Treatment, care and support of injecting drug users living with HIV/AIDS:

Implications for Ukraine

A discussion paper prepared for
Médecins Sans Frontières - Holland Ukraine program

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General findings

Medical aspects of HIV/AIDS among IDUs

- There are likely to be more than 10 million injecting drug users (IDUs) worldwide, of whom at least 1 million have HIV or AIDS. Injecting drug use has now been reported in 129 countries, of which 103 have also reported HIV infection among IDUs.
- There appears to be a similar rate of progression to AIDS for both IDUs living with HIV/AIDS (ILWHA) and other groups such as non-IDU HIV-positive women and gay men. Patterns of drug use, including frequency of drug injection, continuous versus intermittent IDU, do not appear to lead to differences in progression to AIDS, but cocaine users may progress faster than users of other drugs.
- ILWHA have a higher death rate from causes unrelated to HIV infection than HIV-negative IDUs and a higher rate of non-AIDS mortality than other PLWHA. Leading causes of pre-AIDS deaths among IDUs appear to be:
  - Pneumonia
  - Liver disease, associated with HIV and hepatitis C and/or B co-infection
  - Overdose
  - Suicide
- There is disagreement about whether gender influences progression to AIDS among ILWHA. Compared to HIV-negative women IDUs, women ILWHA increased vaginitis, higher risk for changes in the cervix and cervical cancer, and a complex set of issues related to pregnancy, including the effects of continued street drug use or withdrawal on the mother, foetus and newborn, and the effects of HIV on the process of pregnancy, as well as prevention of vertical transmission
- Weight loss and physical wasting can be worse for ILWHA than other PLWHA due to pre-existing malnutrition and poverty, as well as the effects of some street drugs such as amphetamines or cocaine on appetite and weight loss.
- ILWHA are at greater risk for infections related to injecting drug use, including:
  - Abscesses
  - Embolisms
  - Septicemia
  - Endocarditis
  - Bacterial Pneumonia
  - Cellulitis and Phlebitis
- ILWHA seem to have a greater tendency to develop HIV encephalitis.
- ILWHA are at high risk for tuberculosis.
- ILWHA are likely to be co-infected with hepatitis C virus (HCV). Prevalence of HCV in ILWHA in international studies ranged from 52% to 95%. HCV does not appear to affect progression to AIDS or severity of symptoms but there appears to be an increase in the severity of liver disease in co-infected people. Co-infection with HIV and hepatitis B (HBV) can cause ongoing liver damage, though HBV appears not to have an effect on the progression of HIV disease.

Hepatitis D infection can lead to greater liver damage in ILWHA. Co-infection with HIV and syphilis can cause problems in treating syphilis.

- ILWHA are often unable or unwilling to access HIV/AIDS treatments or general medical care. This is due to inappropriately designed treatment services, stigmatisation of ILWHA, negative attitudes towards ILWHA from medical and healthcare staff, and negative experiences among ILWHA of health care.
- Methadone and other types of drug substitution are very useful in medical treatment of ILWHA.
- Information is increasing on drug interactions, especially between methadone and HIV medications, but there is still much that is unknown. There is a wide range of interactions between street drugs and HIV treatments. Protease inhibitors may interact with a wide range of illicit and licit drugs. The strongest effect yet discovered is between ritonavir and methadone. Many HIV treatment drugs have potential effects on the liver. Due to the high rate of HIV and HCV co-infection and the greater level of liver damage in ILWHA, these potentially toxic effects need to be taken into account.
- Pain management is a problem for all PLWHA, but is worse for ILWHA, who usually have a very high tolerance for pain control drugs.
- There are an estimated 250,000 people living with HIV/AIDS (PLWHA) in Ukraine, of whom up to 80% are IDUs.
- For the great majority of people with HIV and AIDS in the Ukraine, there is little or no medical or non-medical assistance available. There appears to be a short period between HIV diagnosis and first manifestation of AIDS in Ukraine and, possibly, between HIV infection and death. Hepatitis C and HIV co-infection may be more common in Ukraine than in other countries both among ILWHA and other PLWHA. Malnutrition is widespread in Ukraine.

Psychological and social aspects of HIV/AIDS among IDUs

- The psychosocial aspects of ILWHA' lives are generally under-researched.
- ILWHA are more likely to experience stigmatisation and discrimination from more sources than other PLWHA.
- ILWHA are likely to experience more profound and more frequent depression, and more confusion about the sources of anger, frustration and stress than other PLWHA. The double stigma of drug use and HIV, may keep ILWHA in the "shock" or "withdrawal" stages of responding to HIV infection, and the ability to feel accepted among other PLWHA and to exhibit altruistic behaviour may also not be possible unless there are specific programs established to foster these relationships and this work.
- Friends appear to be more important to women than to men ILWHA, implying that peer support (from both other HIV positive women and from friends regardless of HIV status) is vital to women ILWHA.
- General practitioners and HIV treatment doctors feel they have not received the training to address drug issues among ILWHA, and are unwilling to treat them unless they quit using drugs. Drug and alcohol doctors and health workers often feel they are not equipped to deal with the additional physical, psychological and social issues affecting ILWHA. Institutionally, there is a tendency for each group to think that ILWHA should be treated by the other group, often resulting in an increased sense of frustration, rejection and hopelessness among ILWHA.

- ILWHA are likely to move through many periods of increased and decreased drug use and, possibly, abstinence during the course of their disease.
- The illegality of injecting drug use means that attempts are made to prevent ILWHA from continuing to use drugs while in hospital or hospice. This can lead to severe problems within the hospital or hospice, especially if methadone or other substitution therapies are unavailable.
- Discovering that they are HIV positive can have a profound effect on PLWHA' sexual relationships. There is no evidence that these effects are different for ILWHA.
- Families of ILWHA often have to deal with both the drug use and treatment and HIV care needs of the ILWHA, but also with stigmatisation of the whole family once the ILWHA's status (as both a drug user and HIV positive) becomes known in the community.
- The greatest difference in community effects of HIV/AIDS may lie in the double stigma attached to ILWHA and pre-existing poverty of injecting drug users. leading to greater impoverishment more quickly among ILWHA than other PLWHA.
- Community tensions may be exacerbated by scapegoating of ILWHA as being particularly "guilty" or "dangerous", which may lead to specific violence against ILWHA.

Conclusions and Recommendations

In Ukraine, a continuum of care needs to be established for ILWHA. This continuum of care should involve currently existing health and social institutions as well as a group of new services (possibly offered by NGOs) in a comprehensive range of care services, all linked by discharge planning and referral processes.

Currently existing institutions which should be involved in this continuum of care include:

- AIDS Centres (where they exist)
- Infectious diseases hospitals especially AIDS wards (where they exist)
- General hospitals, polyclinics and ambulatory clinics
- Narcological hospitals and dispensaries
- Needle and syringe exchange, outreach and peer education programs (where they exist)
- HIV/AIDS focused NGOs, especially PLWHA groups (where they exist)
- Sexually transmitted infection clinics
- Social services (such as social services for youth)
- Ambulance services

New services that need to be started include:

- Needle and syringe exchange, outreach, peer education programs and HIV/AIDS focused NGOs, especially PLWHA groups (where they do not exist)
- Multidisciplinary teams to provide enhanced home care

The first step, after ensuring that the appropriate agencies exist in a city or region, is to co-ordinate services for ILWHA. This is most appropriately done at the health administration of the city or region. Co-ordination should ensure that:

- As a matter of principle, that HIV treatment is not refused or withheld simply

because someone is a drug user
- The therapeutic regimen of HIV treatment is adapted to the needs of the individual, rather than require the individual to adapt to a preconceived clinical ideal
- A network of physicians with experience in providing care and treatment to ILWHA is developed
- Simpler HIV drug regimens are investigated to make adherence easier
- Medical and psychosocial needs of ILWHA are assessed
- Staff working with ILWHA are appropriately trained
- Appropriate protocols for HIV/AIDS treatment of ILWHA are in place
- Discharge planning and referral processes are widely understood and used
- Medical care and HIV/AIDS treatments are available to ILWHA (to the level allowed by the city or regional administration)
- HIV treatment services are provided in ways that maximise the ability of ILWHA to access
- All programs in the continuum address the specific needs of women ILWHA both as recipients and providers of care
- All medical programs address the issue of pain relief for ILWHA both within and outside healthcare settings
- Substitution therapy is included in inpatient care
- Psychosocial issues of ILWHA are addressed within and beyond medical settings
- ILWHA' palliative care needs are addressed.

In addition, NGOs focused on injecting drug use and HIV/AIDS (such as needle exchanges and outreach programs) and/or NGOs focused only on HIV/AIDS (such as counselling programs and PLWHA groups) need to start a new set of services (or adapt existing services) to ensure that:

- Information is provided to ILWHA on topics of interest to them
- Regular publications are produced on specific aspects of HIV/AIDS, identified as important by ILWHA
- A training program is provided for ILWHA both on self care and on peer HIV/AIDS counselling
- A manual on home-based care of ILWHA is produced and distributed to families and friends of ILWHA
- A training program is provided for families and friends of ILWHA on HIV/AIDS, caring for ILWHA at home and dealing with family and social stresses related to HIV/AIDS, and dealing with ongoing drug use or drug treatment
- New models of support are developed, which are suited to ILWHA' lifestyles.

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2. Introduction

Background

Over the past two decades, much work has been done on improving the quality of life for people living with HIV/AIDS and assisting them to live as long as possible with dignity and with as much comfort as possible. However, little research or programming has concentrated on the specific characteristics and needs of people living with HIV/AIDS who are also injecting drug users.

When Médecins Sans Frontières – Holland (MSF-H) carried out an Extended Exploration Mission on the HIV/AIDS Epidemic in Ukraine in May - August 1999, it found that the health and social care system in Ukraine is ill-prepared to deal with the number of people currently living with HIV, most of whom will develop AIDS over the next decade.

"Accurate estimates of the numbers of people with HIV in Ukraine are difficult to achieve, but the modelling carried out by Barnett and Whiteside (1997) suggest that, by the end of 1999, around 200,000 – 240,000 people will be infected.

"Official numbers of HIV infection are 27,145 registered cases (at 1 June 1999) and 46,609 positive test results at the same date (the additional 19,000 being either re-tests or anonymous tests in which the HIV positive person has succeeded in avoiding registration). Of the registered cases, 21,119 or 78% are IDUs.

"It is difficult to make accurate predictions of AIDS cases, but Barnett and Whieside (1997) predict between 46,000 and 72,000 cases within five years. There are now 1032 adults and 40 children officially registered as AIDS patients: 385 adults and 25 children have died from AIDS.

"The bulk of the population of people with HIV in Ukraine appear to be fairly young, male, heterosexual injecting drug users at an early, asymptomatic stage of HIV disease: many seem to be unemployed and most appear to be living with parents or relatives or spouse. However, large numbers of female drug users (up to 30% of IDUs were female in some cities we visited), unsafe sexual practices among female sex workers (including those who inject drugs) and unsafe sexual practices between male IDUs and their non-drug using sexual partners are all likely to contribute to an increase in the number of women living with HIV." (Burrows et al 1999)

Given the above characteristics of PLWHA in Ukraine (which are similar in Belarus and Russian Federation), MSF-H commissioned this discussion paper on the specific characteristics of PLWHA who are also IDUs; types of programs that have attempted to address the medical and non-medical needs of this group; and the implications for possible work by MSF-H in Ukraine to address these needs.

A note on terminology

A new term will be introduced in this report as a method of shorthand. The term is "ILWHA" for "injecting drug user living with HIV/AIDS". The term is used only for shorthand and is not meant to signify that IDUs with HIV/AIDS are completely

different from any other PLWHA, but only to ensure that readers understand that some statements made apply specifically to ILWHA. A ILWHA has usually (though not always) acquired HIV infection through sharing of needles, syringes or other injecting equipment. Examples of other ILWHA may include IDUs who may have acquired the virus either sexually or by equipment sharing, and PLWHA who have taken up injecting drug use since becoming HIV positive.

"Injecting drug user" is also used in both a narrow and wide sense in this report. While a person who injects a drug once in his or her life may be labelled by some an injecting drug user, this report will concentrate on those IDUs who are fairly regular in their drug use and who may have need (from time to time) of drug treatment services or other forms of medical and non-medical assistance related to their drug use. Recreational or occasional IDUs will be referred to at times but "IDU" will generally refer to a regular injector. Its wide sense is that "IDU" in this report generally also refers to ex-IDUs. This is done because:

a) drug users who become ex-users often relapse back into drug use, and many heavily dependent drug users who are trying to quit go through several periods of drug use and abstinence before they quit completely
b) many of the issues related to stigma and other characteristics of the ways drug users are treated may also be applicable to ex-users.

In this paper, HAART refers to highly active anti-retroviral therapy, also known as triple combination therapy.

Methods

This paper is not meant to be read as a comprehensive overview of all aspects of treatment, care and support of ILWHA. From July to December 1999, AIDSline and Medline searches were carried out with various combinations of keywords related to treatment, care and support of injecting drug users. Journal and conference papers and book chapters found during these searches were studied, and the author's personal contacts with individuals and organisations working with IDUs in 20 countries were consulted.

