

# Breaking Down Barriers

LESSONS ON PROVIDING  
HIV TREATMENT TO INJECTION  
DRUG USERS



OPEN SOCIETY INSTITUTE  
International Harm Reduction Development

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Lessons on Providing HIV Treatment  
to Injection Drug Users

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The International Harm Reduction Development program (IHRD) of the Open Society Institute (OSI) supports local, national, and regional initiatives in Central and Eastern Europe, the Russian Federation, and Central Asia that address drug problems through innovative measures based on the philosophy of harm reduction. Harm reduction is a pragmatic and humanistic approach to diminishing the individual and social harms associated with drug use—especially the risk of HIV infection. Harm reduction encompasses a wide range of drug user services including needle and syringe exchange, methadone treatment, health education, medical referrals, and support services.

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Finally, we dedicate this report to people living with HIV, treatment providers, peer educators, and advocates who challenge the stigmas related to drug use and HIV to promote access to treatment for all who need it.

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Case studies from around the world demonstrate that well-designed, supportive programs that address the particular needs of injection drug users can help all individuals adhere to antiretroviral therapy, take advantage of appropriate harm reduction services, and enjoy improved quality of life.

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## I. Introduction

Throughout its 25-year history the HIV pandemic has inflicted its worst damage on disenfranchised and marginalized populations—such as injection drug users (IDUs), sex workers, refugees, asylum seekers, prisoners, and men who have sex with men. That trend continues today throughout Eastern Europe, the former Soviet Union, and Central and Southeast Asia, areas where soaring injection drug use has become a driving force behind the spread of HIV. In several nations, including Russia, Burma, China, and Ukraine, IDUs represent the majority or a rapidly increasing minority of all those living with HIV.<sup>1</sup> In addition, the percentage of all IDUs in these countries who are HIV positive continues to surge.<sup>2</sup>

Elsewhere in the world, too, IDUs are faced with an unparalleled health and human rights crisis that shows no sign of abating. Recent estimates indicate that at least 10 percent of all new infections in the world—a figure that rises to 30 percent when Africa is excluded—can be attributed to injection drug use.<sup>3</sup>

Not all the news is dire, however. Greater global attention to the health and future of people living with HIV, including IDUs, has raised a glimmer of hope in the midst of these devastating trends. Over the past 10 years, global funding for treatment has increased significantly.<sup>4</sup> At the same time, international organizations and activists have been effectively advocating for multinational pharmaceutical companies to lower the cost

of AIDS drugs and for the repeal of patent laws that prevent developing countries from having access to quality, cheap antiretrovirals (ARVs) from generic manufacturers.

Furthermore, a number of case studies originating in parts of the world with widely different HIV epidemics and health care systems—including Argentina, Brazil, France, Spain, and the United States—now offer proven strategies for effectively addressing the health and wellness needs of all HIV-infected people, regardless of where and how they live. These case studies, some of which are presented in this volume, also demonstrate how successful treatment programs have been coordinated at the local, regional, and national levels. All of the studies provide strategies for HIV treatment that address the particular needs of IDUs. They offer evidence that well-designed, supportive programs can help all individuals adhere to antiretroviral (ARV) therapy, take advantage of appropriate harm reduction services, and enjoy improved quality of life.

These developments have understandably engendered excitement among advocates, policymakers, and those living with HIV. But they should also be treated with caution. “Increased funding” is not the same as “sufficient funding,” and government and other service providers will have to struggle with profoundly difficult resource allocation decisions, even as funding for new programs increases. Long ignored, dismissed, and harassed in many nations, IDUs potentially have the most to gain should universal HIV treatment become expected and commonplace. But it is not quite so simple. For example, regardless of whether the World Health Organization’s 3 by 5 initiative is successfully implemented as proposed, there is no mandate that a reasonable proportion of patients treated within the program be IDUs—even though this population’s need is among the greatest.

Such omissions can easily be exploited to exclude drug users from many treatment programs. Policymakers, advocates, and caregivers must resist judgmental and discriminatory attitudes and beliefs: treatment access must be offered to all people with HIV, including individuals whose behavior may be illegal or socially unacceptable to governments or the general population. Historical disregard for the rights of people particularly vulnerable to infection has, in effect, given HIV/AIDS the upper hand—and the belief that the virus would remain within marginalized populations has proved to be not only heartless but incorrect. From every perspective imaginable, all people should be afforded equal access to treatment with the full support of care providers.

Most of the world’s public health agencies and private care providers currently have little experience of treating HIV-positive drug users. But there is no longer a shortage of relevant data and information. The case studies in this report provide treatment models that can and should be adapted by policymakers as they begin the vital work of creating large-scale programs aimed at effective delivery of HIV treatment to all those who need it—with specific focus on IDUs and other marginalized communities. These programs differ from one another in so far as each has been designed with local economic, cultural,

and social factors in mind. But they are linked by the belief that no one living with HIV or AIDS should be denied treatment or offered substandard care, regardless of his or her behavior or current economic situation.

## II. Analysis of the Problem

In the past, IDUs represented only a small percentage of those who had contracted HIV; thus it was relatively easy to ignore their needs, whether reasons for doing so were based on pure discrimination, uncertainty over drug interactions, or outright neglect. Today, however, drug users represent a rapidly growing percentage of all people living with HIV, especially in the former Soviet Union and some Asian nations. Ignoring them now would be even more appalling and destructive in its effect than in the epidemic's earlier years.

That people who inject drugs lack access to HIV treatment is, to some extent, related to their inability to access health care in general.<sup>5</sup> Many drug users (and not only those who inject) fear harassment or arrest and do not trust health officials to safeguard their privacy or confidentiality. These are understandable concerns, given many countries' repressive or unenlightened policies, including the common practice of registering drug users' names at hospitals or the sharing of information between law enforcement and healthcare providers. All too frequently, doctors remain opposed to treating HIV-positive drug users—either because they mistakenly believe that treatment would be ineffective, or because of prevailing judgmental attitudes about drug use and drug users. For all of these reasons, drug users are considered a special category of patient that can be discriminated against with impunity. HIV-positive IDUs subsequently face double stigma that results in the general unwillingness of health professionals to meet their needs and demands.

Examples abound of situations in which individuals with a history of drug use are often explicitly excluded from treatment programs. In Russia, where drug users accounted for more than 90 percent of cumulative HIV cases registered by 2002, AIDS service programs in St. Petersburg and Moscow reported that none of those on ARV were active IDUs.<sup>6</sup> Injection drug use accounts for 75 percent of HIV infections in Kuala Lumpur, Malaysia, but former IDUs make up only 20 percent of those receiving treatment;<sup>7</sup> also, because of Malaysia's strict antidrug policies, no active drug users were receiving treatment. In Ukraine, where, in 2002 some 69 percent of registered HIV cases were among IDUs, they accounted for only 20 percent of those receiving triple-combination ARV. Administrators at AIDS centers in Ukraine were reportedly placing drug users after all others in line for medication.<sup>8</sup>

These policies and attitudes are not only reprehensible from a human rights standpoint, but they are also short-sighted in terms of successful HIV prevention efforts.

Prevention and treatment of HIV are mutually supporting rather than competing goals. People are much better motivated to be tested for HIV when there is some concrete indication of their society's commitment to treatment and support for people living with HIV/AIDS. There is strong evidence that ARV treatment reduces both vertical (mother-to-child) and horizontal transmission;<sup>9</sup> preserves human life, social infrastructure, and the economic productivity necessary for sustained prevention efforts; and helps reduce discrimination by removing some of the overt physical symptoms of AIDS. Evidence also exists—despite longstanding assertions to the contrary—that compliance with treatment regimens by drug users is achievable even in resource-poor countries.<sup>10</sup>

While the extent to which the injection-driven nature of the AIDS epidemic will shape national commitment to HIV treatment provision is uncertain, the danger is clear that treatment will be implemented in such a way that those with a history of drug use receive inferior care. For example, three countries with major injection drug-related epidemics—Burma, China, and Ukraine—have received grants from the Global Fund to Fight AIDS, Tuberculosis, and Malaria (GFATM) for support in treating and preventing HIV. The approved applications include few specifics, however, about how drug users will be included in expanded HIV treatment efforts. Without explicit measures to ensure access for IDUs, scaled-up treatment programs are likely to exclude drug users or offer them substandard care.

The inordinate share of HIV cases attributable to injection drug use in Asia and the former Soviet Union makes addressing questions specific to HIV treatment for IDUs particularly urgent in these regions. What kinds of changes to services, whether in clinic operation hours or consolidation of medications into fewer pills, work best to increase adherence to HIV treatment regimens among users in different countries? What frameworks other than “drug users are the last priority” can be developed to help guide equitable distribution of HIV medications when not all can be treated? What particular treatment interventions might work best in prisons, or for those on methadone? For those with hepatitis C? What reforms of policy and practice are needed at AIDS centers and hospitals to ensure that drug users are included among those who receive care? Without concerted attention to these questions and revised ethical guidelines, it is conceivable that international donors and national governments will expand an AIDS service infrastructure in which care is denied to the majority of those living with HIV.

One additional major barrier to providing healthcare and harm reduction services to IDUs stems neither from a lack of adequate funding nor from the absence of effective treatment models. Instead, it is the prevalence, internationally, of strict antidrug laws that punish the user rather than addressing his or her healthcare needs. In order to successfully address the needle-driven epidemic, drug laws across the world must change—in both donor and recipient nations, and in developed and developing countries. Policies that mandate or emphasize abstinence and that criminalize possession of small amounts

of illicit substances create environments in which drug users fear harassment, arrest, and incarceration; they are subsequently driven further underground, thus limiting their access to services and facilitating the spread of the virus. In the era of HIV and AIDS, the difference between treating drug use as an illness or a crime is the difference between life and death.

### III. Denial of ARV Therapy to Drug Users: Rationalizations Refuted

Several justifications have been put forth over the years for denying ARV treatment to drug users, in particular active IDUs. Some of the reasons are based on a stated objective of punishing lawbreakers, while others are considered “practical” by otherwise well-intentioned policymakers and healthcare authorities. Regardless, the outcome—lack of treatment and increasing numbers of AIDS diagnoses and death—remains the same.

Below is a list of justifications commonly cited by those opposed to offering ARV to drug users, followed by short analyses discussing and refuting each one:

**IDUs cannot and will not succeed in HIV treatment.** Case studies from around the world indicate that this assumption is false. Like any other HIV-positive sub-group, such as exhausted single mothers of young children, farmers in remote villages, and gay men in intolerant cultures, IDUs find it easier to access treatment if specific approaches are implemented to improve their adherence. These approaches include extending the hours that clinics are open, increasing the number of drug dispensary centers and placing them in easily accessible locations, and providing substitution therapy and needle exchange on-site with HIV treatment delivery. It is not illicit drug use but rather the accompanying issues—fear of authorities, lack of social and economic stability—that can make it difficult for a user to access and adhere to treatment. It has been documented that when the needs of active drug users are incorporated into treatment models, they can and will adhere to ARV treatment regimens.

According to findings from Baltimore, Maryland (see p. 32), an integrated care model for populations with complex social, health, or economic problems—such as active drug users living with HIV, the poor, and the homeless—can effectively dismantle traditional barriers faced by disenfranchised patients. Integrated care facilities promote vital collaborations involving medical care providers, psychiatrists, and substance abuse specialists. The Baltimore case study also suggests that when services are integrated at a single site, the results are improved medical *and* substance abuse outcomes.

There is ample evidence that drug users will overcome great geographical, social, and economic barriers to keep up with substitution therapy programs. These programs should be expanded to a scale that allows for enrollment by all opiate users who want

treatment. As evidenced by the successful use of substitution therapies in Barcelona, Hong Kong, and Paris, methadone and buprenorphine have the power to relieve the symptoms of withdrawal-related illness and retain drug users within the healthcare system so that they are able to adhere to ARV treatment at a rate comparable to any other patient.

