deadly combination. How much deadlier than crack alone may be difficult to quantify, but this does point to the crying need for more research into what the interactions are between commonly prescribed AIDS drugs, illicit drugs, and HIV infection.

The effects of all AIDS drugs in persons on methadone, recovering substance abusers and current substance abusers must be studied.

Short pharmacokinetic and pharmacodynamic studies of all approved AIDS therapies and methadone need to be done. All current ACTG studies (which, because of the function of the ACDDC, are assumed to be at least somewhat promising) must design an arm for methadone users.

Ddl must not become the next ZDV; there is still time to stratify the trials to be able to gather more information on the effects of the drug in women, substance abusers, recovering substance abusers, and persons on methadone.

NIAID must work with National Institute of Drug Abuse (NIDA) and undertake research into addiction treatments. It is estimated that within 3-5 years 75% of the newly diagnosed cases of AIDS in NY will be among substance abusers (Chuck Eaton-Director Needle Exchange-NYCDOH-3.1.90). Already in NYC 43-46% of newly (1989) reported AIDS diagnoses are in persons who contracted HIV through IV drug use (NYC DOH--1.12.90). AIDS research must take a proactive stance against the transmission of HIV. Research into prevention must be undertaken to complement research into treatment.

The practice of turning elevated liver enzymes into exclusion criteria as a means of excluding IVDUs and recovering IVDUs must be ended. Again, every exclusion must have a realistic medical justification.

Children

Phase 1 pediatric trials must begin as soon as preliminary safety data from the adult trials have established a safe dose and before adult trials have reached the maximum tolerated dose. Children with HIV have a 50% mortality rate within the first 2 years (NY Newsday 10.17.89). Waiting until a drug is nearly approved for adults is not a luxury children with AIDS have.

In order to be approved, protocols designed for adults must also submit a protocol designed for children. In this manner the time lag between adult and pediatric testing of an agent will be curtailed.

All drugs that have been approved for the treatment of HIV related diseases in adults must immediately be tested in children. It is unethical to deny children the therapeutic advancements the ACTG is striving so hard to discover.

ZDV has become standard of care for children with HIV related disease, lack of FDA approval notwithstanding. An acknowledgement of this advance must be made in the design of all current and future ACTG trials for children with HIV related illness, placebos eliminated, and comparative trials initiated.

Even without an FDA approval, a limited number of children with HIV related disease have been able to access ZDV through trials and now through the Treatment IND. Unfortunately, we are seeing the same patterns in children on ZDV as in adults; the drug is useful for approximately the first year, then its efficacy decreases and children become refractory to treatment. The trial of ddI vs. ZDV for children is still in development. It is time for a pediatric parallel track for ZDV refractory children. A pediatric parallel track would be formulated much as the adult parallel track is and would provide children who have no other treatment options with access to a potentially life prolonging treatment.

Other drugs that could be standard of care, such as PCP prophylaxis with TMP/SMX, have not become standard of care because every healthcare agency, locally and nationally, has shifted the responsibility for providing treatment guidelines for children with HIV related illness into the realm of every other healthcare agency.

NIAID just held a state of the art consensus conference on ZDV usage. Such state of the art conferences must be held for drugs used in the treatment of pediatric HIV infection. The guidelines produced by such a conference should be formulated into a standard of care manual and widely distributed.

Up to one third of HIV+ children in NYC are in foster care (Stephen Joseph, former NYC Health Commissioner, 11.15.89). The ACTG system as a whole needs to work with states' and cities' bureaus of child welfare to create a humane, non-exploitative policy allowing children in foster care access to experimental therapies.

Hemophiliacs

All trials must be designed with an arm for persons with hemophilia, or a parallel trial of an agent in persons with hemophilia must be conducted alongside the primary trial. This applies to every phase of a trial.

AIDS, Reproductive Rights, and the ACTG

Prevention

There is a desperate need for a topical viricide that women can use to protect themselves from HIV infection. Women are among the fastest growing groups of newly infected persons with HIV. Traditional methods of prevention (condoms or safe sex) often fail among high risk women. Only 2% of HIV+ women in a study at the Montefiore Medical Center's Women's Center use condoms (Worth et al., 1989). A major problem with condoms is that women don't wear condoms; men do. Women are in no position in our society to have control over men's sexual behaviors. The development of a topical viricide that women can use to protect themselves from HIV infection must be made a high research priority in the National AIDS Program's effort to end HIV related morbidity and mortality.

Abortion

Some Principal Investigators believe it is the height of unethical conduct for an HIV+ woman to have a child. For others abortion is the wrong. Pregnant women, especially HIV+ ones, are in an extremely vulnerable position for coercion. Regardless of what researchers think, the decision to carry a fetus to term or to abort is not their decision to make. That decision belongs in the hands of women with HIV along with the most up to date information about transmission

risks, services available to HIV+ mothers and their children, the state of pediatric AIDS care, and abortion clinics that accept HIV+ women. (A survey of abortion clinics by the NYC Human Rights Commission found that 66% of 38 abortion providers surveyed will not accept HIV+ women.)

Contraception

All trials require that women be practicing an adequate method of birth control. The definition of adequate is generally left up to the individual researchers to be interpreted as broadly or as narrowly as they would like. This could mean anything from condoms (with problems as outlined above), to sterilization, to a diaphragm and contraceptive foam. The birth control pill has generally not been recommended due to possible drug interactions. There should be a standard definition of the percentage of acceptable risk for the word "adequate" when referring to methods of birth control appropriate for maximum protection from unwanted pregnancy and HIV transmission. This definition should take into account what safe, effective birth control options exist for women and should not be unduly restrictive (such as requiring sterilization or abstinence). This standardized definition should apply to all trials, at all sites.

Pregnancy

Pregnant women must be allowed to participate in all studies, beginning with Phase 2.

Trials must be designed with a contingency plan to stratify women who become pregnant while on protocol and who wish to carry their fetus to term or who wish to abort. Animal teratogenicity studies must be initiated as soon as Phase 1 studies have shown a minimum effective dose or at the end of Phase 1, whichever is sooner. Depending on the known and potential toxicities of a drug a woman may decide to withdraw from a trial during pregnancy. If a woman makes that decision, then there must be a treatment arm for her to return to after she has given birth. If a woman drops out of the trial because of pregnancy, she must be allowed to receive the drug after then trial ends as if she had completed the study. Women must be allowed to receive drugs that are in FDA Pregnancy Category B.

All Phase 2 protocols must be designed with an arm or parallel trial for pregnant women. In this manner the effects of a potential AIDS therapeutic on a developing fetus and the pharmacokinetics of the agent under study in pregnant women will begin to be studied at the earliest possible point in the clinical research process. This is necessary to avoid future scenarios such as we are currently seeing with ZDV, wherein it has become standard practice in some clinics to offer pregnant women the option of remaining on ZDV throughout pregnancy, even though no clinical studies of the pharmacokinetics of ZDV in pregnant women or its effects on a developing fetus and pregnancy outcome have ever been published. The first such study, in fact, only opened to enrollment in the fall of 1989, despite the approval of ZDV in March of 1987, the clinical testing of ZDV since 1985, and the existence of pregnant women with HIV infection since at least the early 1980s.

Women must have the right to base their treatment decisions on more than anecdotal evidence.

Animal Studies

The NIAID must take responsibility for conducting rapid well designed animal carcinogenicity and teratogenicity studies of every drug to be put through Phase 2 trials within the ACTG. In this way animal carcinogenicity data and the preliminary teratogenicity results will be available far in advance of

the approval of a drug. The latter information will expedite the study of the pharmacokinetics of experimental agents in pregnant women and add to early knowledge about an agent's potential to decrease rates of vertical HIV transmission. The ACTG must work expeditiously with all other branches of NIAID's AIDS Program to answer the largest possible amount of research questions within the shortest possible amount of time.

Enrollment

NYC ACTUs as examples of a discriminatory system.

Enrollment of persons in ACTU trials, NYC, cumulative enrollment including affiliates through 1.13.90

Site	Total	Male(%)	Female(%)	Unknown (%)
St. Lukes Roos.	169	154(93%)	11(7%)	4(2%)
Cornell	94	72 (92%)	6(8%)	16 (17%)
Einstein	236	127(59%)	88(41%)	21 (9%)
Mt. Sinai	263	206(89%)	25(11%)	32 (12%)
NYU	392	361(96%)	15 (4%)	16 (4%)
MSKCC	189	165(93%)	13 (7%)	11 (6%)
Total NYC	1343	1085(87%)	158(13%)	100(7%)
w/o Unknown =	1243			
w/o Einstein =	1028	958 (93%)	70(7%)	

Overall, 13% of persons reported with CDC diagnosed AIDS in NYC are women, and 17% of newly reported cases in 1989.

It is interesting to note that 56% of the women enrolled in ACTG trials in NYC are enrolled in one site, Albert Einstein. The majority of these women were asymptomatic (at least on entry) and enrolled in ACTG 019.

Informed Consent

Too much emphasis is placed on obtaining informed consent (a signature) and too little is placed on the process of informing people. Information needs to be presented in different ways to different people.

1. People who are illiterate. 20% of people in NYC are functionally illiterate. Informed consent can be an oral process that is documented on videotape.
2. Language. Informed consent forms must be translated into Spanish for all sites, and Haitian Creole in areas where Haitians live. There must be bi or trilingual staff at each site to speak with people whose primary language is not English. Knowing how to read and write English should never be a prerequisite for trial participation.
3. Print size. It is incomprehensible that trials for CMV retinitis have lengthy single spaced informed consent documents. People with impaired vision simply can't see as well. The informed consents for pediatric trials should be likewise be in a larger type face and double or triple spaced. Many children with HIV are cared for by grandparents or greatgrandparents with impaired vision.
4. Pregnancy. Women who become pregnant while on protocol must go through another informed consent process if they wish to remain on trial.
5. Education Level. Some trials require that participants have a certain education level. Researchers may try to justify this by saying it may in part be necessary to take certain psychological tests, however, it is a discriminatory practice that argues that the tests must be redesigned to conform to the people, not the other way around. You don't need to have a high school diploma to feel depressed or to suffer neurological symptoms of HIV infection.

Dissemination of Information

"To help transfer effective therapies from the research setting to routine patient care" is listed as goal number four in the terms of award between the Treatment Branch of the NIAID and the ACTUs.

This goal has not been met. There is no national system to quickly disseminate information on treatment advances to frontline AIDS doctors. There is no national system in place to quickly disseminate information on empiric treatment advances to the research establishment and to other clinicians. There are no systems in place to regularly update clinicians about the latest experimental therapies, the latest approved drugs, and the latest information about the nature of the disease.

This goal must be met, for it defeats the purpose of clinical research when the results of clinical study are not translated into clinical practice.

NIAID and the ACTG must create a committee to monitor the latest treatment advances. This committee would put out a clinical directive to every physician in the nation who has ever reported a case of AIDS to the CDC or their local AIDS Case Surveillance Unit, to hospitals, clinics, social service agencies and the health departments of city and state governments. When a new drug is approved, when an indication is widened, when vitally important information about the course of the disease becomes known, then this committee must disseminate the information within the week along with information on how to access the new advance.

Unpublished Data

The NIAID and the pharmaceutical/medical complex appear to consider the withholding of life-saving treatment information from PWHIVs a matter of national security. The time lag between submission of a journal article, acceptance for publication, and ultimate publication can be measured in months and thousands of deaths. Immediate publication of trial results is imperative to the implementation of treatment advances. NIAID must negotiate with the medical journals to have ACTG trial results published on a priority basis. Journal criteria that make the dissemination of information forbidden until publication must be examined and discarded. People must always come before profit.

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UNIT 4

PREVENTION THEORY, AIDS & IV DRUG USERS

These 2 units
are a couple of
years old, but
may be of some
help.

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TARGETING AIDS PREVENTION TO IV DRUG USERS

To design and deliver appropriate prevention interventions, we must understand the content and dynamics of the following elements both for the individual whom we are trying to assist and his or her group or community. An assessment of the target groups' knowledge, attitudes, behaviors, and environment will form the cornerstone of an effective prevention program because these characteristics contribute to risk behaviors and will influence behavior change.

Anthropologists define culture as a "group's design for living." It is also its assumptions about the world; other people; goals; and meanings of life; what's right and wrong; what's important; and not important; and beliefs about how to behave and how to expect other people to behave.

TYPES OF CHARACTERISTICS TO BE TARGETED

COGNITIVE

Early on in your work, much of your time will be spent trying to assess how knowledge and information is passed around your community. The conditions under which this takes place are not usually immediately apparent, but are nonetheless important to understand as they influence peoples' willingness to accept new information. How knowledge flows from one person to the next and from group to group depends on certain conditions being met. These conditions are different for every community. If you ask people how they know what they know, their answers may be vague as people are not always sure when or where they came by their knowledge.

Knowledge of AIDS and its means of transmission

It's hard to imagine that there are still people in the United States that don't know that AIDS is transmitted via the sharing of dirty works. Seldom in the history of this country has there been a public health concern that has gotten more media attention than AIDS. The fact that gay men and then IVDUs have been the hardest hit by AIDS receives almost daily attention in most major metropolitan newspapers. How, then, do we account for the fact that IVDUs still share works? One useful way to think about this is in relation to smoking. Do you or someone close to you smoke? The health consequences of smoking have also gotten a tremendous amount of media coverage, and yet millions of people still smoke. But then think about how many people you know who have quit smoking--have changed their behavior to match what they know. The same can also be said about condom use. Here again, it may be hard for us to imagine gay men having anal intercourse without a condom, but we know that they do because of the new cases of previously negative men becoming infected with the virus. They have self-reported their risk as anal sex without a condom. However, the overall rate of

STD's in the gay male community has declined by as much as 80% in some cities, such as San Francisco. That is one of the largest statistical drops in the history of infectious diseases. So we know two important facts about "what people know" and "what they do with that knowledge." First, we know that they will continue that unhealthy behavior in the face of knowing that it is unhealthy. Second, we know that lots of people will stop that behavior. How do we get them from the first point to the second? How do we respect the cultural values of the target communities when we plan prevention strategies based on what people know about AIDS and how its transmitted? Are there myths or misconceptions, or even downright prejudices about AIDS and the people who get it? As part of your ethnographic effort, you must unearth this kind of information. You have to know how people think AIDS is transmitted. You can't assume that everyone knows the facts.

Finding out what folks' stated or unstated prejudices, myths, and misconceptions are will be a very important part of your work. Some people are convinced that mosquitoes spread AIDS. Some people are afraid of kissing or sharing eating utensils. Have you met anyone who thinks you can get AIDS from a toilet seat? Some people think AIDS is a government plot to kill "queers and junkies." They are convinced that there is nothing they can do to prevent it because the government already gave it to them? One worker reported that one of his contacts truly believed that the army put it in all the dope that came into this country, so there was no reason to clean his works because AIDS was in the drugs not in the blood in the needle. Another contact reported that "Satan put it in people". If people really believe that AIDS is transmitted in ways that they have no control over, your work will obviously be more difficult! Some teenagers believe that they won't get AIDS from their boyfriends because they are "in love." As if AIDS recognized "Love," and said "Oops, we won't go there because there is love."

If your project has an evaluation questionnaire, you will be able to determine from them how people think they get AIDS. If not, you can talk to many different people in your community and ask them how they think AIDS is transmitted. Keep track of that information as we talk about other characteristics that will influence your AIDS prevention efforts.