Due to time constraints and difficulties in accessing some materials, not all available papers and reports could be accessed by the deadline for the report's completion. Also, only abstracts and papers in English were consulted, which may result in a serious omission, as some of the programs designed to provide care and support among IDUs are in non-English speaking countries and do not appear to have been described or evaluated in English-language journals. World Health Organization announced late in 1999 that it intends to develop a comprehensive review of issues related to ILWHA. However, no publication date has been announced for this review.

Global estimates of IDUs with HIV/AIDS

During research for this report, the author has participated in another study aimed at trying to determine the number of IDUs in the world, as well as the number of ILWHA globally. The AIDS in the World project estimated the number of IDUs in a sample of countries representing 61% of the world's population as 3.4 million in 1990: extrapolating this to the world, the project estimated there were up to 5.5

million IDUs at that time (Mann et al 1992). AIDS in the World (AITW) estimates were provided for most countries in Western Europe and a few countries in most other regions.

The most recent estimate by the World Health Organization of numbers of IDUs worldwide states: "The number of drug injectors, predominantly opioid injectors, worldwide has been estimated at 5.3 million (Frischer et al.1994). This figure is a conservative one extrapolated from an earlier estimate (Case et al., 1992) and is likely, given the evidence for the spread of drug injection to countries where it was previously unknown, to be an underestimate." (WHO 1998)

In 1992, AITW estimated that 7% of all HIV infections (12.88 million at the beginning of 1992) were IDUs, giving an estimate of 901,600 ILWHA. In 1995, the Commission on Narcotic Drugs estimated that 22% of the 28 million people with HIV/AIDS worldwide were IDUs (UNDCP 1997), giving an estimate of 6.16 million ILWHA globally at that time. This is well above the figure given by AIDS in the World for the total number of IDUs globally in 1990.

Although these figures are somewhat confusing, the evidence being amassed by the current study leads this author to believe that there has been a substantial rise in the number of IDUs and the number of ILWHA globally since the mid-1990s. Although the study is not yet complete, a conservative estimate can be provided of more than 10 million IDUs worldwide, of whom at least 1 million have HIV or AIDS. Injecting drug use has now been reported in 129 countries, of which 103 have also reported HIV infection among IDUs. These countries are on every continent with only Africa largely untouched (Ball et al 1998).

The issues touched on in this discussion paper are likely to be of importance to a wide range of agencies dealing with HIV/AIDS throughout the world. Although the final section of the report provides implications for Ukraine, the remaining sections of the report are written to be of use to anyone interested in treatment, care and support issues among ILWHA.

3. Medical aspects of HIV/AIDS among IDUs

Overall, there are not many major differences between the "natural history" of HIV in ILWHA, when compared with other PLWHA. However, there are significant differences in infections related to injecting, deaths prior to AIDS, co-infection with HIV and hepatitis C and/or B, treatment of HIV/AIDS and related conditions, medical drug treatments and access to treatment services.

Aspects of HIV disease in ILWHA

Progression to AIDS

There appears to be a similar rate of progression to AIDS for both IDUs and other groups such as non-IDU women and gay men (UK Register 1998, Hendriks et al 1998, Prins et al 1997, Pezzotti et al 1992). Age at seroconversion may have an impact (lower age of seroconversion may lead to longer survival times), but this is not confirmed in all studies (see Prins et al 1997 for a discussion of this effect).

Patterns of drug use, based on self-report, including frequency of drug injection, continuous versus intermittent IDU, cocaine alone or heroin alone or both, do not appear to lead to differences in the rate of decline of CD4+ lymphocytes, and therefore progression to AIDS (Lyles et al 1997). However, a recent study showed that cocaine boosts the ability of HIV to infect immune system cells and suppresses the production of immune system chemicals which could keep the virus under control, which may mean that cocaine injectors would progress to AIDS more quickly than injectors of other drugs (Nair 2000).

Median time for the progression to AIDS from seroconversion was found to be 8.3 years in Amsterdam, and median time to AIDS death 10.5 years (prior to the advent of highly active anti-retroviral therapy or HAART), though the high rate of pre-AIDS deaths means that actual median life expectancy from seroconversion to death was 8.3 years (Hendriks et al 1998). Where HAART is in widespread use (for example, in North America, Western Europe, Australasia and a few other countries) life expectancy of ILWHA has increased significantly together with all other PLWHA, if they are able to access this therapy (see below).

Mortality of ILWHA versus other HIV positive people

ILWHA have a higher death rate from causes unrelated to HIV infection than HIV-negative IDUs. A UK study found that 48% of those ILWHA who had died during the study period, died before the onset of AIDS (called "pre-AIDS deaths") (UK Register 1998). However a larger UK study of mortality for all people with HIV from 1982 to 1996 found less than 20% of deaths among IDUs were "pre-AIDS": IDUs with HIV were found to be more prone to pre-AIDS deaths than HIV-positive people who had acquired the virus through homosexual or heterosexual transmission (Laurichesse et al 1998). Two Dutch studies and a meta-analysis of 12 cohorts from three continents similarly found high rates of pre-AIDS deaths among IDUs (Van Haastrecht et al 1994, Hendriks et al 1998, Prins et al 1997). From these studies, leading causes of pre-AIDS deaths among IDUs appear to be:

- Pneumonia
- Liver disease, associated with HIV and hepatitis C and/or B co-infection (see below)
- Overdose
- Suicide

The rate of overdose has been found in several studies to be higher among HIV positive than HIV negative IDUs. There is speculation that these overdoses may in fact be suicides or may be associated with higher levels of depression among ILWHA, or to interactions between street drugs and HIV treatment drugs. Suicide among HIV-positive IDUs does not seem to be immediately associated with receiving their positive test result (van Haastrecht et al 1994).

Gender differences

There is disagreement about whether gender influences progression to AIDS among ILWHA. A decade-long US study found that women with HIV and a background of IDU progressed to AIDS with a lower viral load than men. Using three methods of measuring viral load, women in the study who progressed to AIDS had viral loads measuring 38% to 65% of those in men. Possible explanations for the lower viral loads in women include different HIV dynamics in men and women, gender-based behavioural differences and hormonal differences (Farzadegan et al 1998). However, Prins et al (1997) found little difference between male and female ILWHA in the speed of progression to AIDS. Webber et al (1999) found no difference in mortality between male and female ILWHA.

Bakti and Selwyn (2000) note that, in general, the incidence of gynaecological disorders is likely to be higher among women IDUs than non-IDU women. Common problems include:

- Vaginitis: Drug-using women, with and without HIV infection, have high rates of vaginitis. The most common causes include bacterial vaginosis followed by candidiasis and trichomonas, with no difference in incidence between HIV-positive and high-risk (eg, drug-using) women. Among HIV-infected women, the risk of severe or refractory vaginal candidiasis increases with a declining CD4 T cell count, but in most cases the treatment is the same as for HIV-negative women.
- Cervical abnormalities: HIV-infected women are at high risk for cervical dysplasia and cervical cancer associated with human papillomavirus.

There is a complex set of issues related to pregnancy among ILWHA, including the effects of continued street drug use or withdrawal on the mother, foetus and newborn, and the effects of HIV on the process of pregnancy, as well as prevention of vertical transmission.

Weight loss

By 1999, a great difference had occurred between the developed and developing/ transitional countries in the area of HIV and nutrition. In countries where HAART is scarce, the traditional problem of progressive, lethal wasting associated with opportunistic infections continues to be the most significant nutrition issue. In countries with widespread HAART use, problems associated with subcutaneous fat atrophy and visceral fat accumulation are of greater concern.

In developing and transitional countries (and in some developed countries), IDUs have serious nutritional deficiencies, often caused by having to make a financial choice between food and drugs. For ILWHA, these deficiencies can exacerbate the wasting problems associated with HIV disease. Poor oral intake and malabsorption of nutrients in ILWHA, caused by diarrhea and alteration of levels of endogenous anabolic hormones (especially in men), contribute to wasting (Bakti and Selwyn 2000). In addition, the use of stimulant drugs such as amphetamines or cocaine, can decrease appetite and further exacerbate wasting and weight loss (Patterson 1998).

Non-HIV related medical aspects

ILWHA are at greater risk for infections related to injecting drug use and the infections cause longer-lasting problems than among HIV negative IDUs (Patterson 1998). These infections include:

- Abscesses: Symptoms include swelling, redness, a hard lump or a pus-filled sore located near an injecting site.
- Blood Clot (Embolism): Symptoms include red, swollen and hard veins, tenderness and warmth. Blood clots can form in different parts of the body, including the brain, where they can cause a stroke.
- Septicemia: Symptoms include high fever, chills, night sweats, vomiting, diarrhoea, headache and sometimes confusion. These symptoms occur within a couple of hours after injecting.
- Endocarditis: Symptoms include high fever, chest pain and bruising under the fingernails.
- Bacterial Pneumonia: Symptoms include a sudden fever and a wet cough that produces mucus.
- Cellulitis and Phlebitis: Cellulitis is a swelling of the skin and phlebitis is a swelling of a vein under the skin. Symptoms include swelling, redness, pain or heat at an injection site or all over.

Cognitive functioning

ILWHA seem to have no greater tendency towards dementia than other groups with HIV. However, ILWHA appear to have a greater tendency to develop HIV encephalitis, though the reason for this is unclear (Bell et al 1996). However, duration and frequency of drug use do not appear to affect onset of the dementia caused by HIV encephalitis (Goodwin et al 1996).

Tuberculosis

TB is increasingly common among ILWHA in many parts of the world. In Spain, TB was the most frequently reported AIDS-defining illness in 1995. At highest risk for TB were ILWHA, other young adults and prisoners (Castilla et al 1997).

Co-infection with HIV, hepatitis and other viruses

ILWHA are likely to be co-infected with hepatitis C virus (HCV). In a compilation of 77 studies of the HIV prevalence among IDUs in 28 countries, Crofts et al (1999) showed that an average of more than 60% of IDUs were HCV positive, with some

studies finding HCV in 100% of the drug users studied. Studies which have measured HIV and HCV co-infection have found prevalence of HCV in ILWHA of 52% to 95%, while in non-injecting HIV positive men who have sex with men, the prevalence ranges from 0% to 12% (Crofts et al 1999).

In one of the few studies in Eastern Europe of co-infection with HIV and hepatitis, 81% of 353 ILWHA in Kaliningrad were antibody positive for hepatitis C, 9% for hepatitis B, and 34% for syphilis. Of a further 61 ILWHA in the same city, 97% reacted positively for hepatitis C.

The effects of HIV/HCV co-infection on disease progression is not yet fully understood: at this stage, HCV does not appear to affect progression to AIDS or severity of symptoms. But there appears to be an increase in the severity of liver disease in co-infected people, probably due to enhanced HCV replication in the presence of immune deficiency (Crofts et al 1999). In addition ILWHA appear to be more vulnerable to HCV infection and re-infection, and HCV transmission appears to occur more easily from co-infected ILWHA (Nicholson 1998).

Co-infection with HIV and hepatitis B (HBV) can cause ongoing liver damage, though HBV appears not to have an effect on the progression of HIV disease. HBV vaccine may not be as effective for ILWHA and acute hepatitis B may lead to a temporary halt or reduction in HIV treatment as the liver may be so affected it is unable to process the medications. Hepatitis D (which only occurs in the presence of HBV or HCV) can lead to greater liver damage in ILWHA (Nicholson 1998).

While little literature exists on the topic, some commentators believe that syphilis is more widespread among IDUs than some other groups, at least in some cities or countries. It appears that syphilis can be spread via sharing injection equipment and sex workers who also inject drugs may also be at higher risk of syphilis infection. Co-infection with HIV and syphilis can cause problems in treating syphilis. Yinnon et al (1996) found that patients with syphilis who are HIV positive are less likely to experience serologic improvement after recommended therapy than are patients with syphilis who are HIV negative.

Aspects of HIV treatment in ILWHA

Access to services

Most services established to provide medical and other forms of assistance to PLWHA have been designed to meet the needs of people who acquired HIV infection sexually. They have generally not been specifically designed to meet the needs of ILWHA.

For this reason, and due to the double stigma of being a drug user and HIV positive (see Section 3), ILWHA are often unable or unwilling to access services which can assist them to stay as healthy as possible. Writing of ILWHA in the US, Peter Selwyn saw the accomplishments of identifying HIV and the swift introduction of appropriate treatments as “meaningless if they are not accompanied by equally dedicated efforts to confront issues of access and barriers to care, engagement and

adherence with therapy, and the urgent basic needs of those vulnerable populations most affected by HIV" (Selwyn 1996a).

Several studies have shown that ILWHA access HIV related treatment, care and support services to a lesser extent and later than other PLWHA. In Australia, Burrows (1995), in a national survey of ILWHA used the term "userphobia" to describe the way in which ILWHA feel that they are stigmatised and systematically discriminated against.