The Paris case study in this report also describes how, by staying open late and by offering simple amenities such as washers and dryers and a warm place to relax, HIV treatment facilities were made more welcoming to IDUs. The Jumpstart case study from New York City (see p. 59) found that while homelessness and mental illness were strong predictors of non-adherence, active drug use was not. And in Brazil, it was determined that non-adherence was due less to drug use than to factors including lack of income and education, alcohol abuse, and negative perception of health services' quality (see p. 17).

**Hepatitis C co-infection hampers the effectiveness of ARV therapy.** Skilled and trained physicians can and do successfully treat people co-infected with HIV and hepatitis C; ramping up treatment options for those co-infected requires sharing information about treatment strategies, demanding affordable pricing for hepatitis C medications, and ascertaining political and popular support to do both. Recognition of the ability to treat the co-infected is crucial given that, for example, up to 90 percent of people who became HIV positive through drug injection also have hepatitis C.<sup>11</sup>

**Prevention should take priority over treatment.** The widespread notion that prevention should take precedence over treatment is not only deeply inhumane and offensive, but based on false assumptions as well. Drawing an artificial distinction between prevention and treatment is an unwise and counterproductive public health strategy. Without hope for treatment, many people avoid getting tested; what's the point of knowing bad news if there's nothing that can be done about it? This situation actually increases the likelihood of HIV transmission since people who are unaware of their serostatus are less likely to take measures to protect themselves and others from exposure to HIV. Moreover, prevention and treatment complement each other when harm reduction programs expand their activities to include the provision of care services (including hepatitis vaccination, laboratory tests, and ARV delivery).<sup>12</sup> Put simply, treatment supports and strengthens prevention.

Besides being inappropriate from a human rights standpoint, prioritizing prevention over treatment makes little sense from a financial perspective. First of all, as demonstrated by the Brazil case study the cost of treating all those who require ARV can be kept very low when generic ARVs are introduced, (see p. 17). In Thailand, government-produced triple-combination therapy is available at a cost of less than US\$400 per year (see p. 50). And in the long run, the costs associated with ARV provision are likely to be defrayed by lower rates of hospitalization (usually the single greatest source of healthcare costs) or opportunistic infections for those living with HIV.

## IV. Global Estimates of HIV Infection Among Drug Users

The implications of an injection-driven epidemic are sobering and must be highlighted and addressed. For one thing, HIV statistics are particularly unreliable when it comes to drug users.<sup>13</sup> In the absence of reliable information from many parts of the world it is hard to give an accurate estimate of the number of injection drug users worldwide. However, estimates from regions hit hardest by injection-related HIV paint a troubling picture. In Russia alone UNDP estimates there are as many as 1.5 million IDUs.<sup>14</sup> There are estimated to be 500,000 IDUs in Central Asia;<sup>15</sup> 250,000 in each of Burma and Thailand, and 3.5 million in China.<sup>16</sup>

Despite certain identifiable trends, the injection-driven epidemic remains heterogeneous both internationally and within specific regions. In most countries, a concentration of HIV infection among drug users exists in major cities or along drug trade routes, while other areas appear to have remained relatively unscathed. But this picture is misleading. Most drug users with HIV do not know their serostatus, and by the time large numbers of drug users begin to get sick and die, chances are national and local epidemics have already progressed to the levels currently seen in Russia and China.

In Russia and nearly all other former Soviet republics, socio-economic instability coupled with increased availability of illicit drugs has led to increased drug use and addiction—and repressive drug policies are further fueling the outbreak. In Southeast Asia, both the drug and sex trades are powerful economic and epidemiological forces. Large migrant populations, poor economic conditions, and governmental unwillingness to take preventative measures are setting this region up for future disaster.

As recently as 2001, it was reported that 90 percent of the people living with HIV/AIDS in Russia were IDUs, although this percentage has declined slightly since.<sup>17</sup> In China, too, injection drug use is assumed to be one of the most common modes of HIV transmission.<sup>18</sup> (It is also likely that data provided by the Chinese government are inaccurate, given that China has a history of underreporting the extent of its HIV epidemic.)

If current trends continue, dozens more nations—including those that have yet to record more than a handful of HIV cases, as well as others that have successfully reduced infections among non-drug users but have been less successful in reaching drug users—will soon join the list of nations facing serious injection-driven epidemics.

## V. Current strategies related to injection drug use and HIV/AIDS

Internationally, there is no comprehensive strategy for dealing with injection drug use and the HIV/AIDS epidemic. Global policy is largely piecemeal and influenced by rigid

interpretations of drug control treaties aimed at the eradication of both supply and demand and broad HIV/AIDS measures that often ignore drug users' unique needs by lumping them together with other at-risk groups. Moreover, United Nations conventions on HIV/AIDS are non-binding. This allows individual nations to implement their own policies regardless of whether they have pledged, by signing various conventions, to provide all people living with HIV standardized ARV treatment if they need it.

The drug control treaties continue to be used to justify repressive national drug laws that have contributed to a steady and parallel rise in both the number of incarcerated drug users and the total number of prisoners with HIV. Few facilities provide or allow access to ARV therapy for HIV-positive prisoners; fewer still provide services such as substitution therapy that could slow HIV transmission rates or help opiate-dependent HIV-positive prisoners adhere to treatment regimens. Coercive HIV testing policies, both in and out of prison, further marginalize drug users and make it even less likely that appropriate and consistent HIV treatment will be made available to them. In Russia and Malaysia, for example, drug users are tested for HIV upon arrival at prisons. Once inside, those with HIV are segregated—but no HIV treatment is provided. Malaysian rehabilitation centers also test and separate those with HIV.<sup>19</sup>

It is illegal to carry injection equipment in Malaysia (which has Asia's stiffest drug laws) without a prescription, and possession of even one needle may result in up to two years imprisonment. Possession of any amount of any illicit drug, including cannabis, results in whipping and no less than five years in prison. As little as 5 grams of heroin (10 days supply) can result in a life sentence, and possession of 15 grams or more is classified as trafficking and carries a mandatory sentence of death.<sup>20</sup>

China has made its drug laws increasingly stringent over the past two decades, with the government identifying severe punishment as one of the "outstanding characteristics" of its laws.<sup>21</sup> Drug users can be detained for up to 15 days by police and/or sent to forced detoxification centers for "re-education." Legal penalties include no less than seven years imprisonment for producing or possessing 10 grams of heroin (approximately a three-week supply), and the production or possession of more than 50 grams of heroin is punishable by death.<sup>22</sup>

In February 2003, the Thai government launched a renewed "war on drugs;" since then, more than 43,000 drug "traffickers" have been imprisoned in Thailand and as many as 230,000 have been interned in military-style "treatment centers." Nearly 2,600 people have been killed during the crackdown, in what human rights observers have concluded are extrajudicial murders with the tacit support of the government.<sup>23</sup> The country's only needle exchange program has been closed, and the government has refused to implement accessible substitution therapy programs.

In Vietnam, police have the authority to detain those found in possession of drugs and commit them to compulsory rehabilitation centers where they may be forced

to remain for up to five years. Drug users with HIV are discharged from rehabilitation programs when they become sick.<sup>24</sup> Possession of needles can be grounds for arrest, and sharing of injection equipment can be considered drug promotion and is punished by imprisonment.

Burma criminalizes addiction itself, and the authorities do not require possession of drugs or paraphernalia to convict drug users. Those who use illicit drugs are required to register with the authorities and turn themselves in for treatment. Drug users who fail to do so are liable to be incarcerated for three to five years.<sup>25</sup>

Harsh laws and punitive policies regarding drug use are not confined to Asia and the former Soviet Union, of course. In the United States and Canada, a conflation of drug addiction, homelessness, and urban poverty has created an interconnected public health crisis exacerbated by police abuses in enforcement of “quality of life” laws. Drug users suspected of minor infractions, bylaw offences, or misdemeanors are frequently subjected to illegal searches and seizures, harassment, and excessive force.<sup>26</sup>

The result of such human rights violations is a general mistrust of authorities by drug users. There is no evidence to suggest that IDUs are any less concerned with their health than other segments of the population, but given the prevalence of repressive drug laws and abuse of police power, it is not hard to understand why drug users in China, Kazakhstan, Thailand, the United States, and elsewhere may not pursue available treatment and harm reduction services for their HIV or other drug related illnesses. Draconian drug laws, discriminatory policies, and cultural stigmatization of drug users are incompatible with containing the global HIV/AIDS epidemic.

## VI. Conclusion and Recommendations

Global health policies have begun to emphasize international commitment to universal access to health care. WHO’s policy statement regarding organizing ARV care for people living with HIV states:

*Access to HIV treatment should not be artificially restricted due to political or social constraints. Specifically, there should be no categorical exclusion of injection drug users from any level of care. All patients who meet eligibility criteria, and want treatment should receive it, including injection drug users, sex-industry workers, and other vulnerable populations.<sup>27</sup>*

Similarly, the UNAIDS Interim Report charges donor countries to adopt policies based on universal access to health care: “At the international level, each of UNAIDS’

cosponsors should clearly delineate its role in both the 3 by 5 and long term treatment response. Donor countries should re-examine their own healthcare provision deficits.”

Coupled with significant increases in funding for HIV treatment, such statements by international organizations lend hope that the rights of all individuals living with HIV, including IDUs, may someday be upheld. Successful policies and programs already exist vis a vis treating all people with HIV: it is now a matter of political will to study them carefully and allocate the appropriate resources. The case studies presented in this book offer successful models for:

- ▶ successfully providing HIV treatment to drug users through integrated care models by which HIV treatment is offered in conjunction with substitution treatment and other health care;
- ▶ improving treatment access and adherence by building strong partnerships between HIV treatment providers and harm reduction programs;
- ▶ changing societal perceptions of the drug user as criminal and replacing “just say no” policies with more effective interventions, even in countries that lack resources, in order to reinvent the model for HIV treatment for drug users;
- ▶ creating effective care programs in spite of hostility toward drug users in some medical communities; and
- ▶ coordinating at the city, state, and nationwide levels to create programs to treat drug users who have HIV.

In addition, the case studies indicate that:

- ▶ integrated and coordinated approaches to substance use and HIV treatment in drug users do foster improved HIV treatment outcomes;
- ▶ less wealthy nations can offer treatment to all HIV patients when they are committed to principles of universal access to health care and can also establish inexpensive substitution treatment programs (Argentina and Brazil); and
- ▶ linking HIV care to substance abuse, psychiatric, and social support resources is well received by participants and helps increase communication between HIV caregivers and substance-abuse specialists (Johns Hopkins, USA).

Most importantly, the case studies offer evidence that active drug users can and will adhere to complex ARV treatment programs when their needs are incorporated into treatment delivery programs.

Ideas on how best to proceed can be found on virtually every page of this text. Below is a summary of the major recommendations contained in the case studies:

## Health

- ▶ New treatment models that consider the specific needs of HIV-infected drug users and other vulnerable populations should be developed in order to support adherence to ARV treatment regimens.
- ▶ Clinical studies should be undertaken to determine and evaluate potential interactions between ARVs and the most common illegal drugs.
- ▶ Peer support networks to advocate for fair medical treatment for drug users should be encouraged in all communities.
- ▶ The right of IDUs to participate in the development and implementation of programs should be ensured. Policymakers should seek to inform them of this right and assist them in taking advantage of it.
- ▶ Informed and equal involvement of active drug users in ongoing clinical trials of new anti-HIV agents must be ensured.
- ▶ High-quality and accessible treatment and rehabilitation services for drug users should be ensured, together with appropriate HIV-related information, education and support.
- ▶ Appropriate harm reduction interventions such as needle exchange programs and substitution therapy should be made readily available to all drug users (not only those living with HIV or AIDS).
- ▶ Pilot programs need to be stopped when they have achieved their goals and be implemented as a part of routine health care. This is a large-scale epidemic; therefore, treatment and prevention efforts must also be large-scale.