Knowledge of needle hygiene

With all the media attention around AIDS and needle-use, many rumors have been spread about needle cleaning. Workers all around the country have come across some rather startling myths about ways to disinfect a syringe. Some people really think that water is sufficient to kill the virus and resist workers attempts to get them to use bleach or to boil their works. Others insist that air will kill the virus, so they take their works apart and let them "air." Workers have reported people using perfume, vodka, baby oil, or soda pop. All of these may be

better than nothing, but certainly don't guarantee anything. A lot of people have reported buying new needles, only to discover that they were old needles that had been repackaged! This is very serious. If someone thinks they are protecting themselves by not sharing their works and only using new ones, and then discover that they have possibly been exposed, they may become so disheartened that they stop trying. They may even become exposed to the virus. Even if people have knowledge of this practice, they will probably buy the needles anyway because of the lack of availability of other ones. This means that we should advise people to clean even new needles. Some people hide their works and don't share them. But someone else may know where they are hidden, and come along and use them without telling the owner. If a person's drug use is in the closet, they may think that having a bottle of bleach around would incriminate them even though they share works and know that they can get AIDS by not cleaning them. Works are easier to hide than a large bottle of bleach. When people are on a "run", that is, shooting up repeatedly, they have a tendency to get careless. A group may start by cleaning between partners, but then forget or stop as they get high. Here again, people's knowledge of needle hygiene doesn't always correspond to their practices. Many IVDUs now clean their works with bleach and have reported doing this more than 80% to 100% of the time. However, maintaining safe injection practices is not always easy. Your job will be to target the individuals who have the most influence in their group and convince them to put the word out that it is not cool to share.

Knowledge of safer sex practices

Sex practices may be even a thornier issue than needle hygiene. It may be easier to get people to talk about their drug use than their sex life. As a culture, we are not always comfortable talking about sex, especially our own. Contrary to popular mythology, IVDUs do have sex. They have sex while they are high, and they have sex while they are straight. Here again, almost everyone in this country has heard something about the use of condoms in AIDS prevention. Their knowledge may not, however, extend to assessing their own risk. A lot of people do not consider themselves at risk for AIDS, therefore, having knowledge of safer sex practices is irrelevant to them. They may know about safer sex, but not practice it because they think their partner is monogamous. They may not know that s/he has sex with others at risk. Commercial sex is practiced by both male and female IVDUs. Male IVDUs may participate in male-to-male sexual activity for drugs or money ("gay for pay") or while in prison, but still consider themselves "straight." If they have long-term committed relationships, their partner may not know about this. Female prostitutes are likely to practice safe sex with their customers, but not with their partners, who themselves may be at risk. Also peoples' knowledge about safer sex may not correspond with their personal or religious beliefs. Among older users, condoms still are perceived as "raincoats"--thick, unsensitive, bulky, unreliable artifacts from a man's teenage years. Something he carried around in his wallet only to be used with a prostitute. They

haven't tried the new, thin, sensitive, strong latex ones. They don't know about the vast technical improvements that have been made and still think of them as "rubbers." When gathering this kind of information, you may find that some people aren't actually against using condoms, they just don't know about the new kinds. It is will be important to distinguish between knowledge and values when checking out safer sex practices with individuals in your community.

Knowledge of drug treatment and other local health and social service resources

Many IVDUs know that the best way to protect themselves from AIDS is to get off of drugs. However, they may live in a city that does not have adequate detox facilities, or they may live too far away from them to avail themselves of their services since most programs require clients to present themselves every day for their dose. The local drug treatment program may have an unfavorable reputation (whether it is true or not is almost irrelevant in the community if that's the word that is out about a particular place) so addicts don't use them. In Unit 5 we will discuss this further, but for now think about what your neighborhood knows about the existing local drug treatment programs. Are they inclined to use them? Would a free detox coupon program entice them to enter treatment? What do they think of methadone? In the United States, methadone has been the primary method for detoxing and maintaining abstinence from heroin for over 20 years. Folklore and local myths about it abound in every community. Find out what some of these are as they will affect whether or not your contacts are likely to enter treatment should it be offered to them or available. Some IVDUs swear they'd rather be addicted to heroin than methadone. Some believe that methadone is more harmful to their body than heroin. They talk about how it "makes their bones ache." Others have been on methadone for many years, and are grateful to be off heroin. They have learned to use methadone and counseling to keep them drug free. Are there clients from the local programs around your community who talk about how important their drug program is to them? Have they spread the word about good programs? If your city has a lot of speed and cocaine users, methadone will not be appropriate for them. Do the IVDUs know that there are medical detoxes available for amphetamine or cocaine addictions? Not many cities have such programs, but as the problem of polysubstance abuse increases, more cities will have to incorporate polysubstance abuse programs into their existing facilities if they hope to use drug treatment as one of the tools in the fight against AIDS. Find out what your community knows about drug treatment. Do your contacts think that it costs too much money or takes too long to get accepted? Do the counselors there have a good reputation? Do they get hassled if they have a dirty urine test? Do they have special programs for pregnant addicts? What percentage of the IVDUs in your community use drug treatment programs? Do the programs have special AIDS education components? Since street-based outreach programs are still a

relatively new and rare phenomena in most areas, only in-treatment addicts have received AIDS education at programs where it has been available. For the addict not in-treatment, their contact with you and your program may be their first one-on-one opportunity for an AIDS prevention message or for information about local drug treatment programs. Do they know if the programs are conveniently located or do they think that they have to take several buses to get there? Do they have misconceptions about the hours of operation? Your contacts' knowledge about the nuts and bolts of drug treatment will obviously affect their use and their attitudes and about drug treatment. We'll discuss that further under Attitudinal characteristics.

ATTITUDINAL

Peoples' real attitudes may be masked by overt posturing or manipulative behavior. For instance, perhaps among a group of men hanging out together on the street, none will want to take your condoms. They may tell you that "they don't need any raincoats." They may even act insulted at the suggestion of using condoms and tell you not to ever try to give them condoms. However, you may meet one of the men from that group later when he's alone, and he will ask you for them. In other words, peoples' expressed attitudes in a group may be different from their individual attitude when they are by themselves. Your task will be to sift through this kind of posturing and decide how to best approach your target population. Your understanding of their lives and your street savvy will come in especially handy when dealing with peoples' attitudes. Your community's attitudes towards you and your program will change and hopefully grow as you grapple with these issues and become more experienced in seeing through to what people really believe.

Motivation to maintain/promote health

IVDUs do care about their health. When they are offered reasonable and nonjudgemental methods for needle hygiene, most of them will practice it. They do not want to die of AIDS! This is not to say that there will not be periods in every addict's life when s/he will not take care and protect themselves from getting AIDS. They will use a dirty needle if there's no bleach around or new needles. The high will come first at times like that. Your job will be to encourage them when they fail and to keep them supplied with bleach and condoms. Find that time or that point when they do care about themselves and try to reinforce that attitude. There will be lots of times when you will meet people who don't seem to care about their health, but remember they don't feel like that all the time. No one feels just one way all the time. Our attitudes about our health and our commitment to maintain changes vary constantly. Keep this in mind when you see people who need medical care, but fail to get it for themselves. Sometimes help from someone like yourself will be all that is necessary for that person to take that first step and become sufficiently motivated to take care of themselves. The fact that you are not trying to get them off drugs, but trying to prevent them from getting AIDS will undoubtedly influence their motivation level. Getting clean may

seem too huge an undertaking. Reducing risk behavior may seem a more realistic goal.

Unfortunately, you will probably meet people who already have been HIV-affected. They may even be ill already, but have not gotten any medical care. Street workers in New York, San Francisco, and other large cities already have been faced with this problem and have failed with some people in their attempts to get them into the health care system. These are people who have had very little or no medical care their whole lives. They will wait until they are very ill and have to be admitted to the hospital. The majority of people, however, will be motivated to seek medical treatment if you help them or give them the right information. Do not assume that someone doesn't care about their health just because they haven't gotten medical attention when they needed it. A lot of IVDUs get abscesses from shooting up and will leave them untreated because they are afraid of how they may be treated at the hospital or clinic. Workers report seeing people with abscesses as large as grapefruits on different parts of their bodies. IV drug use in the United States is heavily concentrated in minority populations that have traditionally suffered from a wide variety of economic, social, and health problems. Medical problems, such as abscesses, pneumonia, diabetes, TB, STDs, hepatitis, endocarditis, PID (pelvic inflammatory diseases), unwanted pregnancies, hypertension, etc. are but part of a long list of medical conditions that almost always go untreated until a crisis occurs, such as hospitalization or incarceration. It is not that people don't care about their health! More often than not, people are used to dealing with these problems and accept them because of a variety of reasons that keep them from seeking medical attention. Some of these reasons include ineligibility for medical care, high cost of medical insurance, lack of local health clinics, distrust of local medical establishment, language barriers, lack of information, to name but a few. Drug-use is also a way of coping with ill health and pain. When you are trying to determine your community's attitudes towards health, keep all this in mind.

Beliefs about riskiness of one's practices

Most of us want to believe that we are going to live forever. We live in a culture that hides from death. We believe that we are not going to be in a car crash when we don't put on our seatbelts. When we smoke that cigarette, we believe that it won't hurt us. When someone fixes behind someone else, they believe they won't get infected with hepatitis, endocarditis, or AIDS. However, addicts often have a fatalistic acceptance of the risk of death as part of their life. They may have had many friends die of a drug overdose, so that long before AIDS, death was something they had already seen or thought about. What we believe about the riskiness of our practices influences our attitudes and behaviors. If a woman thinks it's not risky to let her partner fix her after he shoots, she will not insist that the needle be flushed with bleach. She may never hit up behind anyone else, only her partner, and thus truly believe she doesn't share. If a group of sharing

buddies thinks that no one shares outside the group, they won't use bleach because they know everyone they are sharing with. When a woman lets her partner have sex without a condom, she wants to believe he won't give her AIDS or any other STDs. If a man has sex without a condom because the person he is with "looks clean," he believes he won't be exposed to AIDS. If people believe that only gay men get AIDS, they won't use condoms. Because you will have the opportunity to work with people on an individual basis, you will be able to elicit their true feelings about their risk behavior over time.

Attitudes about control over one's life and sense of ability to change

--Do the IVDUs in your neighborhood feel that outside forces not of their own making control what happens to them? Or are they used to taking responsibility for their lives, making choices and taking responsibility for the consequences? Addiction is a powerful disease, sometimes defeating even those with the strongest of will and desire to be free of the "monkey on their back." Think about how much easier it is to ask an IVDU to change only one small part of their drug-using rather than to stop using drugs all together. If your contacts don't believe that they have much control over their lives, their faith in their ability to change will be negligible. But by presenting them with opportunities to make small changes, they may feel empowered by their successes. What is the prevailing attitude in your community about this?

Values about sex, sexual practices, and procreation

Here again we are in a very sensitive area. Often peoples' values about sex are tied into their religious values or beliefs or the values they learned growing up, so you must be very careful not to offend anyone or the community's values. However, people's concerns about AIDS have made all of us more willing to talk about sex in ways we wouldn't have dared several years back. One worker always made a "blanket apology speech" before she began her sex rap. She would explain to people that because AIDS was a fatal disease it was necessary for her to talk to people in ways they may not have been accustomed to in order to give them very specific life-saving information. She would then ask them to "not be offended if she offended them because AIDS prevention was about saving lives, and, in order to do that, a discussion about sex had to be included". For people who have more than one sex partner, they may think you are really putting them down. For people who practice monogamy, they may think you are condoning or promoting promiscuity. Just like with drug use, be sure people understand that you are not judging their choices, but simply offering information for their protection. It is not part of your work to change people's values, but only to help them to look at them to see where they need to protect themselves. For many men, their relationship with their partner may be one of the only places where he feels he has any power. If she introduces changes, such as condoms, he may feel threatened by a loss of power. There have even been reports of men physically abusing their partners when this happened. Usually, these are

relationships where violence has been a part of them for a long time, but you should keep this in mind when thinking about the relationship between people's sexual values and their risk behaviors. Strict sex-role socialization have taught many women to be passive and nonassertive. For some people sex may be the only way they know to achieve intimacy. Women, especially, may fear rejection or abandonment.

Procreation--Deliberate planning for children may not be part of their value system, as children are culturally valued even where there aren't adequate resources to provide for them. Lack of contraception should not be perceived as failure, ignorance, stupidity, or laziness, but rather as a part of a whole value system. Sometimes people think you are really trying to prevent them from having babies and that is really your hidden agenda. This may be especially offensive to people whose religion doesn't allow birth control. Tread carefully.

Self-esteem

--Many psychological tomes have been written about the relationship between substance abuse and self-esteem. Outreach workers should not be trying to play the role of "neighborhood shrink." It is sufficient to determine how much a person cares about him or herself in order to work with them in reducing their risk behavior. Obviously, this will affect their motivation level. Remember, however, self-esteem changes. Some days we like ourselves better than others. Community pride will also influence how an individuals feel about themselves. Perhaps when your community starts making AIDS prevention a neighborhood priority, it will have a positive affect on your contacts who don't have a lot of self-esteem or self-love. (Please note here that we are not talking about the kind of community "responsibility" that involves getting rid of "junkies, whores, and faggots!")

Esteem for peers as models and educators

--Many street-based outreach programs have employed former users (peers) as AIDS prevention workers. They have been successful, but other programs have not used this model, and they have also been successful in reaching IVDUs, gaining trust, and reducing risk behaviors. The point here is that IVDUs do look to others for help in AIDS prevention. Whether or not it is necessary for the educators to be people like themselves that they respect and admire because they got clean, or trustworthy and likeable folks from outside their community is irrelevant. The key is trust and esteem. The gay community has mounted a model public response to the AIDS epidemic, but we cannot expect that kind of model to work for IVDUs without a lot of financial and technical support. ADAPT (Association for Drug Abuse Prevention and Treatment) was started in New York by ex-users emulating the gay community's organizing efforts. It is hoped that they will be successful and that other cities adopt ADAPT's idea. Your ability to develop rapport with your contacts and your knowledge of their culture is ample

substitute for the fact that you may not be an ex-user from their community. However, you will be looking for the people in the community that are esteemed and looked to by others to help get the AIDS education message across. (More on that in Unit 5.)

Attitudes about drug treatment and other health and human service agencies and staff

--As discussed under "knowledge of drug treatment programs," the community's willingness to use local programs and resources is based partly on the information that they have about it. But more importantly, it is based on how they were treated there or on how other people reported they were treated. Courtesy, respect, promptness, friendliness, services, and professional competence inform peoples' attitudes about an organization. Myth, folklore, gossip, rumor, media, etc., enhance, confirm, or deny it. Some food stamp programs have such bad reputations in their community, that people have reported that they would rather starve than subject themselves to the attitudes and prejudices of the staff. Other cities have programs that are staffed by people that are willing to bend every rule in order to qualify people for benefits. How are your local programs perceived? What happens to an IVDU who really wants to get clean, but can't find a program with an immediate opening? Do the contacts believe them, or do they think this is just more "attitude against them? Would someone rather "bleed do death" before they would go to the local county or city hospital?