"One area which has not improved so far is the level of userphobia experienced from health care workers such as doctors and nurses. HIV positive IDUs in Australia believe they are receiving second-class treatment, and often attempt to conceal either their injecting drug use or HIV status from health workers to prevent stigmatisation…IDUs with HIV have also commented on the need for co-ordination between the patient, general practitioner and hospital staff. For those drug users who are on methadone programmes, this co-ordination may also need to include the methadone prescriber." (Burrows 1995)

Samet et al (1998) found that HIV-positive people with a history of injecting drug use in the US on average delayed entering medical care 19 months longer than those with no history of injecting drug use. A French study similarly found that ILWHA rarely sought medical attention until they were close to death due to the attitudes of doctors and nurses towards them and due to their previous health care experiences (Tellier and Sobel 1994). Another French study found most general practitioners (GPs) would prefer to avoid ILWHA as patients. The GPs attributed more guilt and responsibility to ILWHA for their infection than to other patients (Morin et al 1995). O'Connor et al (1994) found that physicians in the US received little training in caring for IDUs and had negative attitudes towards them.

Also in the US, Celentano et al (1998) reported a cross-sectional survey in 404 ILWHA in Baltimore in which only 57 patients (14%) reported receiving HAART. Sixty-three percent of patients reported receiving no (49%) or inadequate (14%) therapy. Active injecting drug use, lack of advanced disease, not being in a drug treatment program, and not having a usual source of primary care or health insurance were associated with not receiving therapy. In addition, 71% of patients with past, but not current, drug use were not receiving HAART.

In Canada, Strathdee et al [1998] reported similar findings among 177 IDUs in Vancouver. Only 71 (40%) were reported as receiving any antiretroviral therapy, most commonly double combination therapy, and only 17% were reported as receiving HAART. Compared with those who received treatment, patients receiving no therapy were more likely to be women, younger, and not in a substance abuse program.

In Scotland, a study of hospital stays by PLWHA found that ILWHA had significantly shorter stays in hospital than other PLWHA, especially AIDS patients and those with CD4 cell counts of less than 200 (Brettle et al 1994a). One interpretation of these shorter stays is that drug users feel less comfortable in hospital (despite being very ill) due to the attitudes of hospital staff towards them. Another possibility is that the lack of ability to take their drugs of choice while in hospital forces them to leave.

The Canadian HIV/AIDS Legal Network (1999) released a major report detailing the ethical and legal implications of these access problems. The authors were concerned that many services for ILWHA were only provided to people who had quit using drugs, and found that this restriction of access was unethical for health care providers:

"From an ethical perspective, the basic issue *is the ethical imperative to mobilize and maintain services necessary to assist people. To adhere to the ethic of humanity, behaviour should not be imposed on drug-dependent individuals that exceeds their current levels of ability…*

"Adherence to treatment is profoundly affected by systems of care. When the healthcare system is adapted to meet the needs of socially maginalized and indigent persons, there is a vast improvement in adherence to treatment. Ethics therefore requires that we not reduce an assessment of treatment compliance to simply the personal characteristics of people with HIV/AIDS. At the same time, there may be situations where it may be justified to delay or, at the extreme, refuse (anti-retroviral treatment). Such a decision would be ethically unjustifiable if it is reached without honouring the characteristics of an authentic healing relationship: humanity (respect for the full biological and biographical particularity of the person with HIV/AIDS), autonomy (respect of the person's way of life and life plans); lucidity (transparent sharing of all relevant information); and fidelity (understanding and respect for the expectations of the sick)…

"Drug users are excluded from studies of HIV/AIDS drugs. In addition, there is little research into the effects of currently illegal drugs on the immune system, or the interaction between HIV/AIDS drugs and currently illegal drugs. This hinders the provision of optimal care, treatment, and support to HIV-positive injection drug users. HIV-positive drug users may have a wider range of immunological deficiencies and a different history of the disease; they may respond differently to treatments than other HIV-positive persons. It is ethically wrong to exclude drug users from the clinical studies that would yield the data necessary to guide both HIV-positive drug users and their healthcare professionals in making informed *treatment decisions."*

ILWHA are not excluded from trials of HIV/AIDS treatments worldwide, but several factors tend to hinder them from participating in such trials. These include:

- bias by researchers who believe that ILWHA will be unreliable or difficult research subjects
- a belief among some researchers that expensive medications should not be "wasted" on drug users
- fears among researchers that ILWHA have a chaotic lifestyle which will lead to lack of compliance with treatment regimens which will distort research results
- fears among ILWHA of mistreatment by healthcare staff in the trials
- lack of information among ILWHA about trials, due to lack of or reduced access to information about HIV/AIDS treatments.

Similar reasons are often given for denial of highly active anti-retroviral therapy (HAART) and other treatments to ILWHA. As recently as 1998, an editorial in the Journal of the American Medical Association recommended that active drug or

alcohol use by PLWHA (those not in drug treatment or on methadone) was a "reasonable reason" to "temporarily defer" starting HAART treatment until the PLWHA entered drug treatment (Sherer 1998).

In addition, many healthcare workers fear accidental transmission of HIV from ILWHA to themselves. Lack of previous experience in working with ILWHA is the most common characteristic of such workers, and frequent work with ILWHA is associated with a reduction in these fears (see for example Connors et al 1991).

These issues may be far more severe for women ILWHA than for men. A Canadian study found that women ILWHA were often the main caregiver for their partners and children and therefore were reluctant to access drug treatment or HIV treatment services. An additional problem is that many women fear disclosing their HIV status to their children or other family members (Marte and Gatell 1999).

Medical drug use treatment

Methadone and other types of drug substitution are very useful in medical treatment of ILWHA. First, substitution treatment can assist in preventing the spread of HIV and in assisting ILWHA to control their drug use. MacGowan et al (1997) found that methadone maintenance programs assisted in reducing the number of injections by IDUs and, more importantly, reduced the number of "dirty" injections in which unsterile injecting equipment is used. This means that uninfected IDUs are less likely to become HIV or HCV/HBV infected if ILWHA are consistently using sterile equipment then disposing of the equipment appropriately.

Second, substitution treatment can be used to attract IDUs into HIV treatment and can assist with treatment compliance, both through regular contact between client and substitute provider, and through an easing of the chaotic lifestyle that often characterises dependent injecting drug users. Third, substitution treatment can assist IDUs to stay in hospitals or hospices for inpatient treatment: without substitution, patients are often in great pain, and the hospital staff need to make difficult choices between allowing the patient's friends or family to illegally supply (and sometimes inject) the needed drugs, or requiring the seriously ill patient to leave the hospital premises to inject, then return for continued treatment.

Brettle et al (1994b) found that missed appointments with HIV treatment doctors among PLWHA in Edinburgh (most of whom are IDUs), fell markedly when the treatment services were offered from an all-day clinic (rather than one with restricted opening hours) which also provided methadone. Women in methadone programs in New York were found to have higher survival rates than women IDUs who were not on methadone. One reason put forward for this effect was the closer medical follow-up provided for women on methadone programs (Laine et al 1998).

Interaction between HIV treatment and other drugs

The issue of drug interactions was the most prominent concern among Australian ILWHA.

"In the first instance, research is needed into the relationship between methadone consumption and the use of antiviral drugs such as AZT, ddI, ddC and 3TC (including

combination treatments of these drugs). The next priority in terms of drug reactions is to investigate the relationship between the full range of HIV treatment drugs and the most commonly used illicit drugs: cannabis, amphetamines, hallucinogens such as LSD and heroin. While very limited research has been carried out in this area, there needs to be a comprehensive literature review on these topics, and policies must be developed to assist HIV positive IDUs to stay as healthy as they can, given their status, their circumstances and lifestyle choices." (Burrows 1995)

Information is increasing on drug interactions, especially between methadone and HIV medications, but there is still much that is unknown. Protease inhibitors may interact with a wide range of illicit and licit drugs. The strongest effect yet discovered is the complex interaction between protease inhibitors and methadone. As a result of this interaction, methadone doses may have to be increased or reduced for ILWHA taking protease inhibitors. In vitro studies suggest all protease inhibitors increase the concentration of methadone, but in vivo studies with nelfinavir and ritnavir reveal reduced concentrations of methadone (Clarke et al 2000; Hsyu et al 2000; Hsu et al 1998). These factors mean that ILWHA on protease inhibitor therapy and methadone need to be monitored closely and the methadone dose should be modified as needed. Any of the protease inhibitors can have an effect on the dose effects of drugs such as MDMA (ecstasy). (Ostrow 1998)

No effects have been found on methadone concentrations by nucleoside analogue reverse transcriptase inhibitors except for abcavir, which increased clearance of methadone by 22% (but this is unlikely to require a change to the methadone dose). Methadone with AZT therapy results in a 40% increase in concentration of AZT (which may lead to greater nausea and headaches). Methadone causes decreases in concentration of ddI (60%), but there is no evidence that this decreases the effectiveness of ddI (Dr Jennifer Hoy, Private Communication).

Selwyn (1996b) noted that when prescribing rifampin to treat TB (Rifadin, Rifabutin, and Mycobutin are in this same family of drugs) to methadone consumers, the dose of methadone should be doubled within two or three days because there is an increase in the metabolism of methadone, which can cause serious, immediate opiate withdrawal. Due to the effects of rifampin in inducing withdrawal, ILWHA often stop taking their medication, thus increasing the risk of spread of drug-resistant tuberculosis. Selwyn recommends breaking methadone dosing into two parts each day.

A complex set of issues surrounds the ways that street drugs interact with treatment drugs. Little research has concentrated on these interactions but Tseng and Antoniou (1997) have provided an overview of potential interactions on the Toronto Hospital Website. (A potential interaction is one that may be anticipated because of knowledge of metabolism: however, in vivo effects may not follow predicted interactions.) They describe potential interactions between:

- Cocaine and the protease inhibitors saquinavir, indinavir and ritonavir; erythromycin and clarithromycin; rifampin and rifabutin: the effects of these interactions are not thought to be of any significance
- Amphetamine (as well as dextroamphetamine, methamphetamine and paramethoxyamphetamines) and protease inhibitor ritonavir; serotonin re-uptake inhibitors fluoxetine, fluvoxamine, sertraline, paroxetine; and haloperidol: can lead to stimulant overdose systems from extreme

exhiliration and agitation to angina, cardiac arrest and cerebral haemorrhage
- Ecstasy with the same drugs that interact with amphetamines: similar results
- Cannabis with the same drugs that interact with cocaine plus fluconazole: interaction effects are unclear but may include heightened strength of cannabis effects leading to hallucinations, panic, increased heart rate, etc.
- LSD with monoamine oxidase inhibitors: may lead to increased effect of LSD and longer duration of effects
- Benzodiazepines (including alprazolam, clorazepate, diazepam, midazolam, triazolam, alprazolam, midazolam) with the same drugs that interact with cocaine: interaction effects may increase effect of tranquillisers leading to extreme sedation and respiratory depression
- Benzodiazepines (lorazepam, oxazepam, temazepam) with ritonavir: may lead to withdrawal symptoms from benzodiazepines if using these chronically; or may lead to reduced effectiveness of the tranquillisers if ritonavir is used chronically
- Heroin, codeine and morphine with ritonavir: may lead to the same withdrawal symptoms noted for methadone and ritonavir, though the interaction between morphine and ritonavir may not be as severe as with the other opiates
- Ketamine with numerous compounds, including protease inhibitors, benzodiazepines, terfenadine, astemizole, and cisapride: effects are difficult to predict but some interactions may lead to increased effect of ketamine including higher blood pressure and, in extreme cases, respiratory depression

Treatment of ILWHA with hepatitis C

It should be noted that many HIV treatment drugs have potential effects on the liver. Due to the high rate of HIV and HCV co-infection and the greater level of liver damage in ILWHA, these potentially toxic effects need to be taken into account when prescribing HIV and OI treatments.

An inadequately researched issue is the effect of HCV treatment drugs on ILWHA with HCV co-infection. An international study has begun to examine the effects of interferon with or without ribavarin, on co-infected ILWHA (Mitchell 1999). The study will also examine drug interactions between HCV and HIV treatment drugs.

Pain

Pain management is a problem for all PLWHA, but is worse for ILWHA. In Australia, ILWHA spoke of the fear of health care workers in giving drug users addictive drugs for pain management. Instead of opioids and other effective pain relievers, drug users were often offered aspirin or paracetamol. Yet injecting drug users usually have a very high tolerance for depressant drugs and need higher, not lower, dosages when they are in pain (Burrows 1995).

Cornell (1999) reported that a 1997 multicentre study in France found that doctors underestimated pain in 52 percent of PLWHA. Among those who had moderate or severe pain, only 43 percent were treated. Cornell also refers to a leading HIV pain specialist in New York City, who said US studies have estimated that doctors provide adequate pain management for only 15 percent of PLWHA with pain. For

former substance users with HIV, that figure dropped below 8 percent. It was likely to be even lower for active IDUs with HIV.

The Australian IV League (1991) has noted that there is a danger that ILWHA with severe pain who are denied adequate pain management "either have inappropriate and unsupervised doses of adulterated drugs smuggled in to them (in hospital) or discharge themselves prematurely from medical treatment". Each of these situations may lead to further medical complications and increased risk of death.