## Law enforcement and legislation

- ▶ Efforts to treat, prevent, and address drug addiction as a disease should originate from a medical perspective and should be taken out of the purview of law enforcement systems. The United Nations should bring all of its resources to bear in leading the global community away from repressive and ineffective “wars” on drugs.
- ▶ Anti-discrimination laws should be reviewed to ensure that persons affected by HIV/AIDS and members of vulnerable groups, including drug users, are protected against discrimination.
- ▶ Drug control legislation and practices should be reviewed to ensure that they do not hinder HIV prevention efforts by perpetuating the stigmatization and marginalization of drug users.
- ▶ Drug laws mandating incarceration for possession of small amounts of illicit substances should be repealed.
- ▶ Methadone should be included in the WHO Essential Drug List (EDL) and rescheduled to a less restrictive category.

- ▶ Police abuse of and legal discrimination toward drug users should be curtailed so that users may seek prevention and treatment for illness without fear of legal persecution.
- ▶ All programs for drugs users should attempt to engage the support of law enforcement and medical professionals to minimize the police harassment and abuse that have impeded access to services in many countries.

International leaders, policymakers, caregivers, and activists must ensure that drug users are included in all current and future efforts to address the HIV/AIDS epidemic. In the new millennium, outside of Africa it is injection drug use that is driving the epidemic. But this trend can and should be broken—not only for the sake of drug users but for all who believe that HIV/AIDS can be defeated.

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Even though public health services and medical interventions to prevent and treat HIV among IDUs have not yet been fully brought to scale, the strong linkage between harm reduction and health care espoused by Brazil's public health policy has been a crucial factor in controlling the epidemic.

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## Brazil: Giving Injecting Drug Users Access to Highly Active Antiretroviral Therapy as a Response to the HIV/AIDS Epidemic

By Fábio Mesquita\*

Government supported universal access to highly active antiretroviral therapy (HAART) and harm reduction services are key elements of Brazil's response to the HIV/AIDS epidemic. These policies increase the quality of life and decrease morbidity for thousands of injection drug users (IDUs) as well as help control the spread of HIV. Even though public health services and medical interventions to prevent and treat HIV among IDUs have not yet been fully brought to scale, the strong linkage between harm reduction and health care espoused by Brazil's public health policy has been a crucial factor in controlling the epidemic in the country. Moreover, Brazil's experience with a successful large scale, cost-effective response to injection-related HIV is a positive example for other developing countries.

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IDUs have had an important role in the HIV/AIDS epidemic in Brazil since the first reported case in 1982.<sup>1</sup> Alongside men who have sex with men, IDUs have always been a major part of the HIV landscape in Brazil. Once considered primarily a transit country for cocaine traffickers, since the 1980s Brazil has become an important market for the consumption of cocaine produced in Peru, Bolivia, and Colombia. To date, in Brazil's major urban centers and coastal regions, 25 percent of HIV cases are believed to have been contracted through injection drug use.<sup>2</sup>

Like many countries in Latin America, Brazil is influenced by U.S. policies, especially those related to drugs. Since the 1971 declaration of President Richard Nixon that illicit drugs are "America's public enemy number one," followed by the Reagan and Bush administrations' "War on Drugs" beginning in the 1980s, Brazil has been at the center of a struggle over drug policies. The Federal Police, the Army, the State Police, most religious institutions, and a majority of politicians have been in favor of the "War on Drugs" approach. On the other side are the public health professionals, activists, progressive politicians, lawyers, and judges who favor alternative policies. In the midst of this debate, Brazil's drug policies have awkwardly balanced harm reduction as the formal national public health policy with the imprisonment of many drug users for drug possession. Very significantly however, a recent bill in the Brazilian Congress seeks to end incarceration for drug possession alone.

## The Policy of Free Universal Health Care

Universal, free access to health care and necessary medication is guaranteed in the Brazilian Constitution of 1988, adopted during the democratization of the country following 20 years of military dictatorship. In 1990, the Organic Health Law was adopted by the Brazilian Congress and was instrumental to putting the principles of the constitution into practice.

In 1991, Zidovudine was first provided to AIDS patients by the City of Santos Health Department through the application of the constitutional guarantees and the Organic Health Law. In 1996, the same arguments were used to provide HAART to AIDS clients in the City of Santos. The constitution and Organic Health Law were later reinforced by a federal law specifically designed to guarantee treatment to AIDS patients all over Brazil. Since then the federal government has fought pharmaceutical companies to lower the price of HAART, and has supported the national production of generic drugs, resulting in dramatic cost savings and making the provision of HAART to every person who needs it possible.

This process has seen some dramatic fights, the most important of which played out in the World Trade Organization in 2001, and resulted in an important victory when

it was decided that Brazil could move forward with the production of generic AIDS drugs. In the World Health Organization General Assembly, Brazil enjoyed another victory in determining that access to HAART is a human right. Brazil's new policies are being supported both inside and outside the country by researchers, health professionals, government, activists, and people living with AIDS.

By the end of 2003, 128,000 Brazilians were taking HAART paid for by the federal Government. The cost of universal provision of HAART accounted for 2.3 percent of Brazil's public health budget in 2003. In 1997, the cost to treat a patient for one year was U.S. \$ 4,860. In 2004, the cost of treatment per client is U.S. \$ 1,000 per year—a five-fold decrease in seven years.<sup>3</sup>

Brazil's policy of universal free access to HAART was harshly criticized at first due to fears that drug resistant "super virus" strains of HIV might develop. These fears were based on the premise that people from the developing world would not be able to adhere to such sophisticated medication regimens.<sup>4</sup> The criticism came from multilateral organizations such as the World Bank and the World Health Organization. Today, we see the same kind of reasoning used to justify the exclusion of drug users from HAART: the possible emergence of drug resistant HIV because drug users will not, or can not, properly adhere to treatment. In the early days in Brazil we always argued that no one knows how take drugs better than a drug user.

## Study on Treatment Adherence by the University of Sao Paulo

In 1999, professors and researchers from the School of Medicine of the University of Sao Paulo sought to refute on clinical grounds the claims of drug user inability to adhere to treatment regimens by conducting a study called "Evaluation of Adherence to HAART in the Public Health System of the State of Sao Paulo, Brazil." At that time almost 50 percent of the total AIDS cases in the country were in Sao Paulo. The study was conducted in 20 different cities and in 34 Public Health Services that specialized in STD/AIDS.<sup>5</sup>

Researchers conducted interviews with 1038 people receiving HIV treatment, 673 (64.8 percent) males and 365 (35.2 percent) females. The majority of those interviewed (562 or 54 percent) had less than four years of formal education. 183 (17.8 percent) had less than eight years, and 291 (28 percent) had more than eight years of formal education. The average age of the participants was 35. Seventeen per cent of participants had no income, 39 percent had an income three times the Brazilian minimum salary (which was equivalent to U.S. \$ 70 at the time of the study), 22 percent had an income of three to six times the Brazilian minimum salary and 21.8 percent had an income greater

than or equal to six times the minimum. The majority of study participants were unemployed (57.4 percent), and the remaining 42.6 percent had some relationship with the job market.<sup>6</sup>

In the multivariate analyses, four factors appeared to be consistent predictors of non-adherence:

- ▶ Formal education  $\leq$  four years
- ▶ No income
- ▶ Current abuse of alcohol
- ▶ The quality of health services available according to the client's perception

The current use of drugs (which appeared in the bivariate analysis) did not appear in the multivariate analysis to be a predictor for non-adherence to HAART.

In this study, adherence was defined as compliance with therapy  $\geq 80$  percent of the time. In the final results, 69 percent of the participants were found to be adherent. These results are quite similar to those of other international studies available at the time, showing adherence of 75 percent,<sup>7</sup> 78 percent<sup>8</sup> and 60 percent.<sup>9</sup> The results emphasized the need to train health care professionals in the specific treatment needs of drug users so that IDUs continue to receive effective HAART treatment.

## Development of Brazilian Harm Reduction Projects

In 1989, the City of Santos Health Department organized Brazil's first needle exchange program (NEP). Santos, on the Sao Paulo coast, is home to the largest harbor in Latin America and at the time was considered to be the capital of the Brazilian AIDS epidemic. In response to the NEP, the state attorney's office took legal action against the health authorities. The lawsuits were based on the attorneys' interpretation of Brazilian drug law: they argued that the health authorities were facilitating the use of illicit drugs by offering sterile needles to users, and accordingly they attempted to prosecute the NEP workers as drug dealers.<sup>10</sup> At that time I was the director of the City of Santos Health Department Program on STD/AIDS. Together with the Secretary of Health, Dr. David Capistrano, I was sued in the criminal court. We received strong support—from the leading officials of the City of Santos, the State of Sao Paulo, the federal government, and many NGOs and progressive politicians—and the moment became a turning point in Brazil's approach to drug policy. A long struggle began to change the policy and thus alleviate the suffering of thousands of Brazilians affected by HIV/AIDS, and to expose an important, but largely unknown public health problem—the use of injection drugs

in Brazil. The lawsuits also brought about the first public recognition of the human and civil rights of injection drug users in Brazil.

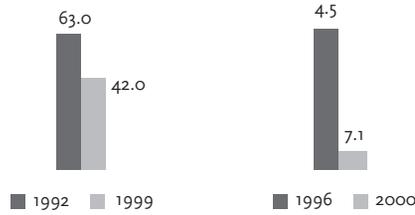
In 1993, IEPAS, an NGO for health professionals in Santos, initiated the first outreach project in Brazil to be supported by the federal government through the National STD/AIDS Control Program.<sup>11</sup> This was the first investment program of the World Bank for the prevention of HIV among IDUs. This pioneering project prompted the United Nations Drug Control Program (UNDCP) to take part for the first time in a broader harm reduction program to control the spread of HIV/AIDS in Brazil. This program brought together the World Bank, the Brazilian Federal Government, UNDCP, state and municipal Governments, and NGOs in an effort to contain the epidemic.

From 1994 to 1996, the Brazilian Government supported a national research program coordinated through IEPAS called “Projeto Brasil.” Projeto Brasil was a multi-city study, including eight cities in four different regions in the country. It was based on the WHO Multi-City Study developed in Brazil in 1991/1992 (phase I of the WHO Multi-City Study focused on the behavior and seroprevalence of HIV among injecting drug users), using a similar questionnaire and methodology. The Projeto Brasil study provided a crucial review of the Brazilian epidemiological situation at that time among injecting drug users.<sup>12</sup> Later, in 1999 and 2000, three of the cities that were included in “Projeto Brasil” (Santos, Rio de Janeiro, and Salvador) became part of phase II of the WHO Multi-City Study of IDU health.

In 1995, the University of Bahia in the City of Salvador began Brazil’s first fully legal NEP.<sup>13</sup> Subsequently, other harm reduction projects were launched in many parts of the country, at first on an underground basis. Finally in 1998, during the opening ceremony of the 9<sup>th</sup> International Conference on Drug Related Harm in Sao Paulo, the State Governor Mario Covas announced Brazil’s first harm reduction law. The law authorized the State of Sao Paulo Health Department to buy and distribute sterile needle and syringes in an effort to contain the spread of HIV.<sup>14</sup> This law opened the door for other state agencies to act, culminating in the January 2002 reform to Brazil’s drug laws authorizing the Ministry of Health to implement national harm reduction initiatives. The new law also facilitated a national response to the skyrocketing rates of HIV infection among drug users, resulting in political support for the implementation of NEPs throughout Brazil.