BEHAVIORAL

Often behavior is determined by some unspoken set of rules or an ideology that is rarely articulated. It is not biologically necessitated, although people like to think that it is. People also believe that their sexual practices are biologically determined rather than culturally constructed. Often people may tell you something about their behavior they believe you want to hear. They don't want to be judged, or they think you may like them better. Your own behavior will influence how people behave and interact with you. Eye contact, touching, social distance, gestures, body language, physical style, verbal interactions, defense mechanism, "manners," and orientation to time are all socially contrived and proscribed behaviors that you will have to become familiar with.

Unfortunately, almost all of the statistics on AIDS transmission are based on self-reported risk. Fortunately, for your work, it is not always necessary to depend on what people report about their behavior. Information can be given in a general way, with the hope that your contacts will take what they can. But for the purpose of information-gathering, think about the complex relationship and interplay between knowledge and behavior. Listen to what people tell you about they think they should behave, and then how they actually behave. Do they always jibe?

Drug use profile

--While using drugs may be the predominant theme in an IVDUs life, there will be days or even months when s/he doesn't use. Not all drug-use episodes end in a run, and users spend much of their time feeling normal. Week-end warriors or people who use drugs intravenously at parties or with friends every few months will also need to be targeted, especially so as they may not consider themselves to be at risk because of the occasional nature of their use. Here again, assumptions or misconceptions about drug users must not get in the way of determining the general drug-use profile of people in your neighborhood. Most people have the stereotype of the "dope fiend" in mind when they think about needle users. Most likely you will come across users who have the same concerns for family, companionship, relationships, and economics as do the other people in that community.

--Street workers report that most hard-core users do not mind talking about their drug use. As a matter of fact, they like to talk about it, much the same as you might like talking about your job. If they trust you, they will tell you about which drugs they use, how often they use, and any other details you need to know. Knowing this kind of information about a person and their group will enable you to tailor your prevention efforts to their specific risk practices. One worker reported that a young woman who lived in one of the downtown residential hotels always stopped to ask her questions about AIDS and IV drug use. This woman said her husband used, but that she had stopped using when she recently got pregnant. For months, they only talked about how she could protect herself sexually, never once having a conversation about her own drug use. One day several months after her baby was born, the worker happened to see this woman presenting herself to be tested at a place where only recent IVDUs could be tested. When the worker asked her how she could qualify to be tested, she showed her a recent set of tracks. She had started using again right after her baby was born. She admitted to letting her husband fix her after he used, thus putting herself at risk. People's drug use changes as their lives change. The same can also be said for groups as the kinds and amount of drugs coming into the neighborhood change. Watch for these fluctuations.

--Although there are a wide variety of illicit drugs available in the United States, most IVDUs use one of the following drugs or some combination of them:

--Heroin is the most widely used. Many heroin users use no other drug intravenously. Smoking "weed", drinking alcohol, or snorting cocaine may take place, but injecting only heroin is the main preference. A lot of heroin users have a regular pattern of use, that is, they shoot up at certain times of day, although they would not refuse an invitation to share other drugs at other times.

--Cocaine is also widely used, but the patterns of use are different than heroin. Some cocaine users do not shoot up any other drugs, and may go days or weeks without using. Then they may go on a run which can last for days because the coming-down period is so uncomfortable. The only

thing they want to do is shoot more cocaine. Some users limit their episodes to social occasions, weekends, or binges. (Crack or rock cocaine has a different use pattern.)

--Speedball or Baluchi is a mixture of cocaine and heroin. Some people prefer the mixture all the time, while others only mix when they are sure there is sufficient amounts of their drug of choice to take care of their craving. Heroin smooths out the crash from cocaine.

--Speed or methedrine are amphetamines, and when done in large amounts or often people say they are "tweaking." They are hyperactive, speedy, and can stay up for days. Unlike heroin users, they usually take a break between runs. Some people make speedballs with heroin and speed.

--Street drugs, illegal pharmaceutical, or prescription opiates, such as codeine, methadone, Percodan, Demerol, Dilaudid, morphine, opium, Darvon, etc., are also illegally obtained and injected either in place of the drug of choice when it's not available or as another high.

--Age is an important factor when determining someone's drug use profile. Many hard core heroin users have been around since the '40s and wouldn't think of using any other drug. Younger users may favor cocaine or speed, depending, of course, on what is available.

--Sex is also a factor in determining a person's drug-profile. Some of these sex differences may have a physiological basis, that is, women on the average weigh about 20 percent less than men, so less drugs are required to attain a particular concentration in the blood. Social factors and social norms, however, account for the majority of these differences. Women don't always have as wide of a variety of contexts to use in as men. Whereas men are usually introduced to illicit drugs by other men, women are usually introduced to them by men, and use is often linked to dating patterns.

Needle-sharing and hygiene practices

--Needle-sharing is not always due to the scarcity of new or clean needles, but more often than not related to the social aspects or social function of this behavior. AIDS is changing this slowly, but it is important to remember that sharing has long been part of the ritual of drug use. Some IVDUs have equated refusing to share needles to sexual refusal between lovers. Needle-sharing bonds people together who may otherwise lack other social supports.

--You will need to know if people always share or are there certain conditions under which they don't? What are their usual habits when they use? Most people like to do things the same way every time once they find out what works best for them. "How" people use is as much a habit as "what" they use. Do they have ready access to new needles? Are hypodermic syringes legal in your state without a prescription? If they are illegal, do the police enforce the law? Many people get their works from diabetics because they usually have a prescription for them. Some people buy large quantities of needles when they are in a state

where they are legal. Is buying new needles an economic priority? Sometimes dealers include them in a buy. Others rent them when they use at large commercial galleries. Many people report only sharing with lovers or family or with people who "look clean." Research about IVDUs sharing practices indicate a mistaken sense of security about needle-sharing partners. The ritual factors that make needle-sharing among friends and lovers an accepted practice in the face of AIDS must be determined. What are the circumstances under which this takes place? Does someone always try to go first in order to avoid a confrontation about sharing? Sit down with a trusted contact and have them explain the whole ritual with you from the time they make their connection to the time when their drugs are finished.

--Needle hygiene practices also vary greatly from community to community. Before disposable syringes, users sometimes made their own rigs from baby pacifiers and eyedroppers. These could be used for weeks and were sharpened on matchbook covers. The plastic works today don't hold up well to repeated use or to boiling. What has been the prevailing method in your neighborhood? If people do clean needles, what method do they use? Do they boil them, soak them in alcohol, peroxide, or bleach? Do they take the time that these methods require to be completely safe and effective? Do they think cleaning is a hassle, or do they like the idea of shooting up knowing that they don't have to worry about a dirty rig?

Sexual practices

--Since drugs and sex are intensely linked and valued because of the strong potential for increased pleasure when combined, you will have to get information about your contacts' risk behavior when high and when straight. People do things sexually when they are high, that is take greater risks, that they would not, do otherwise. Disinhibition caused by drugs and the physiological effects of drugs on libido are the purview of trained professionals. These are complex issues, and it is only necessary for you to understand that people sometimes have different kinds of sex while stoned.

--IVDUs develop long-term stable relationships, although there may be sexual activity outside of that relationship. Since there are so many more male IVDUs than females, it is common for a male user to be involved with a non-injecting female. Sex is usually a valued part of that relationship. Here again, peoples' personal habits are very important. If a person is used to having sex a particular way because s/he knows that will produce the desired result, usually an orgasm, they will not be willing to do anything that will jeopardize that end. When you begin to talk to people in your community about their sexual behavior, remember that talk about their sexual practices may seem to threaten their desire for sexual pleasure. Communities have standards regarding sexual behavior whether or not they are explicitly stated or followed by the members of the community. In some places it is an accepted part of manhood to have relationships outside of marriage. Many communities do not approve of homosexuality, so male-to-male

sexual activity is kept "in the closet," and men who engage in this practice do not consider themselves gay or bisexual. Safe sex messages aimed at the gay community do not reach them since they do not perceive themselves to be in that risk group. Religion has a tremendous influence over sexual behavior and practices. Condoms are often not used because of this. Teenage sex is frowned upon in many communities, so consequently it is not discussed openly. Since even health officials can't always publicly agree on whether or not heterosexuals are truly at risk for AIDS, AIDS is still perceived to be a gay disease in many parts of the country. More people practice anal intercourse than they would admit to because of social and religious sanctions against it. Consequently, it may be difficult to determine if this is a practice that goes on in your community. Oral sex is another sexual practice that is not openly admitted to, and the risk factor is not clear, so it may be harder to convince people to change how they engage in cunnilingus or fellatio. Male and female issues confuse the picture even further. In a lot of relationships, sex roles are rigidly defined and adhered to, making behavioral changes even more difficult. Men may perceive safe sex as unmasculine.

Language and literacy

--One of the most significant repercussions of federal, state, and private funding being given to minority organizations has been that it has increased many organizations' sensitivity so that they now include materials that are appropriate to different reading levels. Producing culturally appropriate and sensitive materials in many different languages will hopefully soon be a goal of all AIDS education efforts. Most of the early AIDS literature was aimed at the gay community, a community that was perceived to be middle-class and well-educated. Early outreach efforts to IVDUs were frustrated by the lack of materials appropriate to their target population. The reading level was too high, and most brochures and pamphlets were only available in English. Even today, many cities have to get their materials from other states because they haven't had the time or the resources to develop ones that are appropriate to their communities.

--If a person can barely read, pride will often prevent them from admitting it. They may pretend that they understand what they are looking at rather than feel shamed for their perceived failure. The same may also be true for someone whose native language is not English. Much of the AIDS literature does not reach them, or they may not understand a lot of the big words like "pneumocystis carinii pneumonia," "Kaposi's sarcoma," "vaginal intercourse," to name but a few. One worker in a Black community reported a "researcher" asked to meet with some of the women in his community. The researcher asked the women there if they used condoms when they had "vaginal intercourse." Some of them said they didn't do that "weird stuff." When he asked them how they happened to have children without having intercourse, they, of course, told him they got them by "fucking, not by doing that kinky stuff." "Cum" is a word that most people know. However, some cities or states won't allow its use and insist that "semen" be used in printed

materials. Workers make jokes claiming that people think they are talking about "men who go to sea" when they use that word. Some English words are not even translatable to other languages. Even the word "condom" occasionally gets mispronounced as "condo" (are we talking about real estate?), and most people seem to be more comfortable using "rubber."

--Be especially sensitive to issues around language and literacy. If you are working in a community where English is not the first language, talk to someone who has been working or living there and get more information about how to handle language differences. Be sure to find out what kinds of printed materials people like and use before you hand any out en masse.

Basic life skills

--The ability to seek help when needed, negotiate and obtain the basic essentials of life (food, clothing, housing, and money) and to form and maintain relationships are basic life skills that are necessary to ensure survival. Some of us accomplish these things with more success and ease than others. We are talking about more than knowing how to pay the electric bill or the phone bill so they don't get cut off. Hard core drug abusers, as compared to intermittent or occasional drug users, have a more difficult time maintaining their lives, and are sometimes oblivious to concerns such as diet, health, employment, or relationships. Some people have never been taught these skills or have had no models to learn from. Others have language barriers and are new in this country and without family. These factors may prevent immediate access to the basic essentials because the life skills necessary here to survive are different from their country of origin. Some IVDUs may rely on illicit activities to earn money both to live on and to get high on. They may not be adverse to trying other ways, but just have never had the opportunity to do so or the inclination. The skills necessary to negotiate life can be learned. However, when people don't have them, their lives will obviously be hard, making your job even more difficult.

Changes initiated in response to AIDS scare

--IVDUs have changed or reduced their risk behavior. Upon questioning, it may not seem adequate or safer, but nonetheless, they may be proud of the changes they have initiated in response to the AIDS scare. Recognize, respect, and re-enforce them. Find out if there are other changes that have been made in your community already.

Use patterns of health and human services, including drug treatment

--Many IVDUs use outpatient drug treatment programs as a way to get a break from their habit. They use a 21-day detox to rest, eat better, in short, to stop "ripping and running." Most states have strict laws that regulate the number of methadone treatment episodes a person is eligible for each year. Some people will enroll in detox as soon as they are eligible again. Think about what was said under "Cognitive and Attitudinal" in the discussion about "drug treatment and

other health and human services." How these facilities get used is dependent on these characteristics.

--Alternative Test Sites report an increase in demand for HIV Antibody Testing every time there is wide-spread media coverage about a particular aspect of the epidemic. If the news stories are about heterosexual transmission, people without any risk in the last five years will call and want to be tested. IVDUs are now starting to come to the testing sites in large numbers. STD clinics are busier than ever. There is a new demand for drug counseling. In Unit 5, we will go into a detailed discussion about health and human services in your community, but for now think about how people in your neighborhood use them.

Residency

--In many Black communities, female heads-of-household are the norm. In the Latino community, more forms of social control are placed on females. Where a person lives affects how they use drugs. If their drug use is hidden in the closet, living with friends or family, such as their mother or significant other, may have them trying to "look sharp," and reduce the amount of drugs they use. Many IVDUs will not use around their small children and wait until they are in school or asleep to shoot up. Obviously, if both partners in a relationship live together and use together, they will use more than the woman who has hidden her use from her partner. Residency patterns are very important to your work. What are they in your neighborhood? Single-family dwellings, large housing projects, residential hotels, apartment complexes, public housing scattered around your city are but a few of the types of housing, but then you need to check with the people in your neighborhood to ascertain the general living arrangements and the relationships of the people living together. If your target population is more transient, you will have to find out where they generally go when they first arrive in your community, and what happens to families who need housing.

Job skills and employment history

--With the high rate of unemployment in this country, and job lay-offs occurring daily, you will meet many people who may have been week-end users, but became heavy users after losing a job. If their job skills are limited and their employment history sketchy, it may be difficult for them to find work again. Unfortunately, many of the minority communities that have high rates of IV drug use also have very high rates of unemployment, particularly among the men and the youth. It is not possible to say enough here about the relationship between drug use and community-wide unemployment. Check the local demographics for statistics on median income and employment rates which have been broken down by race, age, education, job skills, and sex.

ENVIRONMENTAL

Where does your target group live? Where people live is a significant factor in AIDS. The environment in which an IVDU uses drugs, shares works, or engages in unsafe sex is shaped not only by knowledge, attitudes, and behaviors, but also the cultural and ethnic influences and the geography and actual physical lay-out of the community. Economic opportunities or more often the lack of opportunities also affect drug use patterns. These environmental characteristics must be addressed and understood in order for you to be effective because they will influence your AIDS efforts. For example, if you drive by a particular street corner only during the day and don't notice any drug related activity, you may think you don't need to do any outreach there. But on Friday and Saturday night, it turns into a "scene." It may be that a lot of people in that area have jobs, so they only come out at night, mostly on week-ends. Then they buy and use a lot of different kinds of drugs. The prostitutes know this, so they work that area on week-ends too. It is your responsibility to know information at this level. The following list will give you an idea of the diversity among communities that shape environmental characteristics.

Drug use patterns

Drug use patterns vary greatly from city to city. It will be your job to find out the **how, where, when, what, and who** of the drug use in your community. Knowing these patterns will enable you to design and plan intervention and prevention strategies that are pertinent to your community, but may not work in another community.