Ukraine-specific aspects

Burrows et al (1999) stated that the health and social care system in Ukraine is ill-prepared to deal with the number of people currently living with HIV, most of whom will develop AIDS over the next decade. The country has a large number of hospitals - 2714 in all (for a population of 60 million) - but actual health care availability has fallen drastically since 1990. Many aspects of medical care, such as medications, syringes etc. must be purchased by the patient before medical care is provided." The authors found that "for the great majority of people with HIV and AIDS in the Ukraine, there is little or no medical or non-medical assistance available".

HAART is prohibitively expensive for most people with HIV in Ukraine. Barnett and Whiteside (1997) estimated the costs in 1997 as US$12,000 per person per year. The average annual income in Ukraine is less than US$500,

Some authors have argued that there are characteristics specific to PLWHA and ILWHA in Ukraine which have an effect on the course of their HIV disease. Merichev et al (1996) suggested that Ukrainian PLWHA were more likely to die faster from HIV-related conditions because of immunological dysfunctions which had occurred prior to their HIV infection: in their study 0f 33 people with AIDS, 56% died within 1 year of their AIDS diagnosis. While the authors were not very specific about these dysfunctions, they mentioned the widespread radiation fallout from the Chernobyl nuclear power station in the late 1980s as a possible cause.

There also appears to be a short period between HIV diagnosis and first manifestation of AIDS. In Odessa, almost 50% of people with AIDS received their AIDS diagnosis within one year of being diagnosed with HIV, while a further 28% did so within two years. This may indicate that people are not being diagnosed with HIV until very late in the progression of the disease. An alternative explanation is that the particular HIV epidemic in Odessa or Ukraine may result in very rapid disease progression (Burrows et al 1999). In an interview by the author with a narcologist in Vinnitsa (Ukraine), reference was made several times to an Odessa study which had showed the average life expectancy for an ILWHA who did not quit using drugs was 22 months after HIV diagnosis. Further details are being sought of this study.

Vovk et al (1999) found average duration from HIV diagnosis to AIDS was 3-5 years among 449 PLWHA in Ukraine, with injecting drug use a predictor for faster progression to AIDS. A study by the same researchers of the same cohort of 449 patients in the previous year found the most common HIV-associated condition (in 62 patients) was candidiasis of oral cavity, bronchi and intestine. ILWHA usually are HCV and HBV positive. The 40 AIDS patients had various recurrent viral

accompanying infections, such as herpes simplex (in 37 patients), herpes zoster (in 5 patients) and cytomegalovirus infection (in 3 patients). Among the 40 patients with AIDS associated conditions, the researchers found tuberculosis (in 14 patients including 5 extrapulmonary cases), pneumocytosis (7 cases), esophagitis (4 cases), cryptosporidiosis and isosporosis (4 cases), cerebral lymphoma (1 case), cryptococcal meningitis (1 case); and Karposi's sarcoma (in 3 homosexual men) (Vovk et al 1998a).

Hepatitis C and HIV co-infection may be more common in Ukraine than in other countries both among ILWHA and other PLWHA. Tchentsova et al (1998) studied 177 PLWHA, of whom 157 were IDUs and 20 were non-IDUs. More than 83% of ILWHA were hepatitis C positive, as were 45% of the non-IDU group. The need for TB treatment for ILWHA in Ukraine is made clear by Vovk et al's (1998b) findings that TB has became the most common and dangerous HIV-associated condition. The broncho-pulmonary TB frequency in HIV positive patients in Ukraine (2548. 6 per 100,000 of HIV-infected persons) is 74 times higher than among the rest of the Ukrainian population.

Nutritional supplements are used in many countries to assist people with HIV who may experience rapid weight loss. The development of such programs in Ukraine have to be considered in the context of widespread nutritional deficiencies in the country. From 1990 to 1995, consumption of meat fell by 46%, fruit by 22%, eggs by 40% and fish by 75% (Burrows et al 1999).

4. Psychological and social aspects of HIV/AIDS among IDUs

In addition to medical aspects of HIV infection, there are psychological and social effects which may be different for ILWHA than for other PLWHA. Psychological and social reactions to HIV infection can affect the course of HIV disease and affect the PLWHA's ability to cope with the disease and its symptoms. The psychosocial aspects of ILWHA' lives are generally under-researched. Where research is available, it is often contained in drug treatment rather than HIV-related journals and is often concerned with the differences in providing drug treatment to ILWHA as opposed to HIV-negative drug users.

Psychosocial aspects of HIV disease in ILWHA

Much of this section draws on the general literature on psychosocial aspects of HIV/AIDS and tries to ascertain what are likely to be the most relevant aspects related to ILWHA. The overall psychosocial mechanisms of HIV disease are given by Ross (1997) as:

- Social stigmatisation, which may increase feelings of depression and lower self-esteem, with possible effects on the course of HIV disease: discrimination against PLWHA (or some groups of PLWHA) may impact on their health by denying them housing, employment, social support, access to treatments and treatment information etc.
- Challenges to social identity: where HIV is seen as a "gay" disease or "drug users" disease, PLWHA may be seen or see themselves as doubly or triply stigmatised
- Denial, anger and depression may lead PLWHA not to seek treatment information or treatment itself, or interfere with their compliance with treatments, leading to increased opportunistic infections, faster progression to AIDS and greater pain
- Use of drugs (both street drugs and prescribed) may increase among ILWHA and other PLWHA to cope with or escape from the stresses of living with HIV/AIDS: this may lead to further psychosocial problems and increased physical problems
- Relationship effects: HIV can affect all the relationships a PLWHA has with family, spouse, children and friends (whether or not the person discloses his/her status), and can have effects (including emotional, financial, in terms of time and discrimination) on members of the PLWHA's family and social circle.

Stigma and social identity

ILWHA are likely to experience several levels of stigmatisation and discrimination. As mentioned in the previous section, ILWHA' experiences of health care are often negative, due to the attitudes of medical and other healthcare staff towards both IDUs and PLWHA. But discrimination is likely to occur almost anywhere. One of the few reports which has examined discrimination against injecting drug users ((NUAA 1995) found that, of 300 IDUs interviewed in New South Wales, Australia, "bad treatment" had been experienced from police (80%), hospital staff (60%), doctors (57%), pharmacists (57%), employers (47%), dentists (33%), methadone providers

(33%), drug treatment services (33%) and community health workers (7%). As the report noted:

"Experiences of discrimination are so common and relentless many users fail to then recognise they are being discriminated against. It seems normal to be treated badly and vilified if you're a user." (NUAA 1995)

The same report found that this discrimination increased for ILWHA: "after a disclosure about injecting drugs, positive users have often reported that their doctor begins to actively talk down to them, begins to treat them differently and their symptoms are not believed" (NUAA 1995). Fear of this discrimination leads to many ILWHA not disclosing to their HIV treatment doctor that they inject drugs, leading in turn to greater possibilities of misdiagnosis and interactions between HIV treatment drugs and street drugs. Fear of discrimination often leads ILWHA not to seek HIV treatment at all. In addition, Burrows (1995) found that ILWHA often experience discrimination from non-government organisations established to deal with HIV/AIDS and from HIV-positive people's associations.

Because many ILWHA are co-infected with HCV, it should also be noted that a similar Australian study found that IDUs with HCV experienced similar types and levels of discrimination in healthcare settings, employment and other areas of their lives (Burrows and Bassett 1996). Women (especially those who are mothers) ILWHA and people from specific ethnic groups who are ILWHA often face added discrimination.

In addition to discrimination by institutions and family, ILWHA often experience stigmatisation among their drug-using social network if it becomes known that they are HIV-positive. For many IDUs, due to rejection by family and other members of society, fellow drug users are often their closest friends and drug using social networks can form a sort of community. Fear of being "found out" as HIV positive by fellow drug users can prevent ILWHA seeking HIV treatment, especially where this treatment is provided in a designated AIDS centre, AIDS ward at a hospital or HIV medical clinic.

Psychological response to HIV infection

Ross (1997) identified the following stages of psychological response to HIV infection, together with some of the problems that can occur at each stage:

1. Shock: guilt, powerlessness, anger and denial may lead to anxiety, frustration, distress
2. Withdrawal: recognition of stigma and social isolation may lead to fear of infecting others and depression
3. "Coming out" to family and/or friends: testing of others' reactions, stress displacement (from self to others) and feeling the need to be loved may lead to rejection, stress and confrontation with others' reactions
4. Looking for other HIV positive people: the need for sharing stories and problems, trust, positive reinforcement and social support may lead to dependency on others, overinvolvement (with HIV positive groups or associations for example) and loss of anonymity and confidentiality (as increasing numbers of people know the PLWHA's HIV status)
5. Special status: difference becomes special, the feeling of being needed by

others can lead to further dependency on other PLWHA, an "us and them" mentality in which people are responded to mainly on the basis of whether or not they are HIV positive, and over-identification (where HIV status becomes the central defining condition in life and work)

6. Altrusitic behaviour: the desire to give and share and feeling of being part of a community of PLWHA and the wider community may lead to stress and burnout
7. Acceptance: coming to terms with HIV status may lead to apathy and resistance to change.

The model Ross described was developed from work with HIV-positive gay men and there is speculation whether all of these stages occur in the same way for ILWHA. For example, Section 4 will discuss some of the problems which have occurred in attracting ILWHA to support groups and organisations.)

Important differences for ILWHA are likely to include more profound and more frequent depression, and more confusion about the sources of anger, frustration and stress: these may be caused by living with HIV, ongoing drug use, discrimination against IDUs, stigmatisation of HIV positive people, or some combination of all of these. In addition, the double stigma of drug use and HIV, may keep ILWHA in the "shock" or "withdrawal" stages: this may be one of the reasons for such high levels of non-AIDS related mortality among ILWHA. The ability to feel accepted among other PLWHA and to exhibit altruistic behaviour may also not be possible unless there are specific programs established to foster these relationships and this work.

An important gender difference was described by Brook et al (1999) in coping strategies of ILWHA. The coping ability of both male and female ILWHA is affected by personality factors and the strength of ties to family and a significant other (spouse, boyfriend, girlfriend etc). However women ILWHA are much more reliant on both emotional support from the significant other and from friends. The researchers found that friends appeared to be more important to women than to men, implying that peer support (from both other HIV positive women and from friends regardless of HIV status) is vital to women ILWHA.

Drug use and treatment

The biggest difference between ILWHA and other PLWHA lies in the area of drug use and treatment. These terms are used in their widest sense to incorporate all aspects of drug use, including experimentation, recreational and dependent use, and all aspects of drug treatment from self-imposed withdrawal and detoxification through substitution therapy and abstinence-based drug rehabilitation programs.

These differences can be characterised as both institutional and personal. First, drug use (without HIV infection) is normally dealt with by a group of long-standing institutions which focus only on drug use (often only at the personal, psychological level) and have little to do with other aspects of medical or health care. For example, in many countries, drug and alcohol treatment services have developed as part of mental health institutions, rather than general hospitals, and this has influenced the ways that drug treatment services often remain aloof from general health services.

As was noted in the previous section, general practitioners and HIV treatment doctors feel they have not received the training to address drug issues among ILWHA, and are unwilling to treat them unless they quit using drugs. Drug and alcohol doctors and health workers, on the other hand, often feel they are not equipped to deal with the additional physical, psychological and social issues affecting ILWHA. Institutionally, therefore, there is a tendency for each group to think that ILWHA should be treated by the other group, often resulting in an increased sense of frustration, rejection and hopelessness among ILWHA.

Personal issues surrounding drug use, treatment and relapse can be very complex among ILWHA. For a range of reasons, IDUs are often encouraged to quit using drugs if they are diagnosed with HIV. For some, HIV diagnosis acts as a catalyst for major behaviour change and many ILWHA enter drug treatment soon after learning their positive HIV status. For others, diagnosis can lead to an increase in the level and type of drugs injected (MacGowan et al 1997). Others, especially in areas where many IDUs have HIV, may not believe HIV will have any great effect on their lives and continue using drugs in the same way as before (Burrows et al 1999).

ILWHA are likely to move through many periods of increased and decreased drug use and, possibly, abstinence during the course of their disease. No studies appear to have been done on the relapse rate into drug use by ILWHA who have quit drug use, but World Bank (1997) has reported that 70-80% of people treated for heroin use typically relapse to injecting, and there is no reason to believe that the relapse rate for ILWHA would be significantly different.

Illnesses related to HIV and access to HIV treatments may also be factors in changes to an individual's drug use. Initial AIDS symptoms for example can bring on greater depression and a sense that death is imminent, which can lead to relapse for ex-IDUs and to increased use by active IDUs. Access to HIV treatments is, in some countries, restricted to ILWHA who are willing to enter abstinence-based drug treatment. In others, ILWHA are encouraged to enter methadone programs (or in some cases are denied treatment unless they enter such programs). In some countries, HIV treatments are provided only to those ILWHA who can demonstrate that their drug use is sufficiently controlled to allow them to comply with the treatment regimen. Only in a very limited number of countries are ILWHA provided with access to HIV treatments regardless of their ongoing injecting drug use.