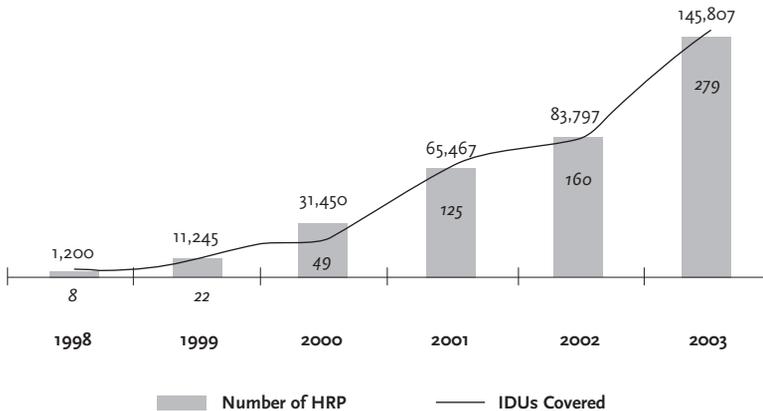
Figure 1 is a comparison of the cities of Santos and Salvador over two periods: 1994/1996 (when harm reduction programs were scarce) and 1999/2000 (when they had become better established in Brazil). As we can see, there is an impressive reduction of HIV seroprevalence rates among IDUs in both cities. Research teams in the two cities have come to the following conclusion: one of the reasons for the decline in HIV seroprevalence is the impact (direct and indirect) of harm reduction strategies developed in both cities.<sup>15</sup>

**Figure 1.** Seroprevalence Reduction of HIV Infection Among Injecting Drug Users in the City of Santo and City of Salvador



Currently, Brazil has 279 harm reduction programs, most of which provide needle exchange. The Ministry of Health supports these projects both politically and financially. Some of the historical information on the growth of Brazilian NEPs can be seen in Figure 2. It is estimated that, taken together, Brazil’s harm reduction projects reach 40 percent of the injecting drug users in the country.<sup>16</sup> There is clearly a need to expand these projects in order to treat all drug users. The hurdles to doing so seem to be more related to a lack of local commitment than a lack of national policy or financial support to do so.

**Figure 2.** Dissemination of Harm Reduction Project by Number of HRP and IDUs Covered, by year in Brazil



Today, small internal changes are being articulated within the government in order to improve the capacity for responding to the epidemic among IDUs, as well as to increase the possibilities of interventions for drug users in general. A major step was the publication of the federal decree on harm reduction. Beyond legalization of harm reduction programs on the national level, the decree formally guarantees substitution therapy for drug users who desire to be treated, and calls for the establishment of safe injection rooms. One of the most visible and telling changes has been the name change of the nation's drug agency from the Anti-Drug Secretariat to the National Secretariat of Public Drug Policies.

## Conclusion

Brazil is developing a unique response to the HIV/AIDS epidemic based on a broad perspective and an emphasis on integrity in public health. Care, prevention, and human rights form the bases of the Brazilian response.

Legal and political resistance to drug policy reform initiatives have been addressed one by one. It has been a long fight to achieve better policies which recognize the existence of drug users, and their right to access care, prevention, and public health programs along with all other Brazilian citizens.

However, the reforms that have been achieved must be protected, and the following improvements must be made to continue the development of an effective response to HIV/AIDS and drug use in Brazil:

- ▶ Coverage of all existing programs must be extended.
- ▶ Development of quality of life projects must follow the extension of programs.
- ▶ Overdose and hepatitis prevention programs, still quite new to harm reduction services in Brazil, should be included in all existing and new projects.
- ▶ Harm reduction programs and universal access to HAART for drug users must be integrated in the Brazilian Universal Public Health System.
- ▶ Harm Reduction Projects should promote safer sex with the same commitment that they have shown to promoting the safer use of drugs: condoms are as crucial as sterile needles!
- ▶ The creation of two drug user associations over the last two years and current efforts to establish a national drug user organization are important developments that must be supported and expanded. Advocacy by drug users living with HIV may be one of the most exciting developments in the evolution of Brazilian drug and HIV/AIDS policies and activities.

After 16 years of effort, advocates for drug policy reform in Brazil still need to keep up the pressure for pragmatic, humanitarian drug and health care policies. There is still much to be done, but we are confident that we are moving in the right direction.

Acknowledgements: to my colleagues and friends Regina Bueno and Daniela Piconez from the STD/AIDS Program of the City of Sao Paulo Public Health Department for their collaboration in the revision and suggestions on this paper.

## **In Focus:** *Pioneering AIDS Treatment in Brazil*

*By Telma de Souza*

It was 1991. I had been the Mayor of the City of Santos for two years, at a time when Santos was considered the capital of the AIDS Epidemic in Brazil. Of the total number of AIDS cases in our city, 50 percent were among injecting drug users. Recognizing this problem, at the end of 1989, we tried to implement the first needle exchange program in Brazil, but were sued by the public prosecutors.

In 1991, Zidovudine (AZT) was first imported from Great Britain. Previously, some affluent patients had been able to buy AIDS medications from abroad, but the government of Santos decided to use public money and make it available to all AIDS patients who needed it. Building on this, in 1996 the Santos government, then led by David Capistrano Filho, brought the first HAART therapy to Brazil. These were among the first steps in Brazil's development of a policy of universal access to antiretroviral therapy.

By 1996 I had become a congresswoman, and I organized a committee composed of City of Santos Supervisors (including Fabio Mesquita) and members of a local NGO of people living with HIV/AIDS to meet the Brazilian Minister of Health, Adib Jatene. We urged him to extend the policies established in Santos to the whole country. Some months later, former president and current senator Jose Sarney proposed national legislation guaranteeing HAART as an essential health right, based on the principles of the Brazilian Constitution.

During this long process we sought to treat drug users as we would any other clients with the same rights and needs. Drug users were totally integrated into our policies, and Santos became famous throughout the country for its response to the epidemic and for being a pioneer in establishing harm reduction in Brazil.

Before I left office as the mayor of Santos, I adopted two AIDS orphans and intensified my commitment to the cause of free access to HAART—not only in Brazil, but all over the world—with particular attention to the needs of drug users. Now, as a

congresswoman representing the state of Sao Paulo and head of the Commission on AIDS of the Brazilian Congress, I am able to bridge my personal dedication with greater government resources in the cause of universal and free access to HAART therapy!

The success of the fight against AIDS in Brazil so far comes from a combination of political will on the part of some politicians, commitment from public health professionals, dedicated pressure from NGOs, and partnerships with many other sectors of Brazilian Society (including the media, churches, universities, and international organizations working in Brazil). I am privileged to have played a role in the initial, decisive efforts that have helped Brazil's fight against AIDS grow and involve thousands of people across the country.

*The author is the former mayor of Santos. She is currently a member of the Brazilian Congress, where she chairs the Commission on AIDS.*

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In Barcelona, we have made progress by helping IDUs reduce their risks by promoting access to care, ensuring that methadone is available for all who require it, and by turning our addiction treatment centers into integrated entry points to the health care system.

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# Barcelona: Changing Approaches to Addiction and Public Health

By Joan R Villalbi, M Teresa Brugal, Patricia Garcia de Olalla, Joan A Cayla\*

## Introduction

When the heroin epidemic began in Barcelona in the late 1970s there was a complete lack of expertise about opiate and opiate treatment facilities. Not only was heroin addiction a previously unknown problem, but mental health was also among the least developed sectors of the publicly financed health system. Under the dictatorship of Francisco Franco, mental health problems were mainly treated in long-term hospitals. Addiction treatment facilities were scarce and specialized in alcohol dependence. This model, based on cure and abstinence rather than care, was adopted to address opiate addiction. Alternative residential treatment centers were expanded—many linked to NGOs. At that time public health services suffered from many problems, including a lack of organized initiatives to treat and control TB and other infectious diseases.<sup>1</sup>

Rising heroin use corresponded with an increase in petty crime. However the media portrayed heroin users as dangerous criminals capable of murder during periods of

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withdrawal, and this became the dominant stereotype. Fear of heroin addicts influenced the development of a policy based on legal intervention—arrest and incarceration. By the mid 1980s the prison population had risen tremendously, and heroin use among inmates was extremely high.

Hospital studies in the 1980s estimated that 40-60 percent of injection drug users (IDUs) were HIV-infected. AIDS cases quickly increased and, in poor areas, AIDS became a major killer and began lowering life expectancy rates. When TB as a presenting disease was included in the definition of AIDS, the number of AIDS cases rose to new heights.

At the beginning of the 1990s a network of addiction treatment centers, both ambulatory and residential, was developed across the country. However these centers emphasized cure and abstinence rather than care, and most opiate users interrupted treatment shortly after starting it. The total number of heroin users in active treatment remained low, and most users had no regular contact with the health care system.

## Changing Approaches to Addiction and Public Health

By the late 1980s, a small but growing number of physicians who worked with IDUs in Barcelona felt the need to develop a new public health perspective toward drug use and addiction. They wanted an approach that allowed for continuous contact with opiate users and created an infrastructure that fostered behavioral change. The goals of this approach were not to cure addiction, but rather to improve life expectancy, to deal with the complications of addiction such as TB or HIV infection, and to improve the quality of life for drug users living with HIV. This new public health approach relied on harm reduction, with methadone maintenance programs (MMP) playing a crucial role.

The physicians in Barcelona intended to establish programs similar to ones in countries such as the Netherlands, where MMP within addiction treatment centers provides a unique opportunity to develop a continuous relationship with the opiate user. After an initial period of adaptation, opiate addicts become patients, and gradually lose the urge to get money and drugs and shoot up. Clients enrolled in MMP may be able to re-establish family ties, to solve some of their legal and social problems, and to care for their HIV, TB, and other health problems. While very few patients in drug-free programs continue treatment for more than a few weeks, we have found that the retention of MMP nears 70 percent even after two years of treatment.

For those IDUs who do not enter MMP and remain active drug injectors—most of whom have a short history of use—there is a need for contact with harm reduction facilities and health care providers who can teach them how to reduce their risks. Drop-in centers provide such opportunities. At these facilities, food and other practical services

(toilets, shower, warm shelter) are offered to active IDUs. Clients who visit such harm reduction facilities also have the opportunity to obtain protective equipment (condoms, clean injecting equipment). Syringe exchange programs in such centers provide safer injecting equipment while recovering used needles which otherwise may be reused or litter the streets, posing a threat to other citizens.<sup>2</sup>

In Spain and Barcelona, however, such pragmatic programs did not exist in the late 1980s. Resistance came from politicians and the professional organizations that sponsored the abstinence-oriented interventions of the time. Many groups considered opiate addicts to be sinners and/or criminals, and therefore rejected harm reduction services, on the grounds that these supported addicts instead of persecuting them. Most of the public and many decision makers, uninformed about the issues, remained initially passive. This diverse opposition presented public health officials and physicians advocating for reform with a significant, but not insurmountable challenge.

## Lobbying For Change

Advocates of reform in Barcelona identified changing official perceptions of the heroin user from criminal to victim as a crucial step toward reframing the issue. They accomplished this by working with and unifying the efforts of political organizations, members of city government, and professional and citizen groups. Together, this coalition created a consensus for a new way of thinking about and treating drug users which was unanimously approved by the city council in 1989.

The media was also involved in the process and did much to alter public perceptions of heroin addicts. A taskforce of journalists covered health issues in daily newspapers and promoted the idea that help could be provided to addicts and their families. The journalists also described to the public how appropriate interventions would decrease the societal problems related to heroin addiction.

These efforts paid off in 1991 when legal reforms in Barcelona made wider methadone prescription possible and soon afterwards methadone was used in the four centers managed by our agency. Only a handful of other centers in the country were following such a policy at the time.

Soon, directly observed therapy (DOT) for TB was integrated in MMP.<sup>3</sup> Screening for health problems including HIV, as well as vaccination for conditions such as Hepatitis B, were integrated into routine care provided by addiction treatment centers. Treatment centers ceased to emphasize abstinence and instead aimed to provide access to the health care system for patients who had been seen as disruptive in other health care models.

The results of these centers were publicized in reports at professional meetings and in papers; among politicians, civic organizations and leaders; as well as in the media.