How

--Are drugs easy to buy, or do people have stand around and wait outside for a long time for their connection to show up? Do they risk being hassled by police or former friends while they stand around and wait? If they are standing in front of a business, do the business people inside hassle them and try to get them to move away? Are they buying from other users who sell in order to support their own habit? Or are they buying from someone in it strictly for the money who give them hard time because they don't like junkies? How reliable is their connection? Can they trust them? We are not looking for information about drug traffic. We are, however, looking for information about how people get their drugs because it influences the amount of drugs someone uses and their sharing practices. **Be very careful when trying to obtain this kind of information.** You will not be working with your contacts at this level until after you have "Cracked the Community" and gained access to your target group (Unit 5). But be thinking about these issues while we discuss characteristics as they relate to drug use patterns. The focus here should be on how drugs are bought, but not the specific people who sell them. (Please leave if drugs are being sold around you. It is never a good practice to be around

when drug transactions are taking place. More on that in Unit 6.) This information can be obtained by talking to a few cooperative individuals.

- Where** --Here again the focus is on what part of town copping and drug use takes place and whether or not there are shooting galleries, hotels, bars, clubs, bath houses, work places, restaurants, coffee shops, alleyways, vacant lots, apartment buildings, housing projects, parks, parking lots, abandoned buildings, garages, etc. that are used repeatedly by the target group.
- When** --Time of day is very important in your work. You want to be able to reach the maximum number of people every day, so you will need to know the appropriate time to plan your outreach activities. This often means working nights and week-ends. If you know that your contacts hang around a particular place for a couple of hours in order to score, you want to time your streetwork so that you are there well before the connection arrives. Hopefully, this will give you an opportunity to talk to folks before they use and to give them bleach. Do not attempt to talk them out of using--that is not your job, especially at this time! If they want to talk to you about that, make arrangements for another time, not while they are waiting to score. In the initial phases of your work, keep accurate records on times and learn when you should do your outreach.
- Who** --More men use intravenous drugs than women. In a lot of communities, it is not even appropriate for a woman to use without her man around. Some women are more apt to keep their use hidden or at least not hang out waiting to cop like men. It is not accepted behavior. These are generalizations, but find out if there are sex differences in the drug patterns in your communities. Make sure you talk to some women IVDUs. Do different groups of people use a particular area at different times of day? One parking lot in San Francisco was used in the morning by older, straight, male heroin users. At night the speed users hung out there. They were usually gay or bisexual men in their twenties or runaway, homeless teens.
- What** --What drugs people use vary by city and availability. On the East Coast there is more heroin use and not that much speed. Cocaine is more available now and cheaper than its been in a long time, and some former heroin users have switched to shooting coke on the West Coast. There is also more speed use in Los Angeles and San Francisco. (Get more info on specific drugs). People who use coke

tend to shoot up more often and to leave the needle in longer. Therefore, if they are sharing, they are at more risk than heroin users because they are in contact with a needle more often and for longer periods, thus increasing their chances of exposure. Drug studies have been done that show the statistical significance of this pattern.

Hangouts (of IVDUs and their sexual partners)

All of the above information will go into your investigation of local neighborhood hangouts. Besides time of day, be aware of weather conditions, holidays, days of the month (assistance checks usually arrive on the fifteenth and thirtieth), current political proclivities of the local government, police practices, or any other factors that may influence or change where people congregate. Sometimes businesses that are near hangouts and affected by congestion, complain to their local business bureau or police about IVDUs interfering with their business. This often results in increased harassment, and forces people to find another place to hang out. In Unit 5 we will discuss more specifics about locating hangouts, so for now think about how the hangouts you know about will affect your outreach efforts.

Systemic connections between IVDU groups

Sometimes people who would not normally associate with a particular group of people find themselves there simply because they use the same drugs, at the same time and place, and in the same way. Their common bond is drugs. They then share some of the same interests and problems. They talk the same language. **This is not to say that all drug users are alike!** We are simply stating that in this one area, the white heterosexual heroin user may have more in common with a black gay speed user than with another white male. As a street worker, you can take advantage of this when thinking about environmental factors that shape what may at first appear to be very disparate groups. You cannot make assumptions about IVDUs as they are individuals, and their behaviors are by no means universal. They do not all use drugs in the same way so we cannot tell you what your neighborhood will look like. You will learn what the realities of your neighborhood are as you become more connected and familiar with it.

Existence of shooting galleries or their variants

New York is famous for its shooting galleries! A claim, we know, it would like to do without! One of the reasons that the AIDS virus has spread so fast on the East Coast is because of the existence of commercial drug use establishments. Some of them are run like real businesses with almost a "menu" of options. It costs more money to be hit with a new or clean needle. Many more people use the same needle. In other parts of the country, much smaller groups constitute sharing networks usually without the existence of New York type galleries.

Copping Patterns

--Usually commercial dealers keep the small-time street dealers supplied. Copping patterns is also one of those elements that vary greatly from city to city, and they are usually hidden far underground and change rapidly. However, any interruption, or even threatened interruption, in a group or an individual's ability to cop, can result in chaos or violence. Also kinds of drugs, quality, quantity, and availability seem to go in cycles. If people think they are being cheated, ripped off, or hustled, this will also cause problems. Your concern should be with your contacts' and your communities' copping patterns as they affect use, not with drug traffic information.

Law Enforcement practices

--In Unit 5 we will go into a detailed discussion about the role of your Outreach Program with the police. For now, think about the effect of the police on your target population. Is the drug use in your city out in the open or clustered in a particular area? Do the police keep a tight rein on this activity, or is it so hidden that it is not possible? Do the police know who the hard-core users are? Do they make periodic sweeps and arrest people for parole or probation violations, outstanding traffic warrants, loitering, drinking in public, solicitation, etc.? Are there informers or undercover operations in the drug-using subculture? Possession and sale of drugs are illegal and a violation of the law. How do the police handle this in your community? How does your target population view the police, and what do they think about how the laws are enforced? How responsive have the police been to the AIDS epidemic? Most IVDUs have had some kind of encounter with the police, and virtually all of your contacts will have an opinion about the local police and their law enforcement practices. What are they?

Housing and employment opportunities

--High rates of unemployment among the more hard-core IVDUs is a known and accepted fact. The affects of this are obvious and don't need to be discussed here. However, you do need to know how lack of housing and jobs effects your community specifically. An environment that doesn't include incentives and opportunities for people to provide the basics of life for themselves or their families aggravates a community's and an individual's drug problems. It is an almost impossible task to educate IVDUs about AIDS when they don't even know where they will be sleeping that night, or if they will be able to feed themselves or their families. These problems will influence your work more than any other environmental factor.

Cultural and ethnic influences

--There is a great diversity among the Hispanic community. It can never be viewed as a monoculture. The same is also true for Black, White, Asian, Native Americans, Pacific Islanders, in short, all ethnic communities. The differences are significant and cannot be ignored when you are trying to learn how a person's

cultural and ethnic environment influence them and affect their risk behavior. Initially, you can draw broad social descriptions of your community and the different groups in it. As you progress in your work, however, be certain to ascertain the subtle nuances and differences in cultural norms that may not be immediately apparent. Demographic data are only useful as a place to begin and will not help you to identify specific cultural and ethnic characteristics. Only by participating and observing your community can you understand the breadth and variations in different groups. Think about what they might be for your neighborhood. Always respect them and realize that they do change over time. In one part of your community, it may be perfectly acceptable to talk about drug use, while in another area, such open discussions will not be initially tolerated.

Health and human services, including drug treatment programs

--In an ideal world, your contacts would live in a neighborhood that not only had adequate and good health and human services, but also ample and respected drug treatment facilities. We don't live in an ideal world, and unfortunately, your contacts will most likely live in an environment that cannot or does not adequately provide for their needs. What kinds of services are provided? How do they affect your contacts' drug use and related problems? Is it an environment that recognizes that people have problems and attempts to meet their needs? Or is it more likely an environment that doesn't have the resources to meet those kinds of needs and concerns? San Francisco has a reputation as a city that has been adequately providing for people with AIDS or ARC. The outreach workers there, however, have found that not to be true at all for IVDUs. It is not a city that has been able to acquire the vast financial resources or professional expertise that is necessary to adequately provide for the needs of IVDUs, which are obviously different from those of the mostly gay, white males who have thus far been hardest hit by AIDS. For that latter group, San Francisco does do a great job of providing for them, but the ability to shift gears and plan for IVDUs has not quite happened. There are still not enough methadone treatment slots available, and there are only a few medical detoxes for cocaine or speed users.

--If there aren't sufficient STD, family planning, or medical clinics, your contacts may not have adequate or complete treatment when they get gonorrhea, syphilis, chlamydia, or pelvic inflammatory diseases. These kinds of traumas, if left untreated, can increase a person's susceptibility to sexual transmission of AIDS. If one of your contacts has finally decided that he wants to get clean so that he won't get AIDS, what will happen to him or her if there isn't a drug treatment slot available? If one of your female clients is HIV positive and thinks she is pregnant, what will happen to her if there is no place nearby for a free pregnancy test? Will she wait so long that an abortion is no longer an option? Women IVDUs have problems with irregular menstrual cycles due to their drug use. Often this results in finding out they are pregnant after their first trimester, which is after the safest time for an abortion, thus reducing their choices or options. If there are no soup kitchens or food programs in your community, people may turn to petty crime just to eat, never mind to score drugs. They will not be open to your message. (More about that in Unit 8--Crisis Intervention.)

AIDS service organizations

--Most AIDS service organizations have been serving gay men. Only recently in places like New York, New Jersey, Washington D.C., Maryland, and California, have they begun to plan for the needs of HIV-affected IDUs. Hopefully, your program will have a positive influence on their future planning (more on that in Unit 5). But for now think about how your target population has come to view these types of organizations, and how that may influence the environment in which your contacts live and in which you work.

Community-based organizations

--Here is where the political strength and power of your community may lie. If your neighborhood is fortunate enough to have several community-based organizations, they may have a positive influence on the lives of your contacts or the potential to affect them if an organization decides to "take on AIDS." Neighborhood organizations have been known to virtually change the face of their community and the lives of its residents. Are there any church or cultural organizations like that in your community? Have they had any contact or influence with your target group? Do the members of these organizations have people in their families or friends who are IDUs?

OUTREACH WORKER ROLES IN MEETING ASSESSED AIDS-RELATED NEEDS

In order to accomplish all of the above, it is necessary for outreach workers to "wear many hats" and to assume multiple roles. Successful intervention requires conducting multifaceted, targeted prevention. The following is a list of the roles that outreach workers have thus far assumed. Can you think of any more?

--**Ethnographer**--Being an ethnographer means continually assessing and documenting the target population and environment in a manner similar to activities in this unit so that outreach strategies can be tailored effectively. Anthropologists say that anthropology is "systematized gossip," that is, ethnographic surveys discern the patterns and systemic relationships expressed in what people say about their lives and their communities. This is then added to what the anthropologist observes or learns when they participate in the life of the community.

--**Strategist on Effective AIDS Prevention with Target Population**--It is not likely that over time there will be many other agency staff that will have the knowledge and expertise that outreach workers will acquire about their target community. Only other workers who actually work on the streets will have that. This level of knowledge is absolutely necessary to designing effective AIDS prevention.

--**Community Health Educator**--The ability to talk to people about health issues does not require you to go to medical or nursing school. This is learned information and an acquired skill. Think about how much you have already

learned about AIDS in only one day. You are not an expert YET, but you can see how it is possible to become a health educator.

--Risk Reduction Counselor to IVDUs and their Sexual Partners--Here again, you don't have to become a trained therapist to do this kind of nitty-gritty counseling. Risk reduction skills require that you listen to what people tell you about their behavior, and then temper that with what you think intuitively about what they are telling you. You then give them the appropriate information and supplies.

--Monitor, Supporter, and Reinforcer of Individual Change--Hopefully, you will form warm and friendly, but always professional relationships with your contacts. Workers report sharing many wonderful moments with folks, such as celebrating two-days without drugs, a successful safe sex negotiation, or the arrival of a HIV negative test result. Working so closely with people on a daily, on-going, one-on-one basis, you have the opportunity to reinforce the changes they have made in their lives, especially when they may be having a hard time maintaining them.

--Trainer of trainers of Drug Treatment, AIDS Services, Community-based, and Other Health and Human Services Agencies-- In Unit 5, you will learn how to work specifically with these kinds of agencies. Your community experiences will hopefully come to be valued by these agencies, and they will turn to you and your program for help and information, not only about the target population, but also about AIDS, AIDS prevention, and drug use. You may find yourself becoming a public speaker and being asked to make presentations!

--Advocator for and Negotiator of Services to Contacts--Again in Unit 5, you will learn what to look for in assessing the service needs of your contacts and their community. You will undoubtedly find yourself in a position of lobbying or even demanding vital services. You will also be called upon by your contacts to help them get services when they have been denied or difficult to get.

--Community Organizer of AIDS-Prevention Groups, Individuals and Resources--You may have the opportunity to help form a local AIDS awareness group, such as ADAPT in New York or the "Junkybonds" in the Netherlands. You may find yourself organizing housing with your community. (Be careful here if you work for a non-profit organization or for the local government as there are strict laws that govern this kind of activity if it becomes political.)

--Community Information Resource on Latest Developments in AIDS, Treatment and Vaccines, and Resources--Existing outreach programs find themselves answering requests for all kinds of information about AIDS "vaccines" and treatments. As part of your on-going responsibilities, you will have to keep up on all the latest developments on these issues. You will have to know where all of the available resources in your city are, and how they are accessed.

After all of this, please remember not to become so overly involved with any one role or contact, that other roles or contacts are slighted. Your overall effectiveness may be compromised. One worker became so overwhelmed by peoples' housing needs that he spent almost all of his time trying to rectify this chronic problem. His supervisor had to remind him constantly that he could not solve this massive problem, and that his primary responsibility was to AIDS prevention.

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UNIT 5

"CRACKING" THE COMMUNITY

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DO NOT QUOTE WITHOUT AUTHOR'S PERMISSION

UNIT FIVE -- TEXT

OVERVIEW

The next six units (Unit 5 through Unit 10) form the core of community outreach work. However, you could not do this work without the basic information contained in the previous four units. Here is what the rest of the training will cover:

1. The purpose of **Unit 5** is to bridge the gap between what you now know about AIDS, and how you reach your target population so that you can impart that information and knowledge to them. It is important to remember that your prevention and education work cannot proceed effectively without community support and a plan. Just as this training was planned by building your skill and information base unit by unit, out in your community you will add to your ethnographic knowledge of it each day in a very specific way. Other cities designed intervention strategies based on very specific plans, and we have included some suggested sample forms for keeping track of information about your target population as you "crack the community".

In this Unit you will be introduced to the four basic principles that guide community work, plus the behaviors that are appropriate to entering and working in the community.

2. In **Unit 6** we will spend more time on personal conduct and on-the-street comportment, and hopefully take care of some of your fears and concerns about potentially sticky situations. Keep this in mind while you learn how to "access" the target community.

3. After you've gained entry and become familiar with the "do's and don'ts" of good street work, **Unit 7** will familiarize you with specific risk-reduction techniques and let you practice the counseling skills that will form the bases for your primary role as an outreach worker.

4. Your contacts will often be faced with a crisis that can interfere with your ability to get an AIDS prevention message across, so **Unit 8** will help you help your contacts clear out their lives enough so you can do your job. You are not a Social Worker or anyone's savior, but occasionally your job will incorporate elements of social work in it.