Entering a hospital as an inpatient, or a hospice, can also affect an individual's drug use. The illegality of injecting drug use means that attempts are made to prevent ILWHA from continuing to use drugs while in hospital or hospice. This can lead to severe problems within the hospital or hospice, especially if methadone or other substitution therapies are unavailable. It is common to hear in conversations (though this is rarely written to protect the speakers from criminal charges) of AIDS wards in hospitals and hospices that have a large caseload of ILWHA allowing injecting to continue by "turning a blind eye" to the practice. The author has heard this from hospital administrators and doctors in Australia, Canada, Russian Federation, Ukraine and United Kingdom.

Sex

Discovering that they are HIV positive can have a profound effect on PLWHA' sexual relationships. There is no evidence that these effects are different for ILWHA. However, it is important to note that post-test counselling continues to be an important motivating influence on ILWHA to practise safe sex. MacGowan et al (1997) found that a counselling program for ILWHA in the mid-1990s led to a substantial increase in condom use by this group, despite more than 10 years of campaigns about the need for safe sex and a high level of knowledge among IDUs about sexual transmission and prevention of HIV.

Family and community aspects

HIV infection, AIDS and death from AIDS can all have profound effects on families and the general community. Impacts on the families of PLWHA can include illness and death of a loved one, impoverishment (if the PLWHA is the main income-earner), changes in roles of family members (one or more may have to care for the PLWHA), stress, inability to parent and care for children, use of scarce financial resources for healthcare rather than other expenses, increased depression in children and other family members (UNAIDS 1999)

Community stresses can include reduced labour resources, increased poverty, inability to maintain infrastructure, reduced access to general health care (as health resources are increasingly used to treat PLWHA), increased stresses (which may emerge as scapegoating, and threats or actual violence towards PLWHA).

These factors are likely to affect ILWHA in much the same way as other PLWHA. The greatest difference may lie in the double stigma attached to ILWHA and pre-existing poverty of injecting drug users. For several reasons (which include the high cost of drugs and the reduced capacity to work of very dependent drug users), IDUs are often among the poorest members of a society. Therefore, additional costs for health care and reduced opportunities for earning income (either due to illness or discrimination) are likely to lead to greater impoverishment more quickly among ILWHA than other PLWHA. Community tensions, especially in areas where IDUs tend to congregate, may be exacerbated by scapegoating of ILWHA as being particularly "guilty" or "dangerous", which may lead to specific violence against ILWHA.

Psychosocial aspects of HIV disease in ILWHA in Ukraine

Burrows et al (1999) found that there are few funded positions in Ukraine corresponding to a social worker's role in many Western health systems – a role which includes assistance with various social needs such as employment, housing, counselling and so on. While there are many psychologists and a few people working in NGOs as counsellors, there has been little specific training on the psychological needs of people with HIV and AIDS, or specific techniques of counselling HIV positive subpopulations such as injecting drug users (IDUs) and sex workers.

The authors found that psychosocial needs were greater than medical needs in Ukraine in 1999 "as such a large number of those infected with HIV are currently asymptomatic. Among the HIV-positive people we interviewed, there was a range of

reactions to the diagnosis of HIV from devastation…to the calm acceptance of a man in his early 20s in Mykolayev: 'A drug-using friend was infected and I had some feeling it might come'.

"Discrimination was a problem for each HIV positive person we interviewed. Tamila of Poltava said: 'My friend had a really bad abscess and they sent him to the…hospital where they treat HIV infected. They treat you there very badly, very very badly, it's scary. This guy had his fingers rotten to the bones – they told him – go home and do something – put compresses - they wouldn't even touch him. One guy died in a house entrance (pod'ezd) – his parents kicked him out of the house – he was a junkie and positive. He stayed in this pod'ezd, nobody would approach him. Once some person brought out some food for him in a tea bowl – the way they put out food for dogs. He died there in the pod'ezd, he died of tuberculosis.' Another respondent said doctors' attitudes were generally okay, but admitted he did not tell his HIV status when he needed surgery on his arm: he went to an all-night hospital where they would not have time to get tests done. He did this because his friend had sought help with dental problems, told his status and was refused…

"Community attitudes to HIV are reflected in the ways that family members and friends deal with the news that a person has HIV. We were told of HIV positive people who had not told certain family members of their status, or who were required to use their own crockery and cutlery when visiting their parents' house. People with HIV have to educate their family members and friends about transmission risks, what is safe and what is not. At Poltava, volunteers at the needle exchange are sometimes called by parents of a drug user with HIV. When they arrive at the home, they find the young person on a bed with his parents standing separately, afraid to touch their child. (Burrows et al 1999)

5. Continuum of Care

The general approach to treatment, care and support for PLWHA recommended by World Health Organization and UNAIDS is to provide a continuum of care extending from home to hospital. WHO (1995) stated that this continuum of care should involve all relevant health and social institutions in a comprehensive range of care services, all linked by discharge planning and referral processes: this means that, before a PLWHA leaves one form of care, the next venue of care (whether it is home or drug treatment agency or hospice) is informed and able to care for the person. Where the PLWHA's needs extend beyond the capacity of any particular care agency, referral networks need to be in place so that the PLWHA can access the additional service(s) easily.

A continuum of care should include:

- Comprehensive care policies and guidelines
  - Clinical management
  - Nursing care
  - Counselling and voluntary counselling and testing
  - Social support
- Mobilising resources to implement care across the continuum
  - Discharge planning
  - Referral networks
  - Government/NGO links
  - Community support to PLWHA and their caregivers
- Integration of HIV/AIDS care with existing services
  - Hospital based in- and outpatient care
  - Health centres and dispensaries
  - Tuberculosis treatment
  - Sexually transmitted infection treatment
  - Reproductive health
- Prevention interventions as part of care
  - Counselling partners of PLWHA
  - Educating family members
  - Supplying condoms
  - Using PLWHA as prevention educators
  - Promoting mutual support among PLWHA

(WHO 1995)

The underlying principles of the above continuum of care need to be applied to caring for ILWHA. To do this, changes may be needed to the ways that some of the components of care are carried out, and several components may need to be added. Marte and Gatell (1999) stated that the overall requirement of care for ILWHA is that the usual demarcations between medical disciplines and between medical, social and psychological services, be broken down. Instead, comprehensive care services are needed which cut across these demarcations and meet the medical, drug treatment, mental health, psychological and social needs of each ILWHA.

As articulated by McAmmond and Skirrow (1997), services or agencies which form an ILWHA continuum of care need to:

- Have a holistic approach that recognises the inter-related needs of the whole

person
- Integrate harm reduction principles and approaches, so that they respect the right of clients to make choices about their drug use and lifestyle, while helping the client to minimise harm to themselves, their families and communities
- Be accessible to ILWHA where they are, in ways that make sense to them
- Include clients as partners in their own care.

Self care

First, it needs to be acknowledged that the high level of stigma attached to ILWHA may prevent them from accessing many of the components of the continuum of care. While changes are needed in the ways that institutions approach ILWHA (dealt with below), in the short term, effective care may need to concentrate on ILWHA themselves and their families and friends.
Assisting ILWHA to care for themselves is seen by some as a waste of time as there is a widely held belief that drug users do not care about their health. This has been disproved (for the majority of IDUs) by the success of education and HIV prevention programs among IDUs in many countries, where IDUs have changed their behaviours (injecting and sexual) to protect themselves from HIV/AIDS. While ILWHA are likely to be under greater stress and more prone to depression than HIV negative IDUs, there is no evidence that they are unable or unwilling to stay as healthy as possible within their life circumstances.

A ILWHA continuum of care must emphasise the role of the individual ILWHA in looking after his/her health: this is called self care or self management. Self management recognises the psychological and social aspects of HIV/AIDS, and:

"aims to help people to learn and practise the skills necessary to carry on an active and emotionally satisfying life in the face of one or more chronic conditions. Effective self management is based on a partnership between people, their families and health professionals. In this partnership, a person is encouraged to play an active role in:

- *monitoring and managing the symptoms and signs of illness*
- *managing the impact of illness on their ability to function, and their emotions and relationships with other people, and*
- *adhering to treatment regimens." (The Hep C Review 1999)*

In several countries, PLWHA are trained to understand their treatment, care and support needs related to HIV/AIDS, and are informed about the likely course of HIV disease and their role in maintaining their health. In a smaller number of countries, this process has extended to training and informing ILWHA, often through groups of HIV positive and negative IDUs (called IDU groups) or, more rarely, ILWHA groups. IDU groups now exist in at least the following countries: The Netherlands, Germany, UK, USA, Canada, Australia, New Zealand, Belgium, France, Slovenia, Spain, Ireland, Brazil, Nepal and India. ILWHA groups exist only, to the author's knowledge, in India and possibly Nepal (though a Positive Users Group ran for several years in the 1990s in Sydney Australia, and Mainliners was a ILWHA group in London UK in the early 1990s).

In Amsterdam, Mainline (a NGO providing injecting equipment and education to IDUs) provides a newsletter on ILWHA issues throughout The Netherlands. The

newsletter uses a circular process in which surveys are carried out with ILWHA to discover what issues are of most interest to them, then an "expert centre" of specialist health educators and outreach workers, finds the technical information required and "translates" it into appropriate language for ILWHA. The newsletter is then distributed together with survey forms asking about the content and about other issues which need to be covered. The newsletter goes beyond scientific information as its goals are to stimulate access to and compliance with HAART, assist ILWHA to support each other and to improve their overall quality of life (Brandsmaa 1999).

Fornataro and Obermeyer (1992) also found that ILWHA often require specially designed, non judgemental informational materials which suit their individual reading levels and educational background. The authors described a project in which educational materials were developed on early intervention in HIV disease, and clinical research protocols. A total of 35 single-page fact sheets were created and 22,000 copies were distributed at neighbourhood meeting centres, drug treatment centres, clinics and clinicians' offices, by mail, and on the streets. They found that one-page, user friendly informational fact sheets distributed by other self-identified IDUs were an effective way to communicate this type of information, and that ILWHA felt more comfortable discussing treatment and research options with their peers.

In Sydney Australia, the New South Wales Users and AIDS Association (NUAA) has worked on issues with ILWHA since it began in 1989. Its work has included starting support groups, assisting ILWHA to advocate for their needs to the national PLWHA groups and to governments and health institutions, and a series of educational materials. The most comprehensive of these educational works is a book "Being positive and a user", a draft of which has been prepared but has not been approved for publication by the government which funded it.

The book, NUAA (1998 unpublished) covers issues for both HIV positive and HCV positive IDUs from the perspective of these drug users, including a general understanding of diseases associated with the two viruses, dealing with a positive diagnosis, transmission and prevention of HIV and HCV (especially to family and household members and friends), safe drug use and safe sex, pain relief, legal and financial advice, and addressing discrimination.

In addition to providing educational resources, NUAA and the seven other IDU groups in Australia assist ILWHA to participate in community-based training workshops on HIV/AIDS treatments and other issues of interest to PLWHA. These programs are run by the Australian Federation of AIDS Organisations (a national NGO network) or State AIDS Councils. While these training programs involve senior HIV specialists and researchers, they are conducted by and designed for PLWHA themselves so that the highly technical information is discussed in ways that non-medical people can understand.

Canada and USA have similar approaches to training on HIV/AIDS treatments issues in some cities with one group at least (TEACH in Philadelphia) specifically designing a treatments information program for active IDUs and delivering the program in conjunction with a needle and syringe program (NSP), which provides injecting equipment and education to IDUs for HIV prevention (Davids et al 1998).

In Toronto Canada, the Community AIDS Treatment Information Exchange (CATIE) has taken a step further and carried out a training program of PLWHA as peer treatments counsellors: the program has included the development of a comprehensive training manual including both presentations and exercises on various aspects of HIV/AIDS treatments and counselling (McClure 1996). Although the manual and program are not specifically designed for ILWHA, they would be easily adaptable to their specific concerns.

A recently evaluated Californian program called Positive Self-Management Program (based on social cognitive theory) places great emphasis on PLWHA developing a range of skills including:

- Skills in accessing information
- Skills for managing and adhering to complicated medication programs
- Problem-solving skills for interpreting new symptoms, identifying and prioritising needs, and locating and using available community resources
- Skills in enhancing relationships with healthcare providers
- Skills in managing stress-related symptoms (relaxation and cognitive coping strategies)
- Skills in maintaining or improving physical function (exercise, rest, nutrition)

Evaluation of the program found that it was effective in teaching these skills, but also that the training group functioned partly as a support group over its seven sessions and led to ongoing support among some participants. However, the program needs to be trialled with ILWHA to determine whether the training and support benefits apply to this group as well (Gifford and Sengupta 1999).