Besides improving the quality of life for many former IDUs, the centers and health reforms continued to have a positive impact within the legal system as further reforms allowed MMP to be introduced in overcrowded prisons and jails.

Despite the growing success, tolerance for MMPs began to decrease when the number of patients exceeded 100. MMP and public health reform advocates responded to this by introducing take-home options for stabilized patients that eliminated a need for daily visits to the center. A mobile unit was also introduced, which allowed harm reduction practitioners to distribute methadone to stabilized patients in remote areas. Later, MMP was introduced at some pharmacies for advanced clients who had a long history of success in methadone maintenance programs.

At the same time that MMP was improved, risk reduction interventions were developed for active IDUs including a night drop-in center in the inner city, a mobile day drop-in center in an area with heavy drug dealing, and several street-based syringe exchange programs. Over time, pharmacies became the focal points for syringe exchange. Currently, more than a hundred pharmacies offer exchange services. These risk reduction programs deal increasingly with active users who have historically been marginalized.

## Positive Results and Emerging Issues

Recent studies in Barcelona suggest huge improvements in lowering the risk of HIV infection, in controlling TB, and in providing access to HIV screening, which is a crucial first step toward treating HIV. One study indicates that 81 percent of those who are HIV-infected in Barcelona know their status, compared to about 60 percent in other cities in Spain.

Studies on highly active antiretroviral treatment (HAART) however, indicate that only about 35 percent of active IDUs who are HIV-infected have ever taken HAART, and only a small number of these people are taking it properly. While HAART does not cure HIV infection, it greatly improves life expectancy and quality of life, and it may decrease transmission of HIV.

HAART is an issue of emerging importance for IDUs. It offers them hope and opportunities for improved health. As it stands, mortality from AIDS is highest among those infected through needle use than groups infected by other means.<sup>4</sup> In Barcelona, studies indicate that about 60 percent of IDUs adhere to their treatment, which is slightly lower than other HIV patients, but still high enough to justify treatment efforts.<sup>5</sup> However, the likelihood of taking HAART medications properly is low among those who remain active IDUs. Unlike most other pharmaceutical treatments in Spain, HAART is prescribed and distributed in hospitals, and active IDUs who have historically been marginalized by the health care system are unlikely to receive it.

We are currently discussing whether strategies used for the control of TB among IDUs could be viable for HAART, at least for patients in MMP. There are also other important issues raised by treating drug users with HAART. First, it is not a cure, although it can decrease transmission. Second, HAART dosages do not facilitate DOT. Third, the treatment may have serious side effects. Finally, resistance to HAART may emerge if compliance is erratic. For IDUs in prison, programs providing MMP and HAART exist, but when inmates leave prison, both treatments tend to be decentralized and interrupted as patients are referred to a MMP for methadone, and to a hospital for HAART. There is clearly a need to integrate these two services.

In Barcelona, we have made progress in helping IDUs reduce their risks by promoting access to care, ensuring that MMP is available for all who require it, and by turning our addiction treatment centers into integrated entry points to the health care system. However, injection drug users who remain active lack access to the same benefits of health care that reach those who enter a treatment program, especially those in MMP.

Young IDUs in Barcelona are moving away from heroin and increasingly using cocaine or mixing both drugs.<sup>6</sup> These users can also benefit from the risk reduction interventions in place for active drug users. However, for cocaine dependence we do not yet have a substitution therapy as effective as MMP is for opiate dependence.

In the near future, we may explore how to ensure better access to HAART for those infected through drug injection by applying the experience gained from DOT to tuberculosis, MMP, and harm reduction strategies. New health care strategies should emphasize high compliance with HAART to prevent resistance strains of HIV from emerging, and should rely on frequent DOT by combining provision of HAART with other harm reduction interventions at an integrated facility. For opiate users, MMP is extremely important, but for those who inject cocaine, new strategies must be developed.

## Lessons Learned in Barcelona

The main lesson derived from our experience in Barcelona is the capacity of existing public health services to confront a new problem by quantifying it, analyzing intervention options, identifying appropriate interventions, ensuring the feasibility of interventions, and then implementing them. Favorable results of new interventions reinforce steady progress and encourage the creation of newer and better programs and policies. This kind of policy reform requires two critical steps: identifying real obstacles, and devising strategies to confront them.

Methadone maintenance programs have been important instruments for change. Ours have been low threshold programs—they have not had time or methadone dose limits. There is no penalty for the use of illegal drugs, and 60 percent of doses are unsupervised. We use methadone in syrup form, and supplement treatment with other

programs in psychotherapy and social and educational issues to address our clients' needs. Our treatment and programs have improved health and controlled TB among IDUs.

As time evolves, new issues emerge and require new answers. Barcelona's success in changing the perception of substance abuse treatment programs should ensure our ability to respond to any new challenges, including making HAART more accessible to IDUs.

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Our pilot study found that linking HIV care to substance abuse, psychiatric, and social support was well received by participants, and was associated with greatly facilitated communication between HIV care givers and substance abuse specialists, and high rates of viral suppression in participants.

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# United States, Baltimore: Drug Use and HIV: Effective Models of Integrated Care and Directly Administered Antiretroviral Therapy

By Gregory M. Lucas\*

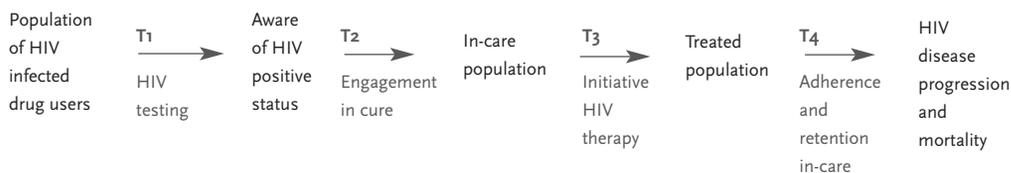
As an integrated model of care, directly observed HIV therapy in conjunction with methadone maintenance—which links substance abuse and HIV treatment, psychiatric care and social support services—has been shown to greatly improve HIV treatment outcomes among drug users.

Achieving optimal treatment of HIV infection entails the successful navigation through a series of steps and transitions (Figure 1). It is likely that active drug use and related conditions serve as a barrier at each step in this process.

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**Figure 1.** Conceptual model of transition through HIV care



For example, community-based cohort studies of injection drug users have found extremely poor uptake of antiretroviral therapy among drug users even in countries where HIV treatment is readily available. The AIDS Link to Intravenous Experience (ALIVE) study is a community-based cohort of injection drug users in Baltimore, Maryland. Celenzano et al. found that only 14 percent of HIV-infected treatment-eligible individuals in the cohort had received combination antiretroviral therapy as of 1997 (19). The study revealed that the strongest risk factor for failure to receive therapy was the absence of a regular source of medical care (OR, 6.9; 95 percent CI, 3.4-14.0) (40). A follow-up study of the ALIVE cohort two years later, a time when highly active antiretroviral therapy was firmly entrenched throughout the United States, continued to show substantial underutilization of antiretroviral therapy by drug users (20). Strathdee and colleagues similarly found that only 17 percent of HIV-infected injection drug users had used combination therapy in a community-based cohort in British Columbia (21). Numerous cohort studies have identified failure to initiate combination antiretroviral therapy prior to a decline in the CD4+ count < 200 cells/mm<sup>3</sup> as a strong risk factor for HIV disease progression and death (22;23). Thus, delays in initiating treatment until advanced immunocompromise can directly translate into increased future morbidity and mortality. Discrepancies in antiretroviral utilization between drug users and non-users have been reported both in the United States (19;20;24), and in countries with universal health coverage for HIV treatment (3;21;25;26), suggesting that financial barriers alone do not explain the discrepancies.

A major goal of the Johns Hopkins HIV Clinical Cohort Study has been to assess the effects of drug use on the natural history of HIV, treatment, utilization, and treatment outcomes (27). Our group evaluated virologic and immunologic outcomes in 273 HIV-infected patients beginning their first combination ART regimen in the Johns Hopkins HIV Clinic (28). Suppression of HIV RNA < 500 c/ml was achieved by 44 percent of the cohort at 3-7 months, and in 37 percent at 7-14 months. In univariate analysis, statistically significant risk factors for failure to suppress viral load at one year included history of

injection drug use (27 percent viral suppression vs. 47 percent in non-users), African American race (31 percent vs. 54 percent in white patients) and prior adherence with clinic visits (23 percent for those with > 20 percent missed visits vs. 61 percent for those with < 20 percent missed visits). In multivariate logistic regression, only previous adherence with clinic visits remained independently associated with failure to suppress viral load at one year. This study highlights the low rates of viral suppression achieved by unselected HIV infected patients attending an inner city clinic. The results suggest that non-adherence with medical treatment is the most important determinant of the virologic response to HAART, and that non-adherence explained much of the observed therapeutic discrepancy in drug users.

To differentiate the effects of active and past drug use on antiretroviral therapy use and treatment outcomes, our working group conducted a cross-sectional analysis (29) of 764 participants in the Johns Hopkins clinical cohort in whom HAART was indicated according to current treatment guidelines, and who completed a standardized confidential survey. The surveys, which were conducted by audio computer-assisted self-interview, addressed substance use in the past six months, current antiretroviral use, and self-reported adherence with therapy. Participants were categorized as 1) non-drug users if they had no history of heroin or cocaine use, 2) past drug users if they had used these substances in the past, but denied use in six months prior to the survey, or 3) active users if they reported use of heroin or cocaine in the six months prior to the survey. Most past and active drug users were not currently engaged in substance abuse treatment. Adherence with therapy was defined as < 2 self-reported missed doses in the two weeks prior to survey.

**Table 1.** Association of drug use status with antiretroviral therapy use, adherence, and HIV treatment outcomes

<i>Outcome Variable</i>	<i>Non-drug users (N=189)</i>	<i>Past drug users (N=376)</i>	<i>Active drug users (N=199)</i>	<i>P value (active vs. non-drug users)</i>
Current use of combination ART, %	82	78	56	<0.001
Adherent with ART*, %	76	83	66	0.05
HIV RNA < 400 copies/ml*, %	46	44	32	0.02
CD4 increase over past nadir*, cells/mm <sup>3</sup>	116	122	65	0.03

\* Analysis limited to subset of participants who were taking ART at interview. Adapted from Lucas et al. (29)

This study demonstrates that active drug use is strongly associated with underutilization of therapy, non-adherence when therapy was used, and suboptimal virologic and immunologic responses to therapy without access to the range of services targeted on adherence support, including drug addiction treatment and social support. Notably, non-drug users and past drug users had strikingly similar measures of HIV treatment utilization and effectiveness. These findings suggest that an integrated and coordinated approach to substance abuse and HIV treatment in drug users may foster improved HIV treatment outcomes.

It may be inferred from the data presented above that there is a need to develop effective approaches for ensuring access to HAART for the IDU patients. The provision of readily available substance abuse treatment, particularly for opioid addicts, has been proven to have a favorable effect on the HIV epidemic. And data from observational studies support this hypothesis. For example, Metzger and colleagues (33) found that enrollment in a methadone maintenance clinic was associated with a substantially reduced risk of acquiring HIV during a time that infection incidence was rapidly increasing among Philadelphia drug users. Other studies have linked receipt of pharmacologic therapy for opiate dependence to improved use of and adherence to HAART (34). For example, Moatti and colleagues (35) recently reported factors associated with antiretroviral adherence in a cohort of HIV-infected illicit drug users in France, where buprenorphine is commonly prescribed by general practitioners as part of ambulatory drug maintenance treatment. They found that younger age, alcohol consumption, and active illicit drug use were associated with non-adherence, while receipt of buprenorphine was significantly associated with increased adherence.