5. Then in **Unit 9** you will learn how to keep records and notes on your work.

6. With additional trainings, special in-services, guest speakers, and close work with your supervisors, you can learn the "art of streetwork." **Unit 10** is designed to help you assess your accomplishments and skills and then develop a plan to meet your additional training needs.

GUIDELINES FOR COMMUNITY WORK

Each community, each city, each region of the United States is culturally and geographically unique. These differences must be respected and taken into account when planning intervention strategies. What works in Florida where the weather is warm, may not work in Chicago where long periods of fierce weather force workers inside. San Francisco has a reputation for being "looser" sexually, so it may be easier to talk about condoms and safe sex there than in a more conservative city like Dallas. So we will do what ethnographers call "mapping" as a way of organizing what you know about your community into a work plan. Using this method, you should be able to avoid the feeling that you have been put into a complex community, and you don't know where or how to begin reaching people, or if what you are doing will even work. You will know what to do every day. We cannot emphasize too strongly the need for a comprehensive work plan and a commitment to follow it and modify it when necessary. By first mapping your community, you will learn where your target population hangs out. You will hopefully be introduced to someone who can "vouch for you" and take you around the neighborhood. "Opinion leaders" influence their peer groups, and by mapping you will be able to know who you should seek out for entry into the target group. It is imperative to know the habits and customs of your contacts, especially regarding drug use and sexual customs and attitudes. **It is not necessary for you to have information about drug traffic.** (More about that in Unit Six.)

Some workers have reported to us that visitors to their field sites have commented that the Health Outreach Workers make the work seem very easy, just as if "you were paid to just hang out on street corners and talk." The ability to appear natural and relaxed while keeping track of all your contacts and the ever-changing scene in your neighborhood is an "art" and an acquired skill. Do not be fooled into thinking that this is easy work and that anyone can do it.

As the Roll Call Sergeant says on Hill Street Blues, "Be careful out there." We would add "Relax and Observe."

FOUR BASIC PRINCIPLES OF COMMUNITY WORK

There really are correct ways to act in the field. Baltimore, New York, and San Francisco have been conducting outreach programs for several years now. The following principles have been derived from their work and are commonsense guidelines for presenting yourself in the community. Think about how you will present yourself with these principles in mind.

Neighborly:

- One of the most important aspects of being neighborly is remembering your contacts' names. Most people are notoriously bad at this. If you can devise a system to help you overcome this, you can almost charm your neighborhood. Just think how good you feel when someone you only met once greets you by your correct name the very next time they see you! On the other hand, though, don't make people feel bad when they can't remember your name. Practice your trick for remembering names with your co-workers. Some people may prefer that you call them by their "street name." Others may not want you to use their names at all. Always check with people if they seem hesitant about using their name. (More about this in Unit 6 when we talk about confidentiality, anonymity, and "Protection of Human Subjects.")
- Remembering what's going on in people's lives is also another way to be neighborly. This gets tricky because folks lead rich and complicated lives. It is not necessary to let them go on indefinitely about their problems as they sometimes will. Letting them know that you care and have information that might be helpful is neighborly.
- Solving peoples' problems for them is not neighborly. Assisting with offers of information or resources is.
- You may find that more and more people will turn to you for help after you have established yourself in the community. A lot of these folks are not IVDUs or even partners of IVDUs. Learning how to steer these folks in the right direction without letting them get in the way of your work with the target population or damaging your credibility and good-standing in the neighborhood will challenge your notions of "neighborly".
- Treating people with respect even when you find it difficult to understand them or how they live is another challenge to being neighborly. You will come across people living on the street or in parks. You might think they're "gross," and yet you know they deserve the same respect as the program director you're trying to get to know. Being neighborly means accepting and treating everyone the same--no condescension or paternalism. Don't try to run the "show"--the neighborhood. This is true whether you have lived there all your life and know everyone or if you've been doing community work for a long time. Be proud of your work and what you know, but don't continually take charge or give the answer or solution before others have a chance to contribute.

Natural:

- Don't try to be "cool or hip," because most of us can look pretty silly when we try. Your apparent natural style was part of the reason you were hired for this job. Your success will depend a great deal on your ability to be yourself and to act natural and at ease. When you feel anxious, please talk about it and share it with your supervisor or co-workers so you can deal with it. That is just another part of being "natural."
- Find a style that fits you and is appropriate to your neighborhood and your role in it. One outreach worker in San Francisco initially felt more comfortable talking to several people at a time than trying to get to know individual people well enough to be able to talk one-on-one. He would stand on a street corner and start his rap. People could really sense that he was not only comfortable doing that, but was also having fun. People would gather around and listen to him and ask lots of questions. His co-worker was terrified at the idea of talking in public like that, but was at ease quietly listening to people and getting to know them. Contacts would ask that worker to come around and visit them to talk some more. Both approaches have merit. Where do you fit?
- Being natural also means taking your time getting to know people and not pushing for acceptance. If you are following your plan and comfortable with who you are and what you are doing, acceptance will come.
- Remember what your unique role in the community is and don't try to be or do more. People may be so grateful for the assistance you provide them that they will try to make you a hero or their savior or even their best friend. This kind of adulation can make you feel good, so it is sometimes difficult to stop people from treating you like this because you may get a lot out of it personally. One worker reported that a female contact of hers called her "MOM" every time she saw her. The contact wanted her to tell her what to do when she was confused and to stay with her. She got upset when the worker said she couldn't do that. She offered her other avenues for emotional support instead, thus avoiding a potentially weird situation from developing.
- Beware of the "Hero/Heroine" trap.
- Be relaxed and easy about your work. AIDS is deadly serious, but that does not mean that we have to always be serious. People might avoid you if your message is always "heavy."
- Naturally, we assume people will protect themselves from AIDS when they have the necessary information and resources. Project that kind of natural confidence in your attitude out on the street.

kNow-Nothing:

- Be like a "sponge and soak" up everything--all the observable activities, patterns, problems, goings-on, events, and the general

scene in your community because there is always something new to learn. Your contacts will be your teachers.

- Learn to be an active listener. Good listening is as important as good speaking. Really hear what people are saying and don't withdraw when not speaking. Realize that active listening is active participation. Don't formulate a response after the first few sentences, not listening to anything from that point on and leaping in at the first pause. Try not to interrupt when people are speaking, except if someone is high and is not going to hear what you say or remember what they say.
- It is not necessary to share every idea and every bit of information you have on AIDS with every contact you meet every time you see them. Hopefully, you will see them again.
- No matter what anyone says about someone else, do not repeat gossip. "Know-nothing" about it.

Nonjudgmental:

- You cannot possibly be "neighborly", "natural," and a "know-nothing" if you are judgmental. Being nonjudgmental means not hassling people about their drug or sex lives. In order to be nonjudgmental, you need to examine your values and attitudes about these big issues. Our culture, our religious teachings, our families, our schools, etc. have laid down very clear and well-defined proscriptions against the very activities that we will be talking to people about--illicit drug use and non-monogamous sex and in some cases, sex-for-pay. How do you feel about your ability to let go of your beliefs, feelings, and attitudes about these issues while you are working?
- If you are a former user and a drug treatment program got you clean so that now don't have to worry about getting AIDS from needles, you may have a strong belief that all users should get into a program. Being nonjudgmental means you recognize that everyone has the right to find his or her own solution, and it may not be what was "right" for you.
- Remember that some people, married or not, are not committed to monogamy. These are lifestyle choices that are not part of your job to judge. Everyone deserves the full range of your services and expertise, regardless of your feelings or beliefs about what "they are into."
- One of the more rewarding aspects of streetwork is the discovery that formerly "suspect" persons or organizations can turn into allies. One worker reported her trepidation about approaching the nuns in her community for support. Her supervisor encouraged her to make the initial contact because the church operated the largest community dining room and medical clinic in her neighborhood, and she couldn't proceed in that neighborhood without their support. As it turned out, the nuns were already dispensing condoms and

bleach information and had been counseling IVDUs and their sexual partners for years about STDs and birth control. The head nun invited the worker and her colleagues back to do a staff training, and then gave them "full reign" in all the church's facilities to do AIDS education and outreach. Never let your preconceived notions about people and organizations get in the way of finding out what they have been doing, and what they might do given the opportunity.

ADMINISTRATIVE CHECK-IN WITH POLICE

Since you will be working in areas where there is a lot of drug traffic and drug use, it is necessary to inform the police about your new program and your presence. The project administrator should meet with the police chief to outline the program's purpose and goals and to explain the role of the workers. A list of the workers may be given to the police with the assurance that workers will have program "ID" badges with them. The police chief should be encouraged to pass this information down the line in writing to precinct commands and/or narcotics or vice squads. The chief should be assured that the workers will never be involved in drug traffic, and that it is not part of an outreach worker's job to be privy to that kind of information. (In Unit 6 we will talk more about that.)

If your city's police department has not had an "AIDS 101" training, perhaps your agency can arrange for one. Some cities have a "neighborhood crime watch" or "crime abatement programs" with their local police community relations department. This may be an opportunity to work with the police and improve community relations. Your project administrator will share these kinds of opportunities with you so you can work together to develop your relationship with the police.

In San Francisco the outreach workers had been distributing bleach and condoms for several months when their contacts started reporting that during police "pat searches" on the streets, the police were pouring out the bleach and either confiscating the condoms or poking holes in them. Workers were concerned that perhaps they should hand out bleach on the "QT" so as to not identify drug users or sex workers to undercover or "beat cops". When the program administrators met with the police chief and the district attorney and explained the program to them, a police order was issued outlining the specific procedures that the police should follow when they found bleach and condoms on suspects. Police were forbidden to destroy or confiscate condoms. They could open the bleach bottles (the order showed a picture of the approved bleach bottle) to determine that it was really bleach, but they could not pour it out. If an arrest was made, bleach and condoms were treated like all personal property and returned upon release. Contacts immediately reported that the police were abiding by the order, and that particular kind of harassment by the police stopped. The police then actually started seeking out the workers and asking them to talk to so and so because they were concerned about that persons's needle hygiene practices. They also started referring sex workers to the rap groups that outreach workers organized for them. The fear that police would identify IVDUs when they took bleach was unfounded--the police already

knew who the local users were. The meeting between the Chief, the District Attorney, and the program directors helped the contacts and the outreach workers without jeopardizing anyone. As a matter of fact, the outreach workers became even more respected on the streets because their contacts could see that their program could favorably influence police policy.

Another program was conducting anonymous HIV antibody testing for IVDUs in a downtown residential hotel. Contacts were lining up outside the hotel early every morning to wait. The police came by to see what was going on, and started hassling people. The program director took them aside to explain what was happening. However, he only told them they were conducting free antibody testing. He did not mention that they were testing IVDUs because he didn't want these people to be identified as such to the police. The police were then pleasant and just asked that the sidewalk not be blocked. Within hours, more IVDUs came by to be tested. They said the police told them to "check it out." Obviously, the police took one look at who was lined up and realized that the program was for IVDUs. The director had to go find the police and ask them to stop making referrals because more IVDUs showed up than could be tested.

It is very important that your potential contacts don't think you are a "narc," but don't overlook the police as possible allies in your work in your zeal to be accepted by your contacts. We will talk more about this later in Unit 6 when we get into issues around information about illegal activities that you may come across in your work.

Other outreach workers have been invited to roll call or shift change at their neighborhood precinct station to talk about their work. This took place after the initial contact by the program director. The police had been working with the local merchants' association who were bothered by the number of runaway youth on the street hanging out and blocking access to their stores. The police were concerned that the outreach workers would add to the congestion on the street if they were standing there talking to the kids. The police and the merchants wanted to hear from the workers themselves how they planned to take care of this concern. By talking together, they came up with a plan that took care of everyone's concerns and needs.

By having your program administrator do the groundwork with the police for you, you won't need to explain yourself to every cop you meet. You won't have to worry that they may think you are a new dealer in the neighborhood! Your contacts won't think you're a "narc" because they won't see you talking to the police except to say "Hi" or for some emergency. If you get stopped by the police, showing your ID should be sufficient to get you on your way if the order has come from the "top down" to cooperate with your program. (In Unit 6 we will talk about what you should do in case you get arrested.)

Think about how your contacts feel about the police. If you have concerns about doing your work under the watchful eyes of the police, talk to your program director or supervisor about it. Perhaps they could arrange for someone from the police department to come to talk at a staff meeting to take care of additional or unforeseen concerns.

BUILDING LINKAGES WITH HEALTH AND HUMAN SERVICES AGENCIES AND STAFF

Your work in the community cannot proceed in a vacuum. Your ability to help people efficiently and effectively will depend directly on how familiar you are with the resources in (and sometimes outside) the community, and how well you and your program are regarded. The basic mapping is the groundwork for building "linkages" with these agencies. Linkages are professional connections between outreach workers and an agency or its staff that can further the work of both sides. Your first contacts in the community may very well be referrals from a local health or human services agency. In conducting AIDS outreach, such linkages will assist you to:

- **Identify availability and character of resources supportive of your work and the impact they have on your contacts.** On the street you will have many requests for information about available services. This information should be at your fingertips at all times in order to expedite your work. You will want to know how well they treat your contacts, and how well prepared they are to deal with HIV-affected people. You may need to refer your contacts to them for services.
- **Identify service gaps in need of development.** Unfortunately, you will find a lot of these! There are never sufficient resources to take care of the needs of the people with whom you will working. If your program is successful, perhaps you will be in a position to help your city develop necessary services.
- **Identify reliable referral links (persons).** Some individuals within organizations acquire reputations as being "easy, OK, fair, or no BS." You will want to identify these kinds of people. These are the ones that you will refer your contacts to. Your field work will go much smoother when you get to the point where you can just make one phone call to get services, such as emergency food stamps, for your contacts.
- **Enable service providers to better serve needs of your contacts.** Existing programs may want you to provide AIDS education to their clients or their staff. AIDS programs that have not been providing services to IVDUs may want your help as they start to provide for the needs of IVDUs who are HIV-affected.
- **Learn rules and regulations for service negotiation by your contacts.** You will want to be able to furnish all the detailed information necessary to ensure that your contacts get what s/he needs, and not waste the time of service providers with inappropriate or ineligible referrals. Knowing the "little things," like which bus goes there, which door to go in at a new agency, the right person to ask for, identification required, or hours of operation, leave your contacts more time and energy to take care of their real problems or concerns. You will enhance your reputation as

someone knowledgeable and professional both to your contacts and to the agencies. People will be more willing to work with you when they know what they can expect.

The following is a description of a step-by-step process for "working" these agencies. Naturally, you and your agency will find ways to do this that are appropriate to your city's and community's unique culture and to the resources available. Undoubtedly, when you begin doing this, you may discover that you already have taken some of the steps, such as the "initial contact" or "personal alliance". We recommend that everyone in your site team work up this map/list together. You will be surprised at how much you already know about your community and your city when you see it written down. This is also how you will find out where the gaps in services are. This information can be used later in helping your city plan to meet the crisis of AIDS. Some agencies or organizations may not have had much experience dealing with IVDUs or AIDS, but are eager to help and to learn. Mapping will help you identify such groups and to help improve or develop the range and character of their services. Some agencies are notoriously biased against IVDUs. Mapping gives you a chance to rate an organization's history of services to IVDUs, and how responsive they have been to the AIDS epidemic.