A ILWHA continuum of care needs to include:

- Information on HIV/AIDS, course of the disease, symptoms, treatments (including complementary therapies), ongoing drug use and drug treatment, psychological and social aspects of being a ILWHA, and dealing with discrimination (especially by healthcare institutions and staff): the information needs to be written by or with ILWHA to ensure that the language is appropriate to the target group, and the final materials tested with ILWHA to ensure that the design is attractive to ILWHA
- Regular publications on specific aspects of HIV/AIDS, identified as important by ILWHA
- A training program for ILWHA both on self care and on peer HIV/AIDS counselling on both treatments and psychosocial aspects of the disease, and on ways to work with treatment providers (including both HIV and drug treatment) to stay as healthy as possible: this is needed due to the mistrust of healthcare workers and institutions, and the problems many ILWHA have in accessing appropriate health care

Care by family and friends

Another way of assisting ILWHA who have difficulties in accessing appropriate health care (and an important part of care for PLWHA in both developing and developed countries) is training of parents, family members, spouses and friends in helping to care for ILWHA in their homes. This home-based care can be assisted by visiting doctors, nurses, psychologists and so on (see below), but it is important for families and friends to understand how to care for ILWHA in the home during those times that other staff are not present.

Access to this type of care can, again, be problematic for ILWHA. Rejection by family and/or friends or homelessness through poverty can mean that there is no home in which the ILWHA can be cared for. In addition, fear of acquiring HIV through caring for a PLWHA has been found to be strong in some countries where there is little general knowledge about HIV disease. In Thailand, for example, Songwathana and Manderson (1998) found that relatives in rural areas in particular were reluctant to care for PLWHA. Because of better access to AIDS information and greater familiarity with PLWHA, urban people were less reluctant to care for PLWHA.

In addition, the role of women in many societies as caregivers can lead to many problems when women themselves are HIV positive. As Bharat and Aggleton (1999) point out from their study of Mumbai India households:

"Husbands and sons with HIV disease tend to be cared for by their mothers, wives and other female relatives. Occasionally, too, male relatives (most usually brothers) will help out. The position of women is very different. Not only do they receive little care and support, when ill, from other household members, but their own healthcare needs also go unmet when caring for husbands and sons...Home-based care is often advocated as a means of meeting the support needs of people with HIV and AIDS. However, such advocacy is not infrequently based on the premise that household resources are equitably distributed, when in reality they are not. Future programs and projects also need to ensure a gender-just approach to address women's needs as caregivers and as infected survivors." (Bharat and Aggleton 1999)

Bharat and Aggleton (1999) also reported that PLWHA required support and advice on how to talk about their HIV status with other members of their households as this may lead to major psychological benefits: "Wherever possible, and without coercion, people should be counselled so that they feel motivated to consider talking about their HIV status to household and family members. 'Coming out' about HIV status can, however, be a slow process and some individuals may need more help in doing so than others."

Manuals on caring for PLWHA at home have been developed for both the developed and developing country contexts (for example, van Reyk 1994 in Australia, and Papua/New Guinea Department of Health 1999). These manuals provide information on:

- Being a carer
- Basic information on HIV/AIDS and related illnesses
- Practical ways to care for the PLWHA at home (including dealing with common problems like dehydration, diarrhoea, lifting the person, dealing with bed sores, everyday hygiene)
- Keeping healthy (including nutrition, relaxation, massage and basic infection control)
- When to get help (including visits by home care health staff, or going to hospital or hospice)
- Legal and financial issues

No such manuals appear to have been produced specifically for caring for ILWHA. In addition, a manual alone will probably not be sufficient due to the stigma attached to ILWHA even among family and friends. A Ukrainian NGO, Substance

Abuse and AIDS Prevention Fund, took an innovative approach to this latter issue by training family members in managing the stress of living with a ILWHA (Pidlisna and Lukyanova 1998). The training program, conducted in Kiev over several months, began by investigating the family life of ILWHA. This resulted in the following list of problems:

- Exclusion of ILWHA from their families
- Lack of knowledge about HIV and AIDS in the family, and fears connected with HIV transmission
- Inability to cope with conflicts
- Inability to distinguish stress and stress-forming situations
- Inability to prevent negative consequences of stress
- Exclusion of families of ILWHA from a normal social life
- Stigmatisation of ILWHA in their own families and stigmatisation of these families in society

The training program then provided information on various aspects of HIV/AIDS, both medical and psychosocial, and on identifying and dealing with stress in the family. The authors reported that, of the 70 families that participated, members of 59 families confirmed after only the first four training sessions, the psychological climate in the family had undergone positive changes. Alienation, anger and despair had almost completely disappeared. ILWHA reported that their families rendered great help and support to them, and conflicts were solved easily; 54 patients believed that they had learned how to cope with stress and that they were not afraid of situations which provoke stresses. In all, 112 members of 62 families confirmed positive changes in their attitude towards HIV/AIDS and to the problems of living with ILWHA.

Another resource of use in home care for ILWHA is the Family Drug Support "Guide to Coping" with drug use by a family member (Family Drug Support/NUAA 1999). This booklet from Sydney Australia assists parents and other family members to live with someone who continues to use drugs or who goes through drug treatment. It provides practical advice on discussing drug use with family members, motivational interviewing, on whether to call the police or reject the family member, why drug use and dependence occur, reducing the harm from drug use, assisting if the family member overdoses, and assisting with detoxification and drug treatment.

A ILWHA continuum of care needs to include:

- Production and distribution to families and friends of ILWHA of a manual on home-based care of ILWHA, together with
- A training program for families and friends on HIV/AIDS, caring for ILWHA at home and dealing with family and social stresses related to HIV/AIDS, and dealing with ongoing drug use or drug treatment
- Sensitivity to the specific needs of women ILWHA both as recipients and providers of care

Models of service delivery – medical

As noted above, the most significant factor in providing effective medical services to ILWHA is ensuring their access to services. One way to do this is to provide HIV treatment options that do not require total abstinence from all drugs. For outpatients, this can include providing HIV treatments from within a methadone

program and linking mobile or stationary medical services to needle and syringe programs. For those ILWHA who are attempting to abstain from drug use, HIV treatment can be provided within drug treatment settings, either by visiting healthcare staff (from a specialist HIV unit) or by combining HIV treatment and drug treatment programs (though it needs to be recognised that a range of access points for HIV treatment are needed, including some which are outside drug treatment settings). Methadone or other substitution therapies must also be made available in a "low-threshold" manner so that they are attractive to ILWHA and are not provided in a punitive framework where clients are rejected due to ongoing drug use.

The Canadian HIV/AIDS Legal Network (1999) recommended that:

- As a matter of principle, treatment should not be refused or withheld simply because someone is a drug user
- the governing approach in providing care and treatment to HIV-positive drug users should be to adapt the therapeutic regimen to the needs of the individual, rather than require the individual to adapt to a preconceived clinical ideal
- a network of physicians with experience in providing care and treatment to drug users be developed
- simpler HIV drug regimens be developed to make adherence easier
- support be provided to drug users who require assistance in adhering to their regimen of HIV therapies, including out reach programs to deliver HIV therapies to drug users.

In the US, Bakti and Selwyn (2000) recently edited a new Treatment Improvement Protocol on Substance Abuse Treatment for Persons With HIV/AIDS, in which the following techniques are described to achieve optimal compliance with HAART:

- Simplify drug regimens--twice a day should be the goal
- Repeat instructions
- Use written protocols where doses coincide with habits or normal schedule
- Use a timing device to ensure that medications are taken at the proper time
- Use lists that clients can post in highly visible places
- Give positive feedback: provide evidence of effectiveness, such as declining viral load
- Have support persons (e.g., case managers, family members) reinforce the importance of keeping appointments and adhering to medication regimens
- Use visual tools, such as pictures of clocks and pills, to help visual learners and those who are illiterate or non-English speaking
- Encourage attendance at an outpatient HIV/AIDS support group. Hearing from others who have successfully weathered the uncomfortable side effects and can give support when discouragement or relapse occurs can be highly reinforcing.

A report from the Europe section of World Health Organisation recommended that drugs and HIV/AIDS services be linked:

This would entail existing infectious disease unit staff likely to be treating HIV and AIDS cases training in drug management and social care issues and health education aimed at reducing further spread of HIV from those already infected. They should also endeavour to establish a close working relationship with local drug services and social services if they exist. Similarly, staff in specialist drug services require training

in the prevention of HIV, counselling and testing for HIV, management of HIV infected clients and recognition of medical complications of HIV and AIDS as well as adapting services to cope with the drug management of those not ready to contemplate abstinence. They too should establish a close working relationship with local infectious disease services and social services wherever possible. Medical and nursing staff in the above medical services would require considerable training and support to be encouraged to attract drug users into clinical services and work humanely with them offering health education, general health care, drug and HIV management if no specialist services exist in their area or in early stages of problematic drug use if specialist services do exist (Buhringer et al 1998).

An example of such a linked service is KRC in Sydney Australia, which was established in the late 1980s to provide primary health care for homeless young IDUs. Over its first decade, the centre added needle exchange, methadone provision and a full range of HIV diagnostic and medical care services, all located in a place that is easily accessible by ILWHA. Psychosocial care is also provided at the centre by psychologists and social workers. All staff receive specific training in working with ILWHA as well as other IDUs, and staff are expected to act in a friendly manner towards all clients to maintain the attractiveness of the centre to the target group.

Rizzi et al (1993) described a cooperative project developed in the Bergamo province of Italy in 1988, where around 80% of the province's 5000 PLWHA were IDUs. The project involved nine drug treatment services (DTSs) and a hospital-base infectious diseases unit (HIDU). The DTSs, serving drug users and their sexual partners and children, provided a wide range of drug treatment services, testing for HIV antibodies, a quarterly thorough medical evaluation for PLWHA, including laboratory assessment of immunological status; monitoring of antiretroviral therapies; prophylaxis, diagnosis and treatment for HIV-related diseases that do not require hospitalization; and, in selected cases, home care for terminally-ill persons. Medical data are collected in a single central file at the HIDU, allowing supervision of the activities of the DTSs, and maintenance of a quality assurance programme. The authors found that the provision of testing and primary care for HIV infection at community-based drug treatment services, seems to ameliorate case finding and holding, while possibly improving the quality of life of patients, and avoiding the creation of huge, hospital-based, "user-unfriendly" AIDS-services.

Marte and Gatell (1999) see the single point of entry to HIV and drugs services as crucial to the success of caring for ILWHA. This can be done by co-location of a range of services as has been done by the New York State Department of Health's AIDS Institute. The AIDS Institute provides most dental, nutritional, mental health, medical and case management services from a single building, and this has successfully attracted many homeless and poor ILWHA who had previously not accessed these services (Marte and Gatell 1999).

For inpatient services, some serious difficulties arise. As the Canadian HIV/AIDS Legal Network (1999) pointed out, there are serious ethical issues involved in allowing ongoing drug use within hospital or hospice. Is it ethically justifiable to allow or tolerate illegal drug use in residences and within palliative care services? How can a facility permit illegal drug use without losing its licence or social authorization to operate? What concerns do staff have about condoning or even collaborating in offences against the law? To what extent can staff allow a resident

to continue to deteriorate under drug use and what rules should be established and enforced regarding tolerable and intolerable behaviour?

These are questions being faced now by staff in hospitals and hospices in many countries. In some, drug use is not tolerated, leading to reduced access to these services by ILWHA and early discharge (sometimes before completion of treatment). In others, substitution therapy is used to prevent withdrawal and to assist ILWHA to remain more comfortable during their stay. In many countries, staff "turn a blind eye" to ongoing drug use.

The Canadian HIV/AIDS Legal Network (1999) recommended that, in the short term, guidelines for ethical practice be developed by professional associations that address the situations of service providers who may be caught between legal constraints and ethical imperatives in providing services to ILWHA. The report also offered long-term recommendations, including decriminalizing possession of currently illegal drugs for personal use.

Bakti and Selwyn (2000) recently provided the following advice on pain management for ILWHA:
"As with all clients in pain, the provider's primary goal is to maximize comfort while minimizing side effects. Local measures (rest, heat, ice, analgesic rubs) should be used as a first line of pain treatment where appropriate. If these measures fail to adequately relieve the pain, a systematic pharmacologic approach is recommended. Initially, over-the-counter medications such as aspirin, acetaminophen (Tylenol), and nonsteroidal anti-inflammatory agents should be used, with dosages increased as needed. Caution must be used in employing acetaminophen in clients with liver diseases such as hepatitis C, as it can worsen liver disease.

"If these medications prove inadequate for pain relief, narcotic analgesia may be necessary. Because of their tolerance for narcotics, clients with opiate use disorders generally require higher doses of narcotic analgesia and more frequent dosing intervals for effective pain control. This is especially true for clients maintained on methadone.

Agents used for persistent neuropathic pain include anticonvulsants (phenytoin, carbamazepine [Tegretal], gabapentin [Neurontin]), tricyclic antidepressants (amitriptyline [Elavil], desipramine [Norpramin]), or topical agents (capsaicin [Capzasin]). These agents may be used alone or in combination with other analgesics. Acupuncture may be particularly helpful in some cases of neuropathic pain.

The treatment plan and the reason for using narcotics for pain control must be clear to both provider and patient. It is important not only that the patient know that her pain is taken seriously but also that narcotic use will not be extended beyond a time-limited period required for analgesia. Late-stage clients with AIDS who have chronic, severe pain syndromes may require long-term analgesia. Attempting to manage pain in methadone-maintained clients by increasing their daily dose of methadone is a common error. Instead, if narcotic analgesics are indicated, providers should continue the client's usual methadone dose and add a shorter acting narcotic for acute pain control. Pentazocine (Talwin) and other mixed opiate agonist-antagonists should not be used for analgesia in methadone-maintained clients because they may precipitate withdrawal.