## Integrated Care for Treating Complex Patient Populations

The integrated care model for complex patient populations, like HIV-infected drug users, is strategically appealing for several reasons. First, integrated care dismantles barriers for the disenfranchised patients: rather than navigating the difficult terrain of unrelated clinics and social services, patients have “one stop shopping.” Second, integrated care models promote collaboration among medical care providers, psychiatrists, and substance abuse specialists, and discourage insular pursuits and artificial fiefdoms. Third, data from randomized controlled trials have suggested that integrating services at a single site may improve both medical and substance abuse treatment outcomes.

For example, Umbricht-Schneiter et al. (36) randomized 51 methadone maintenance recipients with medical problems to attend a medical clinic located two blocks from the methadone facility (referred group) or to attend a clinic at the methadone program (on-site group). During follow-up, 73 percent of the on-site group attended two or more medical visits compared to 4 percent in the referred group. Similar results have been reported in integrated medical care models for alcoholics with medical conditions (37). Correspondingly, a randomized trial performed by McLellan and colleagues (38) suggested that an integrated care model can also improve substance abuse treatment outcomes. Opioid-dependent individuals who were entering methadone maintenance were randomized to minimum methadone services (MMS) - methadone replacement therapy only; standard methadone services (SMS) - MMS plus counseling; or enhanced methadone services (EMS) - SMS plus on-site medical and psychiatric care, employment, and family services. The methadone dosing protocol was the same in all groups. Fifty-five percent of subjects in the EMS group achieved 16 consecutive weeks of negative urine toxicology screens for drug of abuse, compared to 28 percent in SMS, and 0 percent in MMS (38).

A similar finding has been noted in the treatment of tuberculosis. Chaulk and colleagues (39) reviewed the English-language literature on tuberculosis treatment strategies and found that increasing intensity of services were associated with higher rates of treatment completion. Directly observed therapy (DOT) was associated with higher treatment completion rates than non-supervised therapy (Table 2). The term “modified DOT” refers to strategies in which some proportion of doses is self-administered. “Enhanced DOT” refers to integrated care treatment models in which fully supervised DOT is encompassed in a comprehensive social and adherence support system (e.g., case management, and linking patients to needed social, psychiatric, and substance abuse services, etc.).

**Table 2.** Tuberculosis therapy completion rates according to treatment strategy

<i>Treatment Strategy</i>	<i>Number of Studies</i>	<i>Percent Completing Therapy</i>
Non-supervised therapy	8	61.4
Modified DOT	2	80.6
DOT	4	85.7
Enhanced DOT	12	0.2

Adapted from Chaulk et al. (39)

## Directly Administered Antiretroviral Therapy in a Methadone Clinic

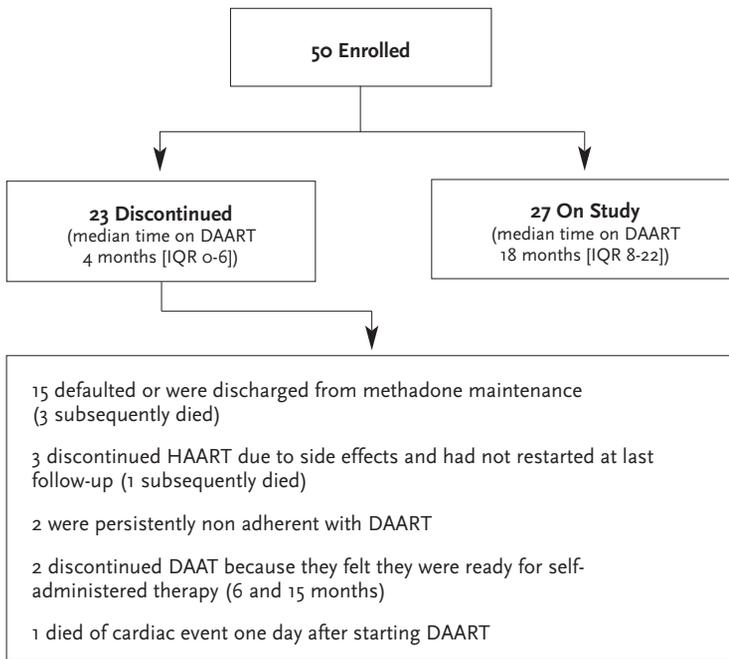
Our group initiated a pilot study to determine the acceptability and feasibility of directly administered antiretroviral therapy (DAART) in a methadone maintenance clinic in April 2001. Preliminary results from the pilot study have been presented previously (40). HIV-infected patients were eligible to participate if they received HIV care through a Johns Hopkins-affiliated clinic, had received methadone therapy for > 30 days, and were initiating HAART for the first time, reinitiating therapy that had been discontinued, or changing their antiretroviral regimen due to treatment failure. Exclusion criteria included clinically significant resistance to the three available antiretroviral classes, or requirement that antiretroviral therapy be dosed more frequently than twice daily. Participants provided written, informed consent and clinicians provided verbal consent. Participants' antiretroviral regimens were selected by treating clinicians. Medications were prepackaged and labeled in single-dose units by a participating pharmacy. Medications for opportunistic infection prophylaxis or other medical or psychiatric conditions were packaged with antiretroviral therapy if this was agreeable to both the participant and his or her treating clinician.

Participants took one dose of antiretroviral therapy on days when they attended the methadone clinic. A nurse or medical assistant observed ingestion of these doses at the methadone administration window or in a nearby private office. Most patients preferred the latter setting because it permitted more time to take the medications and afforded greater privacy. DAART staff members also provided HIV education to DAART participants, inquired about difficulties they might be having, facilitated communication with primary care providers, and helped participants access needed medical and social services. Patients newly enrolling in the methadone program were required to come to the methadone clinic seven days a week. According to protocol at the clinic, patients qualified for "take-home" doses of methadone as substance abuse treatment goals were met. Evening doses of antiretroviral therapy (when required) and doses to be taken on methadone take-home days were given to participants ahead of time in prepackaged units, and taken on a self-administered basis. At study enrollment, participants were also given a three-day "emergency supply" of medications, which could be used if participants were unexpectedly absent from the methadone clinic. This supply was replenished as needed during the study. No financial or other inducements were provided.

Of the 50 participants enrolled, the estimated three-month retention rate was 78 percent (95 percent CI 63 percent-87 percent) and the estimated twelve-month retention rate was 54 percent (95 percent CI 38 percent-67 percent). Of the 23 participants who discontinued DAART during follow-up (Figure 3), 15 (65 percent) discontinued because they defaulted or were discharged from the methadone clinic, 5 (22 percent) discontinued

due to side effects and had not restarted medications at last follow-up, 2 elected to switch to self-administered therapy (after 40 and 48 weeks on DAART), and one died of sudden cardiac arrest shortly after enrolling in the study. Importantly, no participant discontinued DAART because they found the intervention stigmatizing or unhelpful. Subjectively, we noted that DAART led to changes in the HIV “culture” at the methadone clinic, including, greater dialogue among patients and staff about HIV and its treatment, and greater collaboration between substance abuse providers and medical providers.

**Figure 2.** Disposition of participants enrolled in DAART



Although the pilot project was a non-randomized study, we performed a prospective comparison between the DAART group and two randomly-selected, frequency-matched control groups receiving standard care in the Johns Hopkins HIV Clinical Cohort that initiated or changed to HAART after January 1, 2000: 1) a drug user methadone group (DU-methadone)—patients with a history of drug use, who were receiving methadone maintenance therapy. This group was intended to approximate the socio-behavioral characteristics of the DAART group as much as possible; 2) a *non drug user group* (*non-DU*)—patients with no history of drug use. This group was intended to represent patients treated in the same clinic as DAART participants, but in whom drug use was not a barrier to treatment. The comparison groups were frequency-matched to the DAART group by sex and prior antiretroviral experience (naïve or experienced).

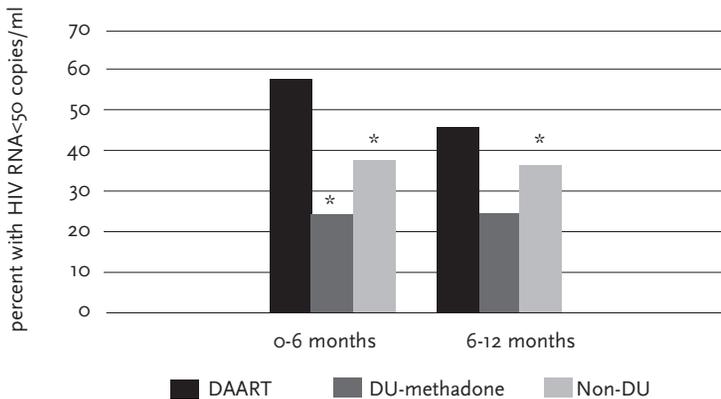
**Table 3.** Baseline characteristics of DAART or cohort comparison patients

Characteristic	DAART (N=50)	DU-methadone (N=90)	Non-DU (N=146)
Female <sup>a</sup> , %	64	61	68
Age (years), median (IQR)	42 (37-47)	44 (38-48)	39 (33-44) <sup>b</sup>
African American, %	88	86	72 <sup>b</sup>
Antiretroviral naïve <sup>a</sup> , %	34	46	40
Date antiretroviral therapy initiated or reinitiated, median	May 2002	February 2001 <sup>b</sup>	March 2001 <sup>b</sup>
CD4+ count (cells/mm <sup>3</sup> ), median (IQR)	140 (40-247)	155 (32-280)	192 (52-382)
HIV RNA (copies/ml), median (IQR)	4.9 (4.3-5.4)	4.8 (4.3-5.4)	4.6 (2.6-5.3)

a. Variables used in frequency match with the DAART group

b. P<0.05 compared to DAART

At the date of last follow-up, at least three months had elapsed since initiation of antiretroviral therapy in 45 DAART participants (90 percent), 90 DU-methadone patients (100 percent), and 145 non-DU patients (99 percent): and these were included in the intent-to-treat six-month analyses. Similarly, at the date of last follow-up, at least nine months had elapsed since initiation of antiretroviral therapy in 37 DAART participants (74 percent), 86 DU-methadone patients (96 percent), and 139 non-DU patients (95 percent): and these were included in the intent-to-treat twelve-month analyses.

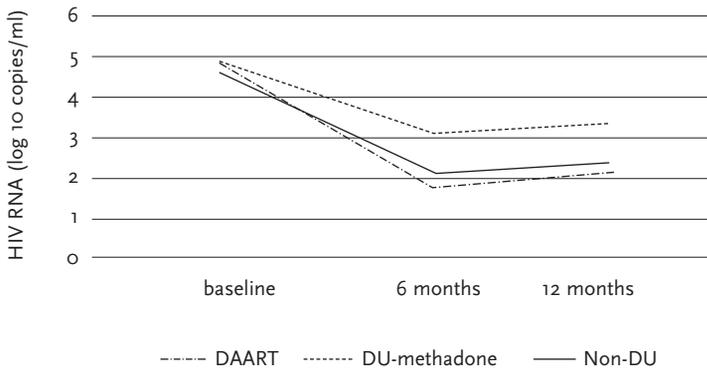
**Figure 3.** Percent of DAART participants and comparison patients who achieved HIV RNA < 50 copies/ml in two time frames after initiating antiretroviral therapy

\*P<0.05 compared to DAART

By intent-to-treat, missing equals failure analysis, 58 percent of DAART participants achieved HIV RNA < 50 copies/ml in the zero-six month time frame, compared to 23 percent in the DU-methadone group ( $P < 0.001$ ) and 39 percent in the non-DU group ( $P = 0.039$ ) (Figure 4). In the six-twelve month time frame, 46 percent of DAART patients achieved viral suppression, compared to 24 percent in the DU-methadone group ( $P = 0.021$ ) and 38 percent in the non-DU group ( $P = 0.45$ ).

Using an intent-to-treat, last observation carried forward rule, the median HIV RNA levels over time are shown in Figure 5 and the median changes in CD4+ cell counts over time are shown in Figure 6.