The "services army" that will be needed to support your outreach efforts ideally would consist of most of the following kinds of health and human services. Since we don't live in an ideal world, however, there will be many gaps in your efforts to build linkages for your outreach work. Consider the following:

- **Food distribution, soup kitchens, and food stamp programs** have been hard hit by budget cuts. You may have to look hard to find out where your local programs are located, and the dates and times of service. Obviously, your contacts' basic food needs have to be taken care of before you can do any kind of education with them. Also these are places where potential contacts can be found and education to staff may be needed.
- **Shelters and housing programs and projects** have also suffered budget cuts. Does your city have "hot-line housing" or overnight shelters? How do clients access them? Do they have to have tickets or vouchers in order to get in? Again, housing is a basic need that has to be met, and you will need to find out how your city deals with this problem. Often churches have shelters for women and families. Think about where you have seen people sleeping in your city's doorways and parks, and where they might go instead. This country is in the middle of a housing crisis with the number of homeless growing everyday. Most cities can't even deal with the homeless numbers now, and haven't even begun to plan for housing the growing number of people with ARC or AIDS or who are seropositive, sick, and undiagnosed, so unqualified for what little services there are. You may have to do some real investigation to unearth this information.
- **Welfare Benefits, such as General Assistance (GA), Social Security Insurance (SSI), State Disability Insurance (SDI), Aid to Families with Dependent Children (AFDC), Medicare, etc.** are state and federally

funded financial assistance programs that have very specific and usually elaborate eligibility requirements. Your program will probably need a special in-service training by your local "welfare office" just to understand what services are available and how to apply for them. All workers should have this information so it can be passed along to contacts quickly and easily. Each state has different regulations for their own programs on top of the federally mandated ones. It is imperative that your program have good strong relations with the appropriate people at your local office in order to expedite the flow of information and to find out what the local requirements are. Develop personal contacts at these agencies.

- **Medical services** in large metropolitan areas consist of a vast network of hospitals, clinics of many types, emergency rooms, in-patient and out-patient wards, doctors, satellite facilities that have special services for women and children, auxiliaries, AIDS wards, and hospices. Decide which ones are most likely to be used by your contacts for basic health care and emergencies and which ones work with people with ARC or AIDS. Concentrate your efforts on those facilities. In smaller cities, there will not be such an array of medical services.
- **Family planning clinics**, such as Planned Parenthood, have been gearing up for AIDS education and prevention. Many of them are located in the inner city have traditionally been used by your female contacts. If there is a women's resource center in your community, they can help you locate other clinics, and should be included anyway in your "army." A large part of your prevention and education activities will be aimed at women, so it is important that all possible avenues to them be explored. (We will talk more later about developing specific outreach activities to women.)
- **Sexually Transmitted Disease (STD)** Clinics have also been used by your contacts and are an excellent place to combine and expand existing educational efforts. Perhaps the education director at the clinic would do an in-service for your staff on STDs. Don't forget that long before AIDS, STD's were a sufficient enough reason to practice safe sex. Do not overlook this valuable resource in your community. These clinics have been doing safe sex education long before the rest of us.
- **Mental Health Services** also consist of an array of in-and-out-patient facilities; locked and unlocked homes; board and care residential programs, self-help centers; day treatment centers; etc. People with mental disabilities should be part of your target population unless there is another group that has targeted them. Don't go under the assumption that people with mental disabilities don't have sex or don't shoot drugs. Include them in your planning and find out which of the local mental health services are most likely to come into contact with people at risk in this group. You will also need to make referrals for your contacts to some of these agencies, so it important to know the variety of services and facilities available. It's also a good idea to check on the services for physically disabled people as they are still a group that have been consistently overlooked in AIDS prevention planning.
- **Drug Treatment Programs and Therapeutic Communities**, especially ones for IVDUs, will hopefully have their own AIDS Prevention Specialist on staff. If they don't, this will be your opportunity to share resources and clients with these agencies. Some programs have refused to conduct needle hygiene education claiming that since their clients weren't using, they didn't need that information. Most programs today have come around, and gladly welcome the opportunity to work with outreach programs, understanding that it's in everyone's mutual best interest to do so. Some programs even have their own outreach component. Programs are starting to learn how to deal with clients with ARC or AIDS, often without any additional financial resources and an already overloaded

counseling staff. Your relations with these programs should be such that you can refer clients there easily, leave educational materials and supplies, and do client and staff trainings as needed or requested. On the street you do not want to be perceived as someone only trying to get people off drugs and into drug treatment programs. You do want to be known as someone who can get folks a treatment slot as soon as possible though. Prevention of drug abuse is a separate issue from AIDS prevention. By doing AIDS prevention, however, you often get the opportunity to work with folks to the point where they realize that detox is the best way for them to protect themselves from AIDS and to improve the quality of their lives. If a contact asks you to sponsor him or her at a methadone maintenance program, we recommend that you help them find someone else. As a streetworker it is not a good idea to get involved in your contact's drug abuse issues. This may get in the way of your first priority, which is AIDS prevention. If they fail in their attempt to get clean, they may avoid you on the street out of guilt or embarrassment or the fear that you may hassle them because they couldn't stay clean. Get to know all your local in-patient and out-patient drug treatment facilities thoroughly, and then work with them closely. Find out how they treat IVDUs. Find out how IVDUs view them. See how you or your program can bridge any gaps. Also check out the local alcohol treatment programs, since people sometimes abuse alcohol instead of drugs simply because it's easier to get, but they shoot drugs whenever they can. Alcohol is also a sexual disinhibitor, and puts people at risk sexually, taking risks they normally wouldn't take. Also find out about your local Narcotics Anonymous (NA), Alcoholics Anonymous (AA), Al-Anon and Nar-Anon (for partners of alcoholics and narcotic abusers).

- **Vocational Rehabilitation and Job Programs** are places where hopefully your contacts can go if they need to or want to. For that reason, you will want to establish and maintain good relations with these kinds of organizations not only as a place to conduct outreach, but also as a place to refer folks when they are looking for work.
- **Youth Services** are targeted to many different teen groups, such as runaway or throwaway teens living on the streets and sometimes turning tricks; high school or junior high students; pregnant or parenting teens; kids that use drugs or alcohol; kids who use counseling or medical support facilities; sexually active kids, both gay and straight; kids who use after-school recreation centers; kids hanging out on street corners, at malls, at playgrounds, concerts, bars, etc. Will your program have a worker specifically for teens, or will they be part of each outreach site? This group has special needs and concerns that cannot be addressed here. If your program has determined that they will be addressing teens, a separate needs assessment may be necessary. Some cities have formed a coalition of all the agencies, including the local school system, that work with teens, and have put together an outreach and education program that has very carefully and systematically looked at the problem and has developed a plan that has community-wide support. Your program director will have

considered all of this, and you will know whether or not you will be doing outreach to teens.

- **Community-based assistance and development programs**, which are often targeted to specific minority communities are an excellent source for community support and an opportunity to talk to the friends, parents, relatives, and neighbors of your target group. These folks know who is at-risk for AIDS, and are usually willing to work with programs like yours as a way of further assisting and developing the character of their neighborhood. Never overlook the opportunity to cooperate and plan events or programs with them. Is there a community center in your site? Does it have visibility and political support from the city? Can this community be convinced that they can respond to AIDS as a community and say "NO to AIDS"? Are they willing to take on AIDS as a community responsibility and develop a grassroots response to it? (We will talk more about this under "Steps for Building Service Linkages.")
- **AIDS service agencies** are non-existent in some cities, under-developed in other cities, and over-burdened in all cities that are fortunate enough to have them. Inevitably you will be working with people with ARC or AIDS, so you will need to be familiar with all of your local AIDS agencies. Undoubtedly, they will welcome your program. They may be a valuable resource for additional training on such issues, as Disease Symptoms and Progression, Experimental Drug Treatments and Therapies, Support Groups, Death and Dying, and other Social Services. If they have literature, perhaps they will supply it free. If they have a budget to develop brochures, posters, bus cards, or billboards, they may rely on you or your program to put together "focus groups." Usually comprised of the target group, folks are formally brought together to give feedback on a draft of a particular promotional campaign or printed materials to the people developing it. Hopefully, support groups are already underway in your city for PWAS/PWARCS so you will have a place to refer your contacts if necessary. If not, maybe your programs can work together to form groups.
- **Churches** are often powerful and influential organizations in a lot of communities. Some ministers and their congregations have already taken strong and active stands against AIDS and would probably welcome additional support and information from you and your program. Women's Auxiliaries should not be overlooked as they usually form the backbone of the Church. These women know what is going on in their community and who is at-risk for AIDS. They have a lot of influence and can be powerful allies in your community. Some church-based services, such as Catholic Charities, already have well-developed social service programs, and have started to work with PWARCS/PWAS, filling in service gaps such as housing, medical, etc. Plan to talk to all the churches in your neighborhood.
- **Women's Groups, Women's Centers, Clinics**, etc., should also be carefully targeted, especially if your program is doing outreach to sexual partners of IVDUs. These can be excellent places to conduct rap groups

or support groups, or conduct trainings for staff. There may also be specific organizations or shelters for battered women, women with children, women with families with drug or alcohol problems, women who have been raped or sexually abused, women with mental or physical disabilities, pregnant women, refugees, and current or former sex workers. Some cities have listings of services and organizations that are only for women. If not, look in the "yellow pages" under "Women."

- **Criminal Justice System, county and city jails, special forensic projects, legal assistance programs, ex-offenders groups** are all institutions or organizations that your target group often interface with because most drug activities are illegal. If your county doesn't already have or isn't planning an education campaign at some of these places, someone from your program may want to determine what would be necessary to start these kinds of prevention activities. Outreach workers have gone to court with contacts and have been character witnesses for them. They have gotten folks out of jail by having them released into their custody. They have helped IVDUs get into drug treatment as a condition of the contact's probation. The Criminal Justice System is vast and complex. If your program expects to have a lot of contact with it, an in-service training from them would be useful.

After thinking about which of the above kinds of groups or organizations you will need to contact, keep the following steps in mind as you approach them. You will not always work each agency in nice, neat steps going from #1 to #8. The goal is to develop and formulate good working relationships with appropriate agencies so that you can cooperate in the fight against AIDS. The following steps are not a recipe, a prescription, a formula, or "the way." They are merely a description of what happened to the outreach workers in San Francisco when they "cracked" an inner-city, low-income neighborhood that was ethnically and culturally diverse and had the highest incidence of drug use in the city and was the center of the sex trade zone. They found that even though there were gaps in health and human services, there were still many more agencies and organizations than they realized before they started systematically investigating them. Hopefully, you and your program will find that to be true also!!

STEPS IN BUILDING SERVICE LINKAGES

1. Initial Contact: If you are working alone, you will obviously make the initial call, but you may want to invite another staff person, such as your director, to accompany you. After it has been determined who makes the initial contact, you will need to find out who is the most appropriate person at the agency to contact. Although most agency directors and administrators are overworked and understaffed, contact them first. You may be surprised at how receptive they will be to your program, especially if they are aware of the issues around AIDS and substance abuse. The aim should be to have support for your program come from the top of an agency down. That should eliminate problems about staff time, responsibility, or conflicts between your program's goals and theirs. If it is not possible to meet with the director, request them to direct you to his or her representative. The goals of the first meeting should be simple:

- **explain your project and its goals and your role in it as a health educator**
- **gather information about their history and experience with IVDUs and AIDS**
- **determine and explore mutual interests; perhaps you have the same target population**

Take notes, especially names, titles and responsibilities, and time and days of operations, noting when particular staff are there. Keep this information handy because you will be using it again later on in your work. We have included some sample forms for this purpose, and we will show you how to use them when we actually start the mapping work. Hopefully, this initial meeting will go well because you are well-prepared and professional in your style and approach (more on that later in Unit 6.) Expect to be invited back to a staff meeting.

Some workers initially only got a chance to introduce themselves to the director or another appropriate person. They found out a more convenient time to call, and then made an appointment for the initial contact.

2. Attendance at Staff Meeting: Most organizations have weekly, monthly, or some kind of regular staff meeting. This will be your opportunity to meet with the line workers, and perhaps give a more in-depth description of your program and the activities planned for this community. Again take notes and ask for suggestions and input from them based on their knowledge, history, experience, and longevity in the neighborhood.

Most organizations or agencies can't avoid having "politics" of some kind. Notice if that seems to be going on, but don't get involved in another agencies internal struggles. One worker found a medical clinic that was located in a storefront and served a lot of IVDUs and their partners. He was anxious to work with them, but the director seemed to ignore his attempts to get invited to a staff meeting. He went on to another agency, made a successful initial contact, attended a staff meeting, and had the director of that agency contact the first agency. It seemed the director of the first agency had a reputation for being suspicious of "new" people and programs. His staff felt isolated and frustrated from the other agencies in the community that were doing some new and exciting work. The phone call from an established agency was what was needed for that worker to get his foot in the door. If you are having trouble getting to Step 2 or any step for that fact, talk to your supervisor or director. They may know someone who can help "smooth the way."

Find out how much time you will have to speak at the staff meeting. Then plan your presentation carefully so you can make your presentation in the allotted time. Be prompt!! Try to remember everyone's name by using it. Introduce yourself to the entire staff, including secretaries, receptionists, and the custodians, and find out what their role is. You will be amazed at how useful that information will be later.

3. Educational Materials Drop-Off: If its appropriate discuss the possibility of using their agency as an educational materials drop-off point. Find out which staff person is responsible for materials and displays. Find out what you would need to do when leaving supplies and materials. If there's a place for posters, see if you can find some suitable ones from either your local or a national AIDS project. Try to order a large quantity, if they are free and especially well-done. People love to be given free posters.

4. Staff In-Service: If the staff have more questions and concerns than can be answered in the allotted time, then suggest you come back to do an in-service training. This is especially important if there is a potential for this agency to become a bleach and condom depot (more about that in Step #7). Determine what they do know, and what they think they know. Staff should be taught the basics of needle hygiene and safe sex if they have direct client contact. They should also know AIDS 101, with an emphasis on the special concerns of IVDUs, their partners, perinatal transmission, and familial AIDS (families where more than one person has AIDS or ARC, such as mother, baby, aunt). If staff have the responsibility of counseling their clients, then you may want to do an AIDS Risk Reduction Skills Training with them. Work with them to determine what their training needs are. For areas that are out of your expertise, see if you can help them find the appropriate people. Do not attempt, under any circumstances, to do training in areas where you have little or no experience or knowledge. Use the in-service time, if possible, to plan a project together.

If you are not comfortable doing an in-service training or even talking about the scope of your program, ask your supervisor or a co-worker to do it. After you have attended several of these, taken notes and studied the approach and the information of the folks doing the training, ask one of them to help you prepare your own. Then, if possible, role play it with your co-workers or supervisor until you feel very comfortable with the material and with speaking in public. Do not attempt to do your first few in-service trainings "off the cuff!" People can only do that and make it look easy when they have been doing them for a long time and are familiar with the information. Ask someone from your agency to attend your first few trainings and to give you constructive feedback and criticism. A good in-service training, even a brief one, depends on thorough preparation. Good trainers are always perfecting their "rap" and learning something new everytime they do one. If at all possible, two people should do them. That way, they can cover information that they other left out. As you become more well-known in your field, you will be asked to make more public presentations and conduct more trainings if you have a reputation for being informative, open, knowledgeable, concise, and maybe even entertaining! Always check with your supervisor before accepting if that is your program's policy.