An example of an innovative inpatient service designed specifically for ILWHA is the Griffin Project of Turning Point in London. Griffin Project is a residential service offering accommodation and specialist care for up to 14 men and women (including couples) usually for 2-3 weeks at a time: some clients return several times. The service aims to:

- Provide health care at all stages of HIV illness (though very few admissions are for people who are newly diagnosed)
- Help clients manage their drug use, including stabilisation and maintenance, and detoxification if desired
- Provide clients with information on HIV and drug use, helping them towards a healthier and safer lifestyle
- Enable clients to access community support to ensure continuity of care after discharge from the program
- Promote client participation in all aspects of care, and encourage their feedback to continually improve the service

A mix of nursing, medical and social care is provided through a multidisciplinary team, including:

- HIV related and general health care 24 hours a day (sub acute, convalescence, respite and palliative care); as well as end-stage care, ensuring adequate pain control)
- Management of drug use: using a pre-admission contract in which the client sets goals for managing their drug use (based on harm reduction, this may include stabilisation of licit or illicit drug use, maintenance on methadone, reduction through methadone or other substitute drugs, detoxification)
- Advice and support with social, legal, housing, financial and welfare issues
- Nutritional support
- Complementary therapies
- Discharge co-ordination (to ensure continuing care in the community).

Drug use is not allowed within the project but, after the first three days (when the patient is asked to stay inside the project so their physical and psychosocial needs can be assessed), patients are free to leave and return when they wish. If ongoing drug use is not within the contract that a patient signed, staff may offer counselling, re-negotiate the contract or, in extreme cases, expel the patient.

Medical programs should also take account of psychosocial issues. One way to do this is the use of psychologists and social workers inside AIDS wards in hospitals and hospices. The Bamrasnaradura Hospital in Bangkok Thailand sees 21,000 outpatients and over 2500 inpatients per year with HIV, many of whom are IDUs or sexual partners of IDUs. The hospital has a collaborative project with the Albion Street AIDS Centre in Sydney Australia, in which training is provided in:

- Outpatient care for people with AIDS
- Inpatient care
- Support for families and carers

As stress and burnout among people working with ILWHA may be greater than for people working with other PLWHA and with HIV-negative IDUs, these should also be the focus of training and organisational support.

One model that crosses the boundary between medical and non-medical services is the use of community care or enhanced home care teams. These are used in

Australia, Italy and the UK at least. A typical team in Sydney (Australia) consists of a social worker, nutritionist, physiotherapist, mental health nurse and community nurse, all specifically trained to work with people with HIV/AIDS. Members of the team regularly visit PLWHA at home, assisting with various social, psychological and physical problems which may not require attendance at a medical clinic or hospital. To adapt this model for ILWHA would require additional skills in assisting ILWHA in dealing with and/or controlling their drug use, detoxification and relapse prevention at home, dealing with additional depression related to drug use, and providing pain management among opioid users with a high tolerance for painkillers.

In Rome Italy, a citywide enhanced home care program was established in 1994, when 63% of all AIDS patients in the city were ILWHA. The home care team was one co-ordinating doctor, six staff doctors, 33 nurses, four psychologists, five social workers and 25 home-help workers. The team provides:

- Medical care (including devising a treatment plan, treating symptoms which do not require hospitalisation, performing simple tests and providing intravenous medications)
- Nursing care (administering medications, checking compliance with treatment, dressing wounds)
- Psychological care (working in particular on depression and on family relationships)
- Social care (financial and legal assistance)
- Home support (house cleaning, washing clothes, sheets and towels, buying food, preparing meals, assisting with transport to hospital etc).

Milanese et al (1997) studied the program from 1990 to 1994, when 372 patients received assistance from the home care teams. They found that ILWHA required four times more medical care visits and three times more social care visits than other PLWHA. As these differences are not noted in other research on hospital and clinic visits by ILWHA and other PLWHA, it may be that enhanced home care like the Rome program is an effective way of attracting ILWHA into medical and social care. The authors noted that about 50% of all medical/nursing visits were for tasks that would otherwise require PLWHA to attend a day hospital (which would have been far more expensive for the health system and very inconvenient for PLWHA).

Another interesting finding was that ILWHA required nine times fewer visits from psychologists, which does not seem to fit with the above-mentioned findings that ILWHA need greater psychological assistance than other PLWHA. As Milanese et al do not mention any specific training of psychologists in drug-related issues, it may be that ILWHA found the team's psychologists to not be useful for issues related to their lifestyle. Sanchez et al reported on a similar home care service in Valencia, Spain.

The home care service in Rome is an example of what McAmmond and Skirrow (1997) labelled flexible delivery sites: "Regular clinical delivery sites often do not fit with the needs and circumstances of IDU clients…Service delivery is needed in a variety of sites where HIV/IDU clients are likely to be, eg, needle exchanges, street health and social service agencies".

Palliative care facilities or hospices also involve both medical and non-medical

activities. Gilks et al (1998) state that palliative care should be an active, holistic approach to care and support for people who have terminal conditions and are nearing death. It should seek to address the physical, emotional, sial and spiritual needs of both the terminally ill person and their family through the interdisciplinary management of distressing symptoms. It should include:

- Enhancement of the quality of life
- Appropriate treatment of acute health problems
- Provision of emotional support to the person and their family
- Provision of adequate pain relief and control of symptoms
- Maintenance of comfort and dignity of the individual
- Training of family members to help manage particular problems
- Bereavement support to the family after death.

A ILWHA continuum of care needs to:

- Ensure, as a matter of principle, that HIV treatment is not refused or withheld simply because someone is a drug user
- Adapt the therapeutic regimen of HIV treatment to the needs of the individual, rather than require the individual to adapt to a preconceived clinical ideal
- Ensure that a network of physicians with experience in providing care and treatment to ILWHA is developed
- Investigate simpler HIV drug regimens to make adherence easier
- Provide support to ILWHA who require assistance in adhering to their regimen of HIV therapies, including outreach programs to deliver HIV therapies to ILWHA
- Ensure that HIV treatment services are provided in ways that maximise the ability of ILWHA to access them (including linking HIV treatments with substitution therapy programs, other drug treatment programs, outreach and enhanced home care)
- For all of the above services, training is needed to ensure that drug treatment staff have an adequate understanding of issues affecting ILWHA and HIV treatment staff understand ILWHA' drug use and drug treatment concerns. Specific concerns that need to be covered in this training include:
  - HIV disease: symptoms, treatments, psychosocial issues
  - Drug use and drug treatment, including both physical and psychosocial issues, as well as relapse prevention and ways to deal with relapse
  - Issues surrounding pain relief for ILWHA
  - Ethics of providing or withholding treatment to ILWHA
  - Working with groups with special needs (for example, sex workers, prisoners, ethnic minorities)
  - Family counselling
  - Death and dying
  - Legal and confidentiality issues
  - Stress and burnout
- Address the issue of pain relief for ILWHA both within and outside healthcare settings
- Include substitution therapy in inpatient care as a basic method of preventing withdrawal and its associated symptoms, and provide adequate pain relief for ILWHA
- Include ways to address psychosocial issues of ILWHA within medical settings

- Address ILWHA' palliative care needs.

Models of service delivery – non-medical

Drug treatment programs (apart from substitution therapy) are normally carried out as non-medical programs (though there may be prescription of drugs during detoxification and there may be medical staff who visit the program). As Levine (1998) pointed out, the role of a drug and alcohol counsellor in assisting in the medical and psychosocial care of ILWHA is complex but critical: "The reality is that (ILWHA) who are in counselling, be it individual or group, have greater contact with their substance abuse clinician than they do with their physician."

Australian ILWHA questioned the role of drug and alcohol treatment services and the attitudes of staff at these services towards HIV positive people (Burrows 1995). In a NUAA (1994) survey of ILWHA about their needs for detoxification and their treatment by detoxification services, it was clear that positive users felt discriminated against within these services with gay IDUs experiencing dual discrimination based on their sexual orientation and HIV status. The NUAA report recommensded that all drug treatment services be based on the principles of harm reduction and consumer participation, and that service staff receive greater training in HIV related issues to make them more effective health care providers. In addition, drug treatment workers need to become better educators to assist in the prevention of bacterial and other infections and re-infection with different strains of HIV and/or hepatitis C. This means that consideration should be given to the employment of peer educators at drugs treatment services: these peer educators should be current injecting drug users or ex-users who are able to provide realistic harm reduction education in a non-judgmental manner.

Residential drug treatment programs need to increase their flexibility and lower their thresholds for admission of ILWHA (Buhringer et al 1998). To meet the needs of the increasing number of infected patients some further organisational aspects have to be considered:

- Duration of treatment: Treatment centres mostly offer a long-term inpatient program, usually of 6-8 months duration. Only a minority of uninfected drug users is motivated enough to voluntarily seek entry to these long-term and demanding programs. For ILWHA who are thinking about their limited life expectancy, short term treatment approaches have to be offered.
- Medical Care: Residential treatment centres are usually not set up to provide the medical monitoring, evaluation, and treatment required by physically ill residents. Related problems involve the question of when to move a sick resident from the treatment program to a hospital. It is also a question to what degree the needs of the other clients should be subordinated to the medical and psychological needs of an individual resident with HIV/AIDS.
- Discharge: Alternatives need to be offered to automatic discharge if ILWHA are found to have used drugs.

Buhringer et al 1998 also recommended that the following principles be used in drug treatment with ILWHA:

- Individual problem analysis: Drug users differ in factors for the onset of

problematic drug use and in the course of their behaviour over time. Major areas for analysis are: motivation for change, previous relapses, other problems in addition to drug use, future perspectives and helpful as well as disturbing factors in the social environment for therapeutic progress.

- Development of a therapeutic alliance between therapist and client: this includes an individual treatment plan, including individual goals and related activities. According to the individual's situation and his willingness for change, the first goals might be very short-term oriented and limited to the improvement of everyday life like offers for day-care, shelter, HIV-testing or exchange of syringes and providing of condoms.
- Basic support for drug users: Despite all therapeutic engagement, some clients might choose to continue their drug use behaviour for a long period of time. But even then some basic support is necessary in order to reduce the risk of long-term health and social problems. There is no untreatable client, and a continuous basic contact might help to motivate some changes even after long periods of time.
- Drug treatment of ILWHA faces difficulties resulting from the severity of the multiple problems presented. It is particularly difficult to motivate HIV-infected patients, who may suffer from anxiety, depression, or demoralisation, possibly combined with physical discomfort.
- Psychological problems are particularly important among ILWHA because they can lead to increased drug use. Drug users may not have adaptive mechanisms that are effective enough to control stress: mood disorders and anxiety disorders are among the most common psychiatric disorders seen in drug users. Psychological support should include strategies for cognitive and behavioural changes and coping strategies for fears surrounding HIV and AIDS. Furthermore, interventions to help with grief and loss can be very important for the patients themselves, who usually are particularly vulnerable when their friends or a family member die. Also it may be necessary to assist patient's family in coping with the impact of HIV.
- ILWHA have far greater needs for social services than healthy addicts do. Social support should involve different levels of intervention as basic as housing, meals, welfare funds, and transportation. They also need to be assisted with regard to family, labour and legal problems. With regard to the family level, children are an important problem - issues of childbearing, child support and custody and the growing phenomenon of "AIDS orphans" are major questions that often require an intense and coordinated effort. In order to prevent dependence on health and social services, patients must be encouraged to continue their work or education and to maintain contact with their families and friends.
- Appeals both to altruism and to self-interest are two counselling strategies may help to motivate HIV-infected patients. Counsellors can attempt to evoke a sense of altruism through educational counselling about using and how sharing needles can spread HIV from the patient to others whom the addict cares about, such as friends and family. The second approach - appeal to self-interest or preservation of health - can also be presented in didactic counselling. This approach addresses the likelihood of increased morbidity associated with continued needle use, because continued parental exposure to foreign antigens may be an activating cofactor for HIV and there is some evidence that decreased needle use may be associated with decreased morbidity in infected injection drug users.

Some programs which have the above attributes are now operating in Western European countries and Australia, but they are rare in the developing and transitional world. One example from India is the SHARAN/Sahara group of programs in New Delhi which attempts to address the needs of HIV positive and negative IDUs from poor areas of the city. For drug users on the streets, homeless or housed, employed or unemployed, HIV positive or negative, there are:

- Outreach services, largely describing the benefits of the Drop-In Centre and drug treatment services, and providing sterile injecting equipment and condoms
- Peer educators talking especially to drug injectors about less risky ways to inject and safe sex

Drug users are invited to the SHARAN Drop-In Centre (situated close to a large drug-using population), where they can access:

- Peer education (as above)
- Psychological counselling
- First aid and basic medical care (most commonly care of abscesses)
- Referral to drug treatment, housing and other services
- Pre and post-test HIV counselling
- Needle exchange for those who continue to inject
- Sublingual buprenorphine (substitution therapy) program for those wanting to stop injecting and gain greater control over their drug use

There are also meetings of drug users and ex-users in a group, Beyond Appearances, which tries to give drug users a voice to talk with other users through a newsletter, and addresses discrimination issues among users; recently, Beyond Appearances has started a support group specifically for ILWHA. There is also a family support group in which family members are educated about addiction, processes of treatment, relapse, methods of assisting drug users, and so on, and where family members provide support to each other. If Drop-In Centre clients want a HIV test or any other referred service, they are usually accompanied by a SHARAN/Sahara staff member.