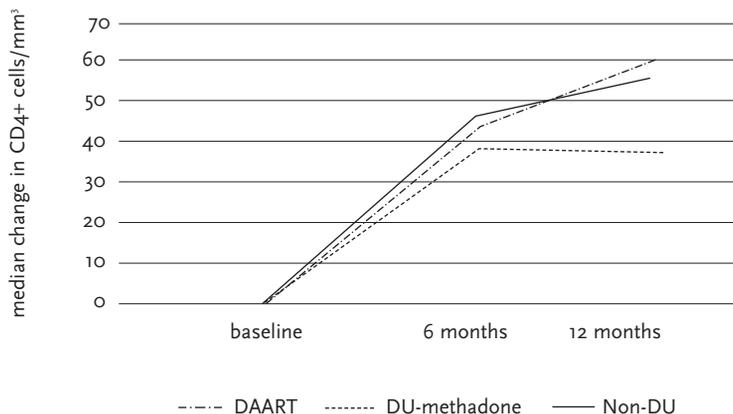
**Figure 4.** Median log<sub>10</sub> HIV RNA over time in DAART participants and comparison patient



\* $P < 0.05$  compared to DAART

The median HIV RNA was significantly lower in the DAART group than the DU-methadone group at six months, but no other differences in HIV RNA levels were statistically significant. There were no statistically significant differences in CD4+ cell changes among the groups.

**Figure 5.** Median changes in CD4+ cell counts over time in DAART participants and comparison patients



## Conclusion

Substance abuse and other psychiatric disorders are strongly over-represented in HIV-infected individuals compared to the general population. Prior research from a variety of groups, including our own, has shown that active drug use, but not past drug use, are significantly associated with HAART utilization, adherence, and clinical responses to therapy. We have also observed, in longitudinal follow-up of HIV-infected patients in Baltimore, that drug use is a dynamic process, with active periods being significantly associated with non-adherence and worsening virologic and immunologic status, and inactive periods being associated with renewed use of and adherence with HAART and improvements in clinical parameters. Linking HIV care to substance abuse, psychiatric, and social support resources is intuitively appealing and supported by clinical research. In our pilot study of DAART, we found that this intensive intervention was well received by participants, was associated with a greatly facilitated communication between HIV care givers and substance abuse specialists, and high rates of viral suppression in participants. These pilot data call for larger-scale randomized controlled trials of integrated-care interventions in HIV-infected drug users. Buprenorphine has now been approved for maintenance treatment of opioid-dependent patients in medical clinic settings in the United States. This offers an additional modality for providing integrated HIV and substance abuse care, and an alternative to methadone maintenance.

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Rationalizations that seek to explain why we cannot provide treatment to opiate addicts who want and need it are unacceptable, for the simple reason that they cost the lives of people who are opiate dependent, and severely detract from the quality of life of everyone else.

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# Hong Kong: Building a Large Scale, Low Threshold Methadone Program

By Robert Newman\*

## Introduction

The worldwide response to opiate addiction is both a good and bad news story; the proverbial glass indeed is as full as it is empty. On the good news side, we know that it is possible to lessen substantially the suffering and costs of opiate addiction and its concomitants—HIV-AIDS, tuberculosis and other infectious diseases, criminality, and death. Effectiveness has been demonstrated with a broad array of interventions, including education, provision of sterile needles and syringes, distribution of condoms, operation of safer injection sites, readily accessible and anonymous testing for HIV status, etc. Significantly, none of these interventions requires much by way of resources: they have been introduced in countries rich and poor, by “personnel” with little if any academic credentials or formal training, in bare-bones facilities (and in some instances, in no facilities at

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all!). The major factors that stand in the way are lack of commitment, disregard for the human rights of those afflicted, and a stubborn refusal to accept and implement “evidence-based medicine.” Particularly when seeking to assist drug dependent people to access and maintain HIV treatment, such barriers are literally a matter of life and death. In sum, there’s a tremendous amount that can be done, and very little excuse for not doing so.

So . . . where’s the bad news? One critical aspect of “the drug problem” that has been widely ignored by harm reduction and policy reform activists as well as die-hard prohibitionists, has been the needs of that segment of the opiate-addicted population whose aim is not the use of drugs in a safer, or less criminal, manner, but rather a life free of the pervasive, all-consuming, physical and/or psychological dependence on narcotics. These users simply want treatment and to eliminate or reduce drug dependency from their lives. Estimates vary as to the proportion of addicts who fall into this category, but it is surely sizable.

Clearly, not all those who would define themselves as wanting treatment are committed to giving up all euphoric substances, totally and forever. Some merely wish to lower the amount they consume and the impact that consumption has on their lives. In essence, they seek a greater degree of autonomy—a freedom of choice of behavior that is almost totally precluded by dependence on narcotics. The belief of most addicts that they will not be able to achieve this goal without treatment is frequently dismissed as a rationalization or, more simply, disingenuousness. However, the pessimistic and occasional nihilistic view that without treatment there is no hope, reflects a reality that most users have experienced personally, often repeatedly, in their own attempts to control or overcome their dependence. The fact that a small handful of others may succeed in doing so is neither a help nor a consolation.

It must be stressed that there is no valid claim to moral superiority associated with a professed desire to stop the use of illicit drugs. Drug use *per se* does not define people as evil, and should not subject them to risks of imprisonment, severe morbidity, and death. By the same token, there is nothing inherently saintly in pursuing a motivation to quit. But if, for whatever constellation of reasons, an addict wishes to change her/his life-style and become free of physical dependence on illicit drugs, help should and can be made easily available. This is a truth shared with harm reduction: namely there really are no insurmountable barriers to ensuring the provision of treatment to every single person who wants it.

## Treatment on Demand: An Achievable Goal

There are a number of dramatic examples where precisely this goal—immediate treatment for all who seek it—has been accomplished. First, there is the case of the New

York City Health Department in the early 1970s, when a methadone maintenance program with 44 clinics was established almost overnight, and at the end of 24 months had an active enrollment of 12,000. At the same time, other addiction treatment programs increased their capacity from 12,450 to almost 43,000, with growth in drug-free services keeping pace with that of methadone maintenance.<sup>1</sup> In the mid-1980s there began a geometric expansion of treatment capacity in New South Wales, Australia, and subsequently in Queensland, Victoria, and other States; the total enrollment rose from about 1,900 in 1985 to 11,600 in 1993—and on to 32,517 in 2001!<sup>2</sup> Europe followed suit: methadone had been illegal in Germany until the late 1980s; by 1992 there were 1000 patients receiving care, 13,500 by 1995 and over 45,000 in 2001. By 2004, the number receiving “substitution treatment”, including those with methadone, buprenorphine, and long-acting codeine, exceeds 60,000.<sup>3</sup> Germany was followed by Croatia, which, after independence, promptly developed a major problem of narcotic addiction and responded by relying on general practitioners to prescribe methadone, as needed and requested. Currently, almost half the estimated 15,000 opiate dependent Croatians receive methadone treatment, with the vast majority provided by community-based general practitioners (of some 2,400 GPs, about 1,000 provide methadone).<sup>4</sup> Most recently, France modified its regulations and policies to permit expansion of “substitution treatment” of opiate addicts from a mere 52 in 1995 to an estimated 80-85,000 at the start of the new millennium.<sup>5</sup>

But perhaps no illustration of making “treatment on request” a reality is more striking than that of Hong Kong.\*\* Within a decade of the prohibition of opium in Hong Kong—enacted by the British colonial government immediately after the Second World War—heroin had become the primary narcotic used by addicts.<sup>6</sup> The problem was exacerbated in the early 1970s, when a highly effective anticorruption campaign greatly increased the cost and lowered the purity of heroin. This caused a sharp rise in crime, and led many addicts to switch from inhalation to injection as the primary route of administration, with higher risks to health and life itself.

By the end of 1974, Hong Kong had a few small drug-free residential programs and a pilot methadone treatment clinic. The total capacity was no more than about 500 patients, yet the heroin addicted population was estimated to be at least 40,000. In the face of this crisis the government decided to not just continue pursuing maximum efforts to control drug trafficking, but also reduce demand for narcotics as much as possible by massively expanding treatment services.

Three highly respected senior physicians were dispatched to observe treatment approaches in the United States and Europe and assess their relevance and application to Hong Kong. The team was headed by of the director of Hong Kong's Medical and Health Services, who was accompanied by a government-employed physician and

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\*\*The following description of the development of methadone treatment is an abbreviated version of an account published previously in the *Journal of Public Health Policy* 6(4):526-538, 1985.

a leading private practitioner. They concluded that while all forms of treatment should be supported and encouraged, the scale of Hong Kong's crisis would require primary reliance on methadone. The specific model they selected was that of the New York City Health Department, which just a few years earlier had launched a methadone program that within 24 months had enrolled almost 12,000 patients (see above). The challenge facing the New York City Health Department was in some ways strikingly similar to that facing Hong Kong's health authorities: neither city initially had any addiction treatment infrastructure, nor any administrative or clinical leadership with experience in addiction issues and policies—let alone methadone treatment.

It must be stressed that Hong Kong at that time was in the midst of a severe economic crisis and had a shortage of all key professionals. Accordingly, they determined early on, largely on intuition, that they would have to deviate from the staffing patterns and other standards that were deemed “necessary” and were enforced by law in America. A description of the network of 28 methadone clinics that Hong Kong established between 1975 and 1977 follows. In virtually every detail the same policies and practices continue to this very day.

## Methadone Treatment Facilities in Hong Kong

Most of the clinics are housed in facilities operated by the Department of Medical and Health Services, which provides primary health care of all kinds to the community. Six of them, in areas of greatest demand, are full-day clinics and operated from 7 a.m. until 10 p.m. The remaining clinics operate in the evening and serve patients from 6 p.m. to 10 p.m. All are open every day throughout the year (during typhoons a mechanism exists to consolidate facilities and serve all patients in predetermined central locations). Administration of methadone is carried out across a simple table with no partition or other separation of staff from patients. Every clinic has required from the outset a payment of one Hong Kong dollar (approximately 15 cents in U.S. currency) at each visit; since all government health services in Hong Kong require some token payment, it was felt that addicts might view a treatment program that deviated from this practice with suspicion.

Admission has been handled expeditiously. The physician assigned to the clinic takes a brief medical and drug use history, performs a cursory physical examination, and prescribes the first dose of methadone—which is administered immediately after a telephone query to a central registry confirming that the individual is not already enrolled in another methadone clinic. The entire process takes less than a half-hour, and applicants begin treatment at once. There has never been a “waiting list” for methadone treatment since the initial program expansion in 1975.

The number of daily patients per facility ranges from about 50 to well over 1,000. No take-home medication is ever permitted—a policy which has posed little problem to patients, perhaps as a result of the extensive hours of operation of the clinics and their widespread distribution throughout the city.

Many physicians are “moonlighters” who are assigned by the Department of Medical and Health Services with only limited orientation to the program. There are almost no nurses employed in the clinics, and the dispensing of medication is left to members of the Auxiliary Medical Service, an organization which might best be described as a sort of medical National Guard. It includes shoe salesmen, bank clerks, housewives, teachers—in short, people from every walk of life, who volunteer to work in health facilities for a modest hourly payment. Very few social workers are assigned, and there are few other staff members who could be labeled as “counselors.”

Support services (medical as well as social) are provided primarily at the initiative of the patients themselves. There generally are no required visits to a physician or to a social worker. There is no formal “treatment plan.” Gradually the physicians have become somewhat more receptive to requests by patients for higher dosages. Urine is collected in all clinics, but haphazardly—urine results are never used to “punish” or “reward” patients.

## The Lessons of Hong Kong

Most international “experts” would be quick to condemn the manner in which methadone treatment is provided in Hong Kong, because it conflicts with deeply ingrained premises which guide “programs” elsewhere. The benefit in examining the Hong Kong experience lies in the opportunity it affords to review some of the fundamental concepts regarding addiction treatment.