5. Client Education: If the agency has direct client services, they may want you to organize a rap group, meeting, or education forum for their clients. If such a request is made, ask for their assistance with this, and then plan it carefully. The goal should be for you to work with key staff on this so that they can take it over in the future.

Unfortunately, it may not be possible for you to do on-going client education groups probably more than once or twice at all the agencies in your neighborhood. Your street work will prevent this. Therefore, be very clear that your goal is to pass this skill and responsibility on to the identified staff member.

When planning a client education or rap group, it's a great idea to serve food. Coffee and cookies are always welcome. An informal gathering might be better than a classroom type situation. There are some excellent short videos on a range of AIDS issues, so you may want to consider some kind of visual aids if they are available. However, it's fine if you just want to have folks talk about their fears and concerns about AIDS, and then teach some risk-reduction skills. Have plenty of supplies of bleach, condoms, brochures, whatever appropriate gimmicks are around. Be prepared for folks to be late if the session is not mandatory. Be prepared for no one to show up! Many workers have found that the best way to get people to attend is to go out and personally round them up about fifteen minutes before the group is supposed to start. One person can recruit, while the other person entertains folks until enough people have been rounded up to start. We have found that is possible to have a very high-energy and successful group with as few as three or four people. Don't be discouraged if that happens to you when you don't have a "captured audience." Music, balloons, childcare, food, or fun are some of the elements you and that agency may want to incorporate into client education planning to insure its success. Consider inviting clients from other agencies if that is appropriate.

6. Personal Alliance: By having gone through the preceding five steps, you will undoubtedly, by this time, forged personal alliances and cooperative working relationships with key staff who either have the responsibility for working with IVDUs or

are sympathetic to the needs of this population. These relationships are precious, and should be professionally maintained. If this agency has resources, services, information, etc. that will be needed by your target group, you will now be in a position to help them access them readily. Sometimes it might take your contacts days to figure out what they need, where they should go for it, and who they should call. Now you can give them the exact information or, if necessary, make the phone call for them, thus insuring their immediate access to services if they are eligible for them.

One worker had gone through these steps with the local WIC (Women and Infant Care) office. She had worked closely with one of the WIC eligibility workers, who had told her to please call her if there was anything she ever needed. The very next day, the worker came across a female IVDU with a baby who had just arrived in the city and didn't have money for food for the baby. Voila, one phone call to the woman at WIC, and her contact had milk and food for herself and her baby in about two hours. By all means, initially concentrate your efforts on the health and human service agencies that you know will be needed the most or are the most difficult for contacts to access.

7. Condom and Bleach Depots: One of the ways that you may maintain contact with these agencies, once firm relations have been established, is to ask this agency to be a drop-off point for safe sex and needle hygiene supplies. Before they agree, ask them if they will mind if non-clients come in to get them. After you have been assured that staff are familiar with the rudiments of proper use, explain to them that you will keep them supplied on a regular basis. One such agency, not only allowed, but encouraged the outreach worker to make a large and colorful display of these materials. Think about appropriate displays or methods of distribution, keeping in mind the client flow, quantities required, space limitations, or other considerations not mentioned here. Ask one staff member to be responsible for calling you if supplies run out before you return. Just have them leave a message for you if you are not there, letting you know what they need. Watch out, condoms are getting very popular, and it has become difficult for outreach programs to keep up with the demand! Once you are established in the community, spread the word that these supplies are available at such and such a place, and they should get them there when you are not around. If you have to fill your own bleach bottles (and we don't know a program that doesn't), you may be hard pressed to keep up with requests for these also. Perhaps the clients and/or staff could have a "bleach party." You supply one hundred empty bottles, tops, labels, and a gallon of bleach, they supply the labor. By all means, encourage the agencies that dispense a lot of bleach to get in the habit of filling their own bottles.

The "depots" are a good public relations tool. Contacts can see that other agencies care about them and are working with you to help them. Agencies that are not directly working with AIDS may have felt left out of the war against AIDS, and can now know that they are doing their bit. It's also a clear message to the rest of the community that there are agencies that care about IVDUs and others at risk for AIDS.

8. Neighborhood AIDS Planning Organization: At this point in the process of "cracking the community," you will know whether or not there is a local AIDS planning group or some informal network or committee that has been dealing with some aspects

of the AIDS epidemic. By all means, if appropriate, join and make attending their meetings a regular part of your work schedule (with your supervisor's permission). If none exists, you should now be in a position to organize one because of the relations you have developed with the agencies and staff in your community.

Start putting the idea out there in your community, and get the feel for it. Do you feel people will be receptive to it given most people's already overloaded schedules? You should have a sense of this already from your meetings and discussions with them. Identify at least two key people in the community to co-sponsor the first meeting with you. Ask them if they would be willing to work with you on this. If they agree, three or four people should have a planning meeting to outline the agenda, the goals of the first meeting, the agencies and people from the community or city government to be invited, and to pick a convenient and comfortable place, time and date for the first meeting. Check around to make sure there is nothing else going on that day that might prevent people from attending, such as another important meetings, a Federal holiday or the dedication of a new park!

Determine the agenda and then plan to write it on a flip chart or large sheets of paper. Decide who should chair or facilitate the meeting. Having two people be responsible for the conduct and order of the meeting is often helpful. If you are not comfortable doing this, try to learn how to do it by watching people at other meetings do it. Make sure the chair(s) or facilitator(s) has had experience with this and is comfortable and diplomatic cutting people off when they talk too much.

The goals of your Neighborhood Planning Organization will be determined by:

- **the concerns and needs of the community**
- **the ethnic and cultural flavor**
- **the interests, energy and time constraints of the participants**
- **the existing resources of the community and your city**
- **the gaps in services**
- **the unknown and unforeseen!**

Mail or personally distribute the meeting announcements. If possible write or type the names on mailing labels. This way you will have a record of who was invited, and they also can be used for future meetings. Divide the list up, if there are a lot of names on it, and each of you could call your section the day before the meeting to see if they are coming. If they can't attend, ask them if they can send someone else. If they can't, ask them if they would like to be included in future meetings. Also find out what days and times are not convenient for them to meet so they can be included in future ones. You may also post notices in public places so that interested neighborhood residents can attend and become involved.

A sample agenda might look something like this:

1. Introductions
2. Brief History of AIDS in your city and your community, including morbidity and

mortality rates and any seroprevalence studies done; list of resources and agencies already working on the problem; description of the problem of AIDS and IVDUs, their sexual partners, perinatal transmission, and familial AIDS;

3. Role and goals of new outreach program
4. Open Discussion by participants, perhaps by going around the room and giving everyone a minute to talk about their concerns or answer questions
5. Brainstorm of Community Needs
6. Where to go from here?
7. Next meeting
8. Evaluation?

Pass a sign up sheet around and get everyone's name, address, and telephone number. It's always wise to keep notes or minutes of every meeting. Hopefully, someone will volunteer to do this. They could be sent to the people who weren't able to attend this meeting, but want to come to other ones. Minutes should include information about future meetings, including time, date, place, and a contact number.

Whether this group decides to have on-going meetings and become a network for the dissemination of information, assume the mantle for community planning, become a steering committee, or have elections and form a Board of Directors will be determined at either this meeting or the next few. Whatever is decided, the best interests of the community, and not one organization, should be the basis for all decisions.

NOTE: Please keep in mind that your participation in this kind of organizational or planning work will have to go on while you are still conducting your street outreach activities. By the time you get to Step #8, you will have gained entry to your target population, and you will need to maintain your visibility with these contacts. Your prevention activities must always come first. It is, by no means, necessary or even desirable for you to complete Step #8. Remember, this is just a suggestion. Do not attempt to do this without having discussed this in-depth with your supervisor and project administrators. They may already be involved with other organizations at this level and not want you to do anything other than educational and prevention work. Proceed carefully. Good luck.

MAPPING TARGET SERVICES AND PLANNING LINKAGES

1. Mapping

You and your site teams, along with your supervisor or project director should do this group work together. This is a way of formally organizing what you know and have learned thus far in the training into a work plan. You should also do this later for other neighborhoods that you will be working in and haven't covered in this group work. Basically you will be organizing what you and your co-workers already know about your target community, the character of any linkages already established, and then developing a team approach to building additional linkages.

On Pages 5-7 through 5-10, there are "mapping forms" that you can use or modify for your project. Follow the instructions, keeping the following in mind:

- **Under "Contact,"** always start with the "known agencies" and with the name of the director or another contact person there. Note the name of the worker who holds that contact. That person will be responsible for initiating the next step or introducing another appropriate co-worker to that agency.

Example:

Three years ago, your co-worker was in a 21-day detox program at the local methadone clinic. He says that he had a wonderful counselor there, and he has heard that she is still there. Even though he won't be working in that neighborhood, he agrees to make the first phone call and find out the name of the Program Director from her. His initials will go after "Contact."

- **Under "History,"** which is your chance to rate an agency's record of services to IVDUs on scale of 1-3, where 1 = poor and 3 = excellent (? = unknown), think about "rumors or gossip" that you have heard about that agency over the years. Has anyone told you about "those horrible people" at such and such a place? "They treat you like dirt," or "There's a real nice lady there who helped me. " Have you had positive or negative experiences with them yourself? This information may be difficult to quantify, so you may want to keep notes on the back on this type of information. (During the course of your work, you may favorably influence an agency and change their "1" to a "3.")

Example:

Your co-worker reports that he was treated very well at that methadone clinic. He would give them a "3" based on his experiences with them. The rest of you agree that you have heard good reports about this clinic. They have a reputation for treating IVDUs fairly and compassionately.

- **Under "AIDS,"** you will want to know the degree to which the agency's services are responsive to AIDS prevention and/or treatment issues, where 1 = poor and 3 = excellent. Here again, you may have to rely on information that came to you "on the grapevine" and not firsthand.

Example:

Three years ago most methadone clinics weren't yet dealing with the problem of AIDS and IVDUs. Therefore, your co-worker doesn't know what the clinic is doing now about AIDS, or if they have special services for HIV-affected clients. No else in your team knows either. Put a "?" there. If your co-worker can get that information when he calls his former counselor, then record the appropriate number.

- Under "Step," look on page P5-6, to see the highest (numbered) step that any of you have already taken with this agency.

Example:

Since your co-worker has a "Personal Alliance" with a counselor at the clinic and has had some "Contact" with this clinic, write #1 and #6 under "Steps."

Work through all the known agencies. Hopefully, you will be pleased to discover that between you and your colleagues, you already have a handle on some of the agencies and organizations in your neighborhood. (If you don't have much information about services in the community, move on to "Developing a Work Plan," so that you can start to establish service linkages.)

When you've exhausted what you know, enter under "Unknown," agency types from that list that your group compiled on P5-5. Review this list of types of health and human services that you and your co-workers identified as being critical to support your AIDS outreach efforts.

Do you have three or four "known contacts" or the names of three or four agencies? If so, you now have a place to begin a "work plan." This will be an on-going project, and an especially valuable one as your project grows and develops into other areas. If you transfer to a new area, your replacement will not have to "start from scratch" because you have kept these detailed lists.

2. Planning

In order to develop a work plan for building service linkages, you will now list the agencies you just "mapped" (from the previous page) on P5-10. The goal of this planning work is as follows:

- Under "Mapping Work," list all the "known" and "unknown" agencies as well as those for which you have identified little pertinent information (e.g., no contact or service history). You will need to do general "reconnaissance" around the community to gather this basic information. Check with the local health department for lists of such agencies.
- "Initial Contact" doesn't always have to be with the program director, since any contact at an agency is sufficient to get you started. If you have some service information about an agency, but have not initiated formal linkages, make a note of that here. Consider calling an agency and asking the receptionist to give you the name of the director.
- "Strengthening Linkages" is an on-going objective in your work. The goal is to bring the pertinent agencies or organizations from Step #1 to possibly

Step #7 or #8. Note the agencies here for which you have taken a formal "linkage step," and the ones you need to plan future steps for strengthening relations.

Now return to your three lists of your work plan, and determine how and who will begin the work that needs to be initiated with each agency. You may want to set up a timetable for this phase of the planning. The following needs to be considered and noted on the "work plan:"

"Mapping Work"

1. How will you physically locate these agencies and organizations? List your methods.
2. How will you find out about their service and AIDS-related histories? Record how you plan to go about it.
3. Who are the most appropriate members of the outreach team to do this? List the name of the person(s) responsible for this. (Note that responsibility might shift for this later.)
4. For services where you have large gaps in your knowledge, what resources do you have at your disposal now to begin the work? Are there local directories, experts, former clients, etc. in your community that can help you with this phase? Don't forget the Yellow Pages. You know what they say about "your fingers" and the Yellow Pages. List the resources you have for gathering this information.

"Initial Contact"

1. How will your knowledge, preconceived notions, or lack of information about a contact person or service history shape your initial approach? Note any problems you can foresee here.
2. Should one person make the initial approach? Should other team members be included initially or later on? Discuss this carefully and record what you decide.

"Strengthen Linkages"

1. What is the next step to take to convert existing linkages into strong allies for your work? How will you make friends with these people? Particularly think about the agencies that you want to "work" from Step #1 to Step #7 or #8. Record the goals of this phase.
2. If some team members have already established such groundwork, how can they help other team members take advantage of their information, experience, exposure, etc.? Who can share the responsibility so no one person gets "burned out?" Record how you plan to take care of these issues/concerns.

APPROACHING TARGET GROUPS

Now that you have laid a good foundation of support for your work, you are ready to slowly and carefully begin approaching your target populations. Even if your community is geographically spread out, and you could only find three agencies in it to contact, only getting to Step #3, you will at least be familiar with the neighborhood and recognize and be recognized by some of the residents. (If your mapping work has not brought you to at least this point, you will need to work with your supervisor or program director to develop a plan to overcome these obstacles. **Do not begin your outreach efforts until you have established a firm base in the community and have developed a plan for your intervention activities.**)

Review and remember the "Four Ns." They are even more important now that you will be working more directly with the target group. Think about the objectives of approaching your target group:

- **You will need to establish your new role and your credibility as an AIDS educator.** Since most neighborhoods have never had an AIDS educator, never mind one who is working directly on their streets, your role may be viewed as somewhat of a novelty. Most IVDUs will be amazed that someone cares enough about their health to talk to them about it. The fact that you have information and supplies that will protect them when they use drugs or have sex, will make you popular and welcome.
- **An on-going part of your work will be to inform yourself about the level of AIDS awareness, risk practices, and any related circumstances within your community.** Some programs require their workers to formally interview/survey their new contacts using a detailed questionnaire. This gives "base line data" to measure what people know about AIDS. It also enables them to measure and evaluate the effectiveness of the intervention efforts after a second survey is completed about six months later. If your program has an evaluation component, you will be trained separately for that.

It is not necessary for every program to do this. It is imperative, however, to make accurate and detailed observations and to keep notes on information such as the kinds of drugs in use; neighborhood drug patterns and history; needle availability; needle hygiene practices; sexual attitudes, knowledge, and behavior--the information covered in Unit 4. Go back to Unit 4 and review your notes from the section: "Characteristics of the Environments in Project Target Areas" found on P4-5. You and your project staff should complete this assessment together if you haven't done one for your neighborhood. Use the forms on P4-6 through 4-8. Keep these questions and characteristics in mind as you begin your work. Understanding social organization and conducting ethnography is an on-going task and is necessary to shape and tailor your prevention activities.