From any of the above Drop-In or outreach programs, drug users may be found to be HIV positive. If they are staff or volunteers of SHARAN/Sahara or they are at great health risk, HIV positive men can sleep at a shelter (which includes both drug users and ex-users) called the SHARAN Crisis Care Shelter. This shelter provides assistance to PLWHA in crisis: with no social support, their health deteriorating, drug use perhaps growing more chaotic, no access to hospital care due to their HIV status and/or their drug use history. It was intended to provide 15 days of shelter to stabilise health, assess their needs and then if necessary refer on to appropriate services, but many residents have been too ill to move, so they have stayed for several months. As well as medical care, the shelter staff provide, support through counselling, personal interaction, information and education sessions. In most cases, the residents return to their previous environments - on the streets, under bridges, etc. They may move on to Sahara House, or even to Michael's Care Home (see below). When possible, the men are linked into some form of support service and follow up is provided.

From any of the above Drop-In or outreach programs, drug users may request drug treatment. Their first step is detoxification, which is carried out either in the

SHARAN detoxification centre or a detoxification camp (set up close to where a group of drug users is living), or some other detoxification centre. After detoxification, the user is encouraged to attend Narcotics Anonymous meetings. Users may leave the drug scene in Delhi at this point (usually temporarily) or they may:

- return to drug use (detoxification, relapse and treatment are often repeated many times before a drug user stops using altogether), and therefore to the Drop-In Centre's services
- enter drug treatment

If the user enters drug treatment apart from Sahara House, SHARAN staff will try to keep track of them and visit them to ensure that they are not mistreated in the treatment centre and to encourage the person to stay abstinent from drugs. If they enter Sahara House, they usually stay for 3-12 months in treatment. While there, they receive vocational training, often for work within the expanding SHARAN/Sahara organisation. If they are ill (especially with HIV related disease), they are moved from Sahara to Michael's Care Home (or if very ill to a hospital or hospice), from which they can return to Sahara whenever they are well enough. There is no segregation of HIV positive and negative clients but there is now a separate program and accommodation for women and children (with Sahara only accepting men). If the person is in hospital or hospice, they are visited by SHARAN/Sahara staff.

After completing treatment, users are encouraged to stay at a Sahara halfway house for six months to assist them with their return to outside society. If a person uses drugs while at Sahara or in the halfway house or when employed by Sahara/SHARAN, they are counselled and if they keep using they are required to leave, when they return to either:

- the Drop-In Centre programs OR
- the Detoxification Centre.

All of the agencies participate in research projects examining features of drug use and HIV infection among IDUs, evaluating services and reporting on care and support needs of users and their families (Personal communications Dorabjee J, Sampson L, Thapa D, Aulich D 1999).

Another example of a non-medical shelter for ILWHA is the recently established Pelangi Community Project in Kuala Lumpur Malaysia. Staff working at IKHLAS (a NGO providing medical and psychosocial care for street IDUs in a drop-in centre in Kuala Lumpur) realised that there were almost no support services for drug users and prisoners with HIV. The PLWHA support groups were not able to deal with care for drug users as they felt their problems were related more to drugs than HIV. Many drug users came out of hospitals to the streets with HIV medications but had nowhere to store them. Consequently their health deteriorated and they went back to hospital and the circle continued. Pelangi Community Project had nine drug users in the home at the end of 1999, two of them recovering from surgery, one bedridden, while the other residents are providing the support, cooking, cleaning and learning to provide medical care. Some residents are also involved in attempting to set up a small scale income generating project (Personal communication Narayanan P 1999).

A common method of providing psychosocial care for PLWHA is the establishment of

support groups where PLWHA feel comfortable in talking about their lives and problems. These in turn may lead to the development of PLWHA groups which now exist in most countries with large numbers of PLWHA to provide support to wider circles of PLWHA, sometimes to provide specific services such as producing publications and videos by PLWHA for PLWHA, food distribution or providing common meals, vitamin buyers clubs, and so on. They also often advocate for better treatment of PLWHA. However, there has been little research into the experience of ILWHA with support groups and few examples of specific ILWHA groups being established.

Burrows (1995) found that Australian ILWHA reported several problems with support groups which have generally been established by and for other groups such as HIV positive gay men or positive women: "Drug users talked of the need for new models of support which were suited to drug users' lifestyles, were accepting of IDUs' choice to use drugs, and which were able to accommodate those HIV positive drug users who were afraid of disclosing either their HIV status or their drug use. One popular model was the HIV Awareness and Support group in Sydney run by the NSW Users and AIDS Association (NUAA). This group met regularly on Wednesdays over a meal provided by NUAA, and was advertised as a support group for positive users, their friends and carers. There were no exclusions from the group at the beginning so that people could attend without disclosing their HIV or drug using status. As the group progressed towards taking greater control of group meetings and activities, it became a specific, focussed support group for people who were open about their drug use and HIV status." The Australian experience suggests that support groups need to be specifically created to suit the needs of ILWHA. ILWHA groups may be successful if started through IDU groups or, in areas where most PLWHA are IDUs, as the main PLWHA groups.

In Ukraine, Burrows et al (1999) reported that support groups for ILWHA were not always successful. "A man and his girlfriend in Mykolayev, both HIV positive ex-IDUs, considered joining a support group. The man joined but his girlfriend did not participate in the group as she wanted to keep her HIV status confidential. He said: 'It didn't work. Some people were still using drugs'. We asked what would make it work better? 'The people who run the group should be very professional, understand the aim of the group, the meaning of the group…It should help with psychological counselling. There was one girl in the group very preoccupied with her diagnosis. She was only recently diagnosed. She was very nervous, always in a vacuum, totally self-oriented. She went into the disease, only read newspaper articles about HIV. She died very quickly, I think because of this lack of psychological counselling.' "

An example of an ILWHA group is Shapagat at Temirtau in Kazakhstan, started in 1999. Together with other NGOs, Shapagat has been attempting to create a benevolent and non-judgmental attitude towards PLWHA in Kazakh society. The organisation's work has been supported by the mass media, and at the AIDS Center in Temirtau, with the active participation of the members of Shapagat, the first state counselling center in Kazakhstan has been established to provide pre- and post-test counselling. The organisation has also helped to start a centre for psychosocial help for PLWHA and a self-help and support group for ILWHA and their relatives.

Another method of providing support to PLWHA is one-to-one emotional support,

sometimes called “buddy schemes”. These are in place in many parts of the world, but have mainly been established for gay men and for women. To the author’s knowledge, no buddy systems have been set up specifically for ILWHA, though informal support processes often occur through IDU groups.

A ILWHA continuum of care needs to:

- Ensure that drug treatment services are appropriate to the issues facing ILWHA, and linked to medical care, IDU-oriented programs (such as needle and syringe exchange, outreach and peer education), and other psychosocial care services (such as shelter and food programs)
- Investigate new models of support suited to ILWHA' lifestyles, which are accepting of IDUs' choice to use drugs, and able to accommodate those ILWHA who are afraid of disclosing either their HIV status or their drug use.

6. Conclusions and recommendations for addressing treatment, care and support of ILWHA in Ukraine

Lert and Marne (1992) concluded a French study of the problems related to IDUs accessing HIV related services:

"In order to maintain a good standard of care (for HIV positive IDUs) and avoid stigmatisation, a reassessment of the social, psychological and therapeutic needs of seropositive drug users is called for with a view to possible changes in staff skills, manpower and therapeutic strategies."

In Ukraine, a continuum of care needs to be established for ILWHA. This continuum of care should involve currently existing health and social institutions as well as a group of new services (possibly offered by NGOs) in a comprehensive range of care services, all linked by discharge planning and referral processes.

Currently existing institutions which should be involved in this continuum of care include:

- AIDS Centres (where they exist)
- Infectious diseases hospitals especially AIDS wards (where they exist)
- General hospitals, polyclinics and ambulatory clinics
- Narcological hospitals and dispensaries
- Needle and syringe exchange, outreach and peer education programs (where they exist)
- HIV/AIDS focused NGOs, especially PLWHA groups (where they exist)
- Sexually transmitted infection clinics
- Social services (such as social services for youth)
- Ambulance services

New services that need to be started include:

- Needle and syringe exchange, outreach, peer education programs and HIV/AIDS focused NGOs, especially PLWHA groups (where they do not exist)
- Multidisciplinary teams to provide enhanced home care

The first step, after ensuring that the appropriate agencies exist in a city or region, is to co-ordinate services for ILWHA, based on the model provided by SHARAN/Sahara in Delhi, India. (This set of services looks at the IDU's needs from the drug user's viewpoint, then creates or adapts services yo meet those needs.) This is most appropriately done at the health administration of the city or region. Co-ordination should ensure that:

- As a matter of principle, that HIV treatment is not refused or withheld simply because someone is a drug user
- The therapeutic regimen of HIV treatment is adapted to the needs of the individual, rather than require the individual to adapt to a preconceived clinical ideal
- A network of physicians with experience in providing care and treatment to ILWHA is developed
- Simpler HIV drug regimens are investigated to make adherence easier
- Medical and psychosocial needs of ILWHA are assessed
- Staff working with ILWHA are appropriately trained: so that drug treatment

staff have an adequate understanding of issues affecting ILWHA and HIV treatment staff understand ILWHA' drug use and drug treatment concerns. Specific concerns that need to be covered in this training include:

- ❖ HIV disease: symptoms, treatments, psychosocial issues
- ❖ Drug use and drug treatment, including both physical and psychosocial issues, as well as relapse prevention and ways to deal with relapse
- ❖ Issues surrounding pain relief for ILWHA
- ❖ Ethics of providing or withholding treatment to ILWHA
- ❖ Working with groups with special needs (for example, sex workers, prisoners, ethnic minorities)
- ❖ Family counselling
- ❖ Death and dying
- ❖ Legal and confidentiality issues
- ❖ Stress and burnout

- ⇤ Appropriate protocols for HIV/AIDS treatment of ILWHA are in place
- ⇤ Discharge planning and referral processes are widely understood and used
- ⇤ Medical care and HIV/AIDS treatments are available to ILWHA (to the level allowed by the city or regional administration)
- ⇤ HIV treatment services are provided in ways that maximise the ability of ILWHA to access them (including linking HIV treatments with substitution therapy programs, other drug treatment programs, outreach and enhanced home care)
- ⇤ All programs in the continuum address the specific needs of women ILWHA both as recipients and providers of care
- ⇤ All medical programs address the issue of pain relief for ILWHA both within and outside healthcare settings
- ⇤ Substitution therapy is included in inpatient care as a basic method of preventing withdrawal and its associated symptoms, and provide adequate pain relief for ILWHA
- ⇤ Psychosocial issues of ILWHA are addressed within and beyond medical settings
- ⇤ ILWHA' palliative care needs are addressed.

In addition, NGOs focused on injecting drug use and HIV/AIDS (such as needle exchanges and outreach programs) and/or NGOs focused only on HIV/AIDS (such as counselling programs and PLWHA groups) need to start a new set of services (or adapt existing services) to ensure that:

- ⇤ Information is provided to ILWHA on HIV/AIDS, course of the disease, symptoms, treatments (including complementary therapies), ongoing drug use and drug treatment, psychological and social aspects of being a ILWHA, and dealing with discrimination (especially by healthcare institutions and staff): the information needs to be written by or with ILWHA to ensure that the language is appropriate to the target group, and the final materials tested with ILWHA to ensure that the design is attractive to ILWHA
- ⇤ Regular publications are produced on specific aspects of HIV/AIDS, identified as important by ILWHA
- ⇤ A training program is provided for ILWHA both on self care and on peer HIV/AIDS counselling on both treatments and psychosocial aspects of the disease, and on ways to work with treatment providers (including both HIV and drug treatment) to stay as healthy as possible
- ⇤ A manual on home-based care of ILWHA is produced and distributed to

families and friends of ILWHA, including information on:

- Being a carer
- HIV/AIDS and related illnesses
- Practical ways to care for the PLWHA at home (including dealing with common problems like dehydration, diarrhoea, lifting the person, dealing with bed sores, everyday hygiene)
- Keeping healthy (including nutrition, relaxation, massage and basic infection control)
- When to get help (including visits by home care health staff, or going to hospital or hospice)
- Legal and financial issues
- Dealing with drug use and treatment
- Dealing with family and community stresses related to drug use or HIV infection

- A training program is provided for families and friends of ILWHA on HIV/AIDS, caring for ILWHA at home and dealing with family and social stresses related to HIV/AIDS, and dealing with ongoing drug use or drug treatment
- New models of support are developed, which are suited to ILWHA' lifestyles, accepting of IDUs' choice to use drugs, and able to accommodate those ILWHA who are afraid of disclosing either their HIV status or their drug use.

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