Share your notes with your co-workers to compare neighborhoods and approaches.

- **Look for natural opportunities for AIDS education in your community.** Check bulletin boards for announcements of up-coming activities or events, such as street fairs, sporting events, art shows, special cultural celebrations, etc. Determine the times of the day when foot traffic is at its highest and at which places. If you want to leaflet, where would you go? Where do people hang out? If your neighborhood has more than one park, find out who uses which ones and when.
- **You will want to gain access to and establish relationships of trust with the highest-risk individuals and their partners.** You will need to know them on a first name basis. You want to be able to really penetrate into the heart of the IVDU community by finding out who the "gatekeepers" or "opinion leaders" are. Remember that you will need to proceed cautiously because first impressions are most important and will have a favorable or negative impact on all your work.

We will discuss three general approaches to entering your target group. There are others that are appropriate and will look different depending on the outreach worker and his or hers individual "style." The idea is to use approaches that gain you increasingly "closer in" access to contacts who may need risk-reduction counseling.

THREE GENERAL APPROACHES

1. **Leafletting** is a good introductory approach for workers who are not yet "wired in" to their community, but is also a useful on-going strategy. Some workers use leafletting as a tool for finding out who's on the streets and as a method for engaging folks in discussions about AIDS and finding out about their level of awareness.

Remember the worker from the beginning of this unit who loved to stand on streetcorners and "rap" AIDS? Think about yourself doing that. Don't overlook housing projects, laundromats, playgrounds, shopping areas, and even churches. Consider leaving flyers in places like the local welfare and food stamp offices, hotel desk and lobbies, clinics, donut and coffee shops, stores, churches, adult schools, bars, and all the health and human service agencies identified earlier.

Only distribute interesting and relevant leaflets! This may seem obvious, but in areas where there aren't a lot of colorful, graphically bold, culturally appropriate, and easy to read leaflets, you may have trouble finding them. English may not be the first language of your community or the reading level of some brochures is too high, so choose your educational brochures with care. Someone at your organization should be responsible for

ordering leaflets and keeping the workers well-supplied. Make sure everyone knows where supplies are kept, and notify the responsible person when supplies are low. Investigate all the different leaflets, and only use the ones that people seem to relate to even if there are other ones that have more information. People don't always want to be bothered reading them, especially if there's a lot of text and no pictures! Have more than one kind on you when you leaflet so if someone has a question or wants some other kind of information about AIDS, you are prepared. If your budget covers it, consider writing your own, and then having an artist who is a professional at this do the graphics and a typesetter do the printing. Never write a pamphlet without circulating a draft of it to other agencies and to the intended audience. Their feedback and suggestions are vital. One program director wrote a brochure aimed at women and never asked for suggestions, help, or feedback from any women. Naturally, the brochure was a failure! Try to work on brochures or flyers as a joint project with other agencies.

Always carry several different kinds of leaflets with you even if you don't plan to leaflet. Your contacts may need them.

2. **Getting to Know Gatekeepers** should naturally happen in the course of leafletting. One worker leafletted near a shoe shine stand. The stand operator had been on that same corner for 30 years! After the worker introduced herself to him and told him what she was doing, he immediately started quietly pointing out different people to her as they came by. He knew everyone and actually overwhelmed the worker with the amount of information he had. After he decided she was "OK" and her program was "legit," he introduced her to lots more old timers in the neighborhood and to many IVDUs and sex workers. It took that worker almost three weeks to get more than a block from that corner because there were so many people to meet and talk with everyday. To this day, that gatekeeper still sends people to talk to that worker.

Think about the bars in your neighborhood. Do you know any friendly bartenders? What about residential hotels? Do you think you can get to know the desk clerks, the managers, the janitors? They live closest to people and may give you entry into the "insiders." They can inform you about drug scenes and needle sharing groups. They may also know who the natural leaders in your target group are. Small grocery or candy stores are frequented by IVDUs. Get in the habit of stopping by and making some small purchase at the ones in the heart of your community. Introduce yourself and perhaps leave some flyers. Hang out at the local coffee shop and observe the scene. In short, become known around the neighborhood. Gatekeepers are not always obvious, but with careful attention, you should find at least three or four who are not only willing to introduce you to IVDUs, but will "vouch" for you. They will let people know you are not a "Narc" or some nosy social worker. You will be surprised

how concerned folks are about AIDS. They want to help.

Think back to the some of the agency staff that you met during your initial mapping phase. If they were sympathetic to the problems of IVDUs, and you think your target population trusts them (very important), contact them for leads. Ask them to introduce you to "insiders" in the IVDUs groups. Enlist their help in planning educational gatherings or other neighborhood events. Remember to cultivate these relationships.

3. **Gain Escort by Insider**--arriving at the heart of a particular IV drug-using scene will be the crux of your work. Hopefully, now you understand why you needed to work so slowly and cautiously. If someone invites you to come to their place, use **common sense** when deciding whether or not to accept. Don't go because you want to be "cool," or you're anxious to make contact. If it seems that this person is genuinely responding to your need to meet IVDUs, by all means accept. If you think they have some other motivation, suggest an alternative, such as meeting at the donut shop. (More on potentially "compromising situations" in Unit 6.)

When you are there, notice if there is someone in the group that you could identify as the "opinion leader"? This is the person who initiates action, whom people give deference to, ask questions of, and gather around. This is the person that will help spread the good word about you and your program once he or she accepts you. If you can succeed in getting him or her to reduce their risk behavior, they will most likely pass that information on to the others in the group. As a matter of fact, if you are really successful, peer pressure could mount to the point where it becomes "uncool or stupid" to not use bleach or condoms. Keep that goal in mind when you work with folks. You do not have to get into an in-depth discussion of risk behavior during the first visit.

One worker reported that he was immediately invited to return anytime he wanted to. "The door is always open to you." He knew he had arrived! Then he could relax and just talk with folks. To the group it probably seemed like he was just "in the neighborhood" when the "gatekeeper" invited him over. Only he knew how hard he had worked, and how much time it took to get to this point. We are not saying that you will necessarily have a difficult time getting to the heart of the IVDU scene. We are just recommending that you move according to a well-developed plan, carefully built and grounded in the community.

You don't need to immediately start talking about AIDS and the seriousness of the epidemic, but you should make it clear who you are and what your role in the community is. Then talk about whatever anyone wants to talk about. TV, sports, the high cost of living, whatever. Find common ground--it's usually quite easy. Don't be pushy, acceptance will come when folks see your face often and realize that you are who you say

you are, doing what you really said you would be doing.

Judge the time you feel is appropriate to stay. Take nonverbal cues, and leave when it feels right. Ask if they would like some supplies before you go. Offer to explain their use. Don't expect to get into a group or individual discussion of risk behavior unless the group initiates it. Remember, you will see these people again if you are doing your job right (assuming your neighborhood isn't highly transient), and will have further opportunity to talk with them either alone or in the group again. You will be surprised at how soon you will probably meet them out on the street. If appropriate, leave your phone number at your agency, letting them know when it's a good time to reach you. Never leave your home number (more on that in Unit 6).

Start practicing the "fine art of hanging out." One worker was invited to watch "Bugs Bunny Cartoons" after he got in. Sitting there for fifteen minutes and watching the TV helped him to relax. Another group of IVDUs watched "the Soaps" everyday. That worker got in the habit of stopping by to watch a few minutes of "All My Children." There are a lot of sex scenes on the show, so during commercial breaks, the worker used examples from the show to talk about sex in a very light-hearted manner. Since she basically knew the plot of the show, she could use that information as common ground for discussion whenever she met anyone from that group on the street. "How's Jessica" (the star of the show) was usually all that was needed to start a discussion with a contact who admittedly didn't practice safe sex. This gave the worker the opportunity to steer the conversation around to sex. "Jessica was always having unsafe sex with someone!" (More about specific risk-reduction techniques in Unit 7.)

If you have not spent much time around drugs and needles, you may have some preconceived notions about what you might find if you've been invited to someone's house, room, or apartment. Most workers discover that even if their contacts have just used, it's more than likely that they will have a perfectly natural conversation with them. Even people who use more than once or twice a day are not always in the middle of some drug crisis. Problems do not occur with every drug episode.

Your big moment! Be natural, and remember those 4Ns.

PERSONALIZING ONE'S APPROACH

One of the many rewards of streetwork is the fact that you are "paid to be you." Think back to our discussion about the "4Ns," and to what we said about being "natural." Part of being natural is developing your own personal approach that capitalizes on your own innate sense of style and capacities. If you are from the community where you will be working or have lived near there, think about your own history in that neighborhood and your relationships to the people living and working there. This process can be anxiety-provoking for all new outreach workers, especially those who are returning to their own community.

There are many techniques, gimmicks, approaches, tricks, etc. for doing street-based outreach. The San Francisco Community Health Outreach Workers (CHOWS) got together once a month to trade "tricks" and stories. There are plans for a national conference of AIDS Prevention and Outreach Workers, where people will get the opportunity to share skills and experience. There may even be other outreach workers in your community for different kinds of outreach work, not AIDS-related. You might want to talk to them. There is no pat formula for doing this work. However, one way to reduce any anxiety you may be feeling and more quickly discover an appropriate individual approach is to begin to imagine oneself doing the work.

Please read through the following three "Approaches." Then imagine yourself handling each situation. How did you see yourself handling the parts that are underlined? Was it anxiety-provoking or did you feel confident of your ability to handle it? If you felt unprepared and ill-equipped, please be patient and remember to give yourself enough time to develop your own personal approach when you are actually out on the street. You may want to role play with your co-workers some situations that are particularly anxiety-provoking. If, once you are on the streets, you still continue to feel anxious, you may be proceeding too quickly. Slow down. Talk with your supervisor. You may be trying to handle situations that you aren't ready for. (If you are actually fearful, you are definitely doing some wrong! You are probably some place that you shouldn't be. We will discuss those kinds of problems in detail in Unit 6.)

VISUALIZATION EXERCISE:

1. **Leafletting:** Imagine you have identified a place--a street-corner, a park, a candy-store--where you feel fairly comfortable and a lot of IV drug users also happen to pass by or congregate. What does the place look like, and feel like? Imagine yourself "setting up shop" in that place. Will you set up a table? Move around the area handing out materials? Some variation of these methods? See yourself engaged in this activity. Imagine yourself encouraging folks to take the materials, to notice them. Imagine someone refusing to take your materials, or passing by without noticing. How does that feel? What will you do to encourage the next person? Imagine someone accepting the material. What did you say to them? How did you act?

2. **Gatekeepers:** Imagine it's some weeks later, and you've come to realize that the owner of the nearby store has been around for ever and knows most everybody. You realize he could probably help you reach more IV users more "close in." Why? What about him makes you think that? What does he do, how does he behave in his store operations that makes you think that? He also seems to be warming up to you and your "AIDS education bit." What did you do to gain his interest? Think back--what about the way you've been dealing with the people in the area might have caught his interest? How did you treat him? How does he express interest in you? Now that you believe you have his trust, how will you approach him for assistance? Imagine yourself picking a right time. What kind of help will you ask for? Imagine how you will put it to him. Imagine his responding with enthusiasm.

3. **Key Escort:** Imagine now it's many weeks later, and you and the store owner have become strong allies in community AIDS education. So strong, in fact, that he offers to introduce you to a person you've noticed in the area--you suspect a dealer. Develop a picture of such a person in your mind. How do you feel at the prospect of meeting this person? Despite some nervousness, you decide that meeting this person would be a good idea. You know you need to talk on a more intensive, one-to-one basis with people than you have been able to so far. Imagine being introduced to this. Where would you meet? How would you put your request to this person? Imagine the person being unresponsive to you. How does that make you feel? Despite how you're feeling, think about what you need to notice about the person during this meeting to stimulate a different response down the line.

You may want to think about some other possible situations and how you would react in them. All the situations in this manual really happened to outreach workers. We didn't make anything up! Be prepared for the unexpected!

ASSESSING TARGET POPULATION CONTACTS AND WORK PLANNING

This last section of "cracking" the community will help you plan for getting "close in" to the target groups. Again, we have broken it down into the three general approaches of "leafletting", "gatekeepers", and "escorts". (Note that sometimes there's no clear difference between a gatekeeper and an escort!) Also, we are still trying to get you see how much you may already know and have learned thus far in the training, just as we did with the health and human service agencies. The forms on P5-14 and P5-15 will help you and your group organize that information. As a team, you will determine what contact points and persons you and your coworkers ALREADY have for the target group. Then you can plan your initial approach.

PLANNING AN INITIAL APPROACH TO THE TARGET POPULATION

1. ASSESSING CONTACTS

On page P5-14 list all the contact points that you and your colleagues have identified and/or established in your community. List them under one of the three approaches:

- **Leafletting Points** -- all the streetcorners, parks, facilities, check cashing places, public events, etc., where you can reach your target group with materials, supplies, presentations, informal raps, posters, etc.

One worker made it a point to be outside the post office on the 15th and 30th of each month so that when folks came out with their checks, he could give them supplies. Where do folks pick up their checks in your neighborhood?
- **Gatekeepers** -- Again these are the people that you may have identified from some of the above locations. They are familiar with IVDUs and have a lot of contact with them.

The man who runs the newspaper stand near "the stroll" where the sex workers solicit customers has allowed you to leave condoms there for the working women. Is there a place like that in your neighborhood?
- **Escorts** -- These are the people who say "you're OK" and introduce you to IVDUs, sex workers, or partners of either. These are "legitimates" or what some people call "opinion leaders." Their support is vital to your work. The owner of the newspaper stand might be willing to introduce you to the working women on this block. Who do you know like that in your area?

As you talk about your area, itemize each of these contacts points or persons to determine the following:

- Is there someone in your group who knows these places or these people? Put their initials on the form. If there is more than one person, decide who will do it.
- How strong is the contact with the escort or the gatekeeper on a scale of 1-3, where 1 = have only been introduced and 3 = strong, trusted contacted.

2. APPROACH PLANNING

Now you are ready to begin planning your approach. You will want to take advantage of what is already known and of individual worker's strengths. See the example of this on P5-13. Can you think of some other examples of situations where one worker might have the strongest contact, but wants another worker to develop it?

The "Action Steps" to be taken should be specific, noting what the particular "Objective" is, and which worker will be taking responsibility for that particular step.

For example, if the team has identified the local women's shelter as a place where women who use drugs go, and Tom used to date the director, you would fill it out like this:

<u>Action Step</u>	<u>By Whom</u>	<u>Objective</u>
Approach Director of Women's Shelter	Tom	To explain project; To explore willingness to assist;

If, however, the group decided that it would be better to have a women worker doing outreach in the shelter, then you could plan it like this:

<u>Action Step</u>	<u>By Whom</u>	<u>Objective</u>
Approach Director of Women's Shelter	Tom	To explain project; To introduce Carol;
	Carol	To leave materials on future AIDS rap display & plan

When you have completed this section of Unit 5, keep these forms with the ones from "Mapping Target Services and Planning Linkages." This work will form the basis for "Cracking the Community." Good Luck!