The reality of what has been accomplished in Hong Kong is unmistakable, and cannot be ignored. One can not dispute the fact that a large, well-trained, multidisciplinary staff may be desirable, but it is definitely not a *sine qua non*. The same is true of comprehensive medical and social services as adjuncts to methadone treatment; they are desirable but *as Hong Kong demonstrates, programs can and do operate successfully without them.*

The Hong Kong experience does not address the reasonableness of the existing requirements imposed on methadone treatment programs by federal and state regulatory agencies in America, and by governments of most other countries of the world. Nor does the Hong Kong experience support or discredit such requirements. Yet the question is largely irrelevant. The real issue concerns the price associated with these requirements

when they curtail the number of patients who can be treated in the clinics which we operate. It is all well and good for experts to debate the desirability and necessity of each of the myriad regulations that exist. But these same experts must recognize, unequivocally, that their conclusions, which are often reached in an academic or bureaucratic vacuum, result in forcing street addicts who want and need treatment to continue to shoot dope because the clinics they turn to are at “maximum capacity” and cannot admit more patients due to regulatory constraints. In other words, what the controlling agencies are really saying is that it is better to remain a junkie, maintaining an illegal, socially destructive, medically hazardous, illicit dependence on heroin, than to enroll in a methadone treatment program which does not have quite enough nurses, whose counselors do not have the proper degrees, whose physical plants are less than ideal, that are located a few meters too close to a church or school or residence or shopping area. This is a very real, negative consequence of regulations. There is no escaping this reality.

What sets Hong Kong apart is that Hong Kong has accepted this reality. In fact, this is the *only* difference in perspective between Hong Kong officials and their counterparts in the United States and elsewhere. No one in Hong Kong argues that social workers and other types of counselors are unnecessary to provide optimal addiction treatment. No one expresses a preference for part-time, minimally trained, paramedical personnel as opposed to nurses. No one believes that there is some inherent goodness in providing methadone to over 1,000 patients in a single facility. But what the government officials and the clinicians in Hong Kong have recognized is that there is one bottom line that takes priority over all other considerations: a medical alternative to the continued use of illicit narcotics is known to be available, is known to be safe, is known to be effective—and thus must be made available to every single addict who seeks it.

In the United States and many other countries, critics and proponents of chemotherapeutic approaches to addiction have often heatedly vied with each other in insisting that medication can be only one small component of treatment and one which, by itself, is so inadequate that it must be legally proscribed. And so it has been. In trying to come to terms with the radically different practice in Hong Kong, and before dismissing the practice there as anathema, it is useful to contemplate how the more conservative, all-or none, perspective is viewed from afar. In countries like America, addicts who support costly heroin habits through petty crime, who risk HIV/AIDS, hepatitis, cellulites, and overdose with every single injection, and whose parents, spouses, children, and neighbors are endangered by their narcotic dependence—thousands of these addicts voluntarily apply for methadone treatment, only to be told to wait weeks or months for admission. Contrast this with Hong Kong, where enrollment in treatment has been encouraged actively for several decades through daily public service announcements in the mass media! The illogic of the former is mind boggling; the common sense of the latter is self-evident.

## Quantifying Effectiveness

Clearly, accepting the orientation that prevails in Hong Kong hinges upon the determination that the treatment provided is indeed “effective.” Accordingly, it is necessary to consider some of the changes with respect to the narcotic situation that have been associated with the establishment of Hong Kong’s network of treatment facilities.

Perhaps the most important judges of effectiveness are the individuals the program is intended to serve. This parameter is easy to measure, since “addicts vote with their feet.” Similar to the experience in the United States and in virtually every other country that provides methadone treatment, the demand for this form of medical help has been enormous, the paucity of “supportive services” notwithstanding. At the end of 1974, just prior to the initial expansion of the methadone program, there were some 500 patients enrolled. Immediately after the expansion, the enrollment rose to 2,000. In 1976, following further expansion, over 10,000 additional addicts were admitted. And yet, methadone has not replaced the other major voluntary treatment program, but rather complemented it (Table 1).

**TABLE 1.** Admissions to Hong Kong Addiction Treatment Programs, 1969-1981

<i>Year</i>	<i>Prison Treatment Centers</i>	<i>Voluntary Inpatient</i>	<i>Methadone Treatment</i>
1969	1,054	865	-
1974	1,960	2,337	1,480
1975	2,037	2,551	3,392
1976	2,160	2,413	10,400
1977	2,269	2,594	9,834
1978	1,999	2,767	10,291
1979	1,655	2,254	10,782
1980	1,518	2,592	8,046
1981	1,675	2,706	9,997

Of course, dropouts do occur—surely more than is necessary in consequence of the persistent reliance by physicians on relatively low doses of methadone (gradually, especially in the last 5-10 years, physicians have been more willing to prescribe higher doses of methadone). Nevertheless, the continued daily attendance at methadone clinics of some 8,000 patients—roughly one-fifth of the estimated target population—clearly has an enormously positive impact on the patients themselves and on the general community. Intuitively, it seems clear that among the great majority of these voluntary patients who go to clinics daily and pay their dollar for their medication, illicit narcotic consumption is reduced markedly—if not eliminated altogether.

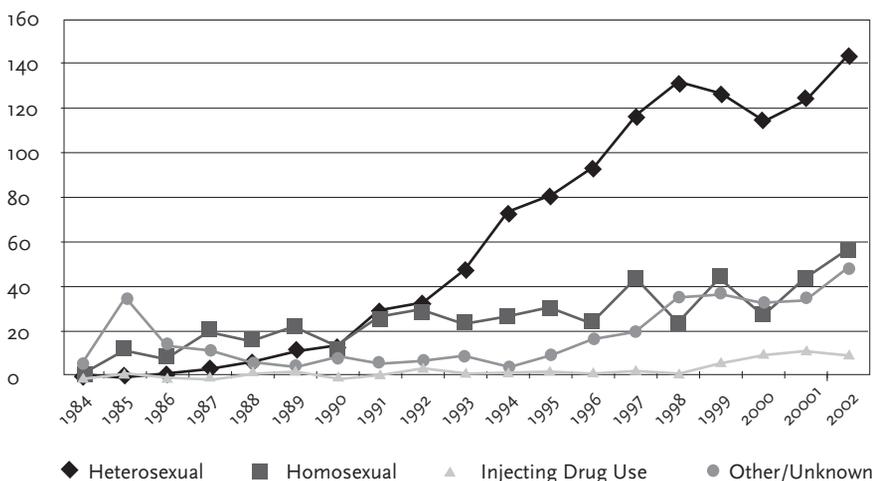
It is not necessary to rely on intuition alone, however, to document the impact which methadone treatment facilities have had. For instance, during the first five months of 1979, the daily attendance rate of the program averaged 6,550. In June of that year, as

a result of the drought in the “Golden Triangle,” which supplies Hong Kong with its heroin, there was an acute shortage and a sharp rise in street price. There was an immediate increase in attendance in the methadone clinics, and by the end of July the number reached 8,000—without additional staff. It takes little imagination to predict what would have happened without the availability of methadone treatment at this time: crime would have increased, lives would have been disrupted, and the costs would have been shared by addicts and the general community. The same pattern repeated itself in early 1982 and again in 1984 as a result of particularly large seizures of heroin-base by the Customs Service, and concomitant enhanced policing on the streets. On each occasion the supply of illicit drugs was curtailed sharply, and there was an abrupt increase in attendance at methadone clinics. The value of the methadone clinics as a “safety-net” both for the addict and the community at large is thus clear. This benefit, of course, is in addition to the role played by the program with respect to the sizeable cadre of stable patients who remain continuously in treatment regardless of the price of heroin.

The benefits associated with the availability of methadone treatment on demand to all addicts in Hong Kong are reflected as well in data of the criminal justice system. During the five years following the initial expansion of the methadone clinic network, the number of addicts sentenced to prison declined by 70 percent. This drop mirrors not only of the striking decline in individuals charged with relatively minor drug offenses, but also those convicted of non-drug criminal offenses.<sup>7</sup>

Finally, the experience of Hong Kong in containing the HIV-AIDS epidemic is particularly striking, especially when compared to most countries in Asia and the world. As indicated by Table 2, the association of opiate addiction and transmission of the human immunodeficiency virus has been minimal.<sup>8</sup>

**Table 2.** Risk of HIV Infection in Hong Kong (1984-2002)



Source: HIV Surveillance Report 2002 Update (Dept. of Health, Hong Kong S.A.R. Nov 2003)

## Conclusion

A well-known adage proclaims that “power unused, is power abused.” This definitely applies to the power to do good, to enhance lives, to reduce mortality, and to benefit not only the immediate targets of the intervention of power but the entire society. With regard to providing effective treatment to opiate addicts who want and need it, the ability to intervene, with benefit for all, is incalculable. Rationalizations that seek to explain why “we just can’t do it,” or “we just can’t do it here,” or “not just now,” or “not as well as we’d like,” may be offered in good faith. But they are unacceptable, for the simple reason that they cost the lives of people who are opiate dependent, and severely detract from the quality of life of everyone else.

Unlike so very many other tragic dilemmas facing modern society, “the drug problem” is one that can be addressed, and addressed with great success. We must respond to the challenge this capability represents.

## **In Focus: *Promise and Reality in Thailand***

*By Paisan Suwannawong,*

Underlying Thailand's treatment model is the premise that treatment is a right. This important principle is an outcome of five years of organizing and lobbying by people living with HIV/AIDS (PLWHA) and allied activists, and our commitment to working with the government to make AIDS treatment an immediate reality. But that reality does not yet extend to injection drug users (IDUs), who make up a major part of the epidemic in Thailand.

Today, approximately 20,000 Thais receive free ART through the government-operated program. Pilot projects providing ART to prisoners (currently 500 patients) and resident non-citizens and migrants are underway. For ex-users, technically it should not be a problem to access treatment, though there is still a great deal of discrimination within the health system against people with a history of drug use. Current users are in a much more difficult position. Until recently, the national treatment guidelines stated that current injectors had to quit using. Providers claim this is no longer a criteria, but in practice users face major obstacles because the health system lacks any additional support that could help them access and succeed in ARV treatment. Just as important, doctors are often not educated about possible interactions between ARVs and street drugs which would require different ARV dosing or drug combinations, or about hepatitis C co-infection.

The fundamental problem is the services that support current users, particularly in AIDS treatment. Health care providers and doctors have the attitude that IDUs are incapable of adhering to treatment because of their drug use. Methadone, which could help stabilize drug users who need HIV treatment or otherwise want to moderate or stop using street drugs, is to some extent available for free in Bangkok, but elsewhere in the country drug users must pay. Even in Bangkok, methadone is prescribed for detox rather than maintenance, and so dosages—and the period in which a person can be eligible for prescription—are limited.

Even in drug treatment centers it is hard to find information about HIV or hepatitis. Government policy does not target IDUs at all. There is no targeted prevention and treatment is almost impossible to access. The World Health Organization recently stated that the Thai government is “weak and ineffective” in providing treatment and prevention services to IDUs and other vulnerable groups, despite their success in reducing HIV prevalence in the general population and getting many people on free ART.

My case is a good example of the lack of knowledge in Thailand—among both HIV positive people and doctors. Five years ago my AIDS doctor tried to start me on treatment. I felt that my HIV was under control, but because he was concerned about my hepatitis C he wanted to start me on ARV treatment. I could not tolerate ARV treatment (AZT 3TC indinavir and ritonavir) at that time, and stopped after two months.

On a recent trip to the United States, I found out that my hepatitis C is becoming worse. A doctor there said that I probably need a biopsy and treatment. I met a friend with Hep C, who told me about the need for getting vaccinated against hepatitis A and B. In Thailand, I had never heard even this basic information necessary for protecting myself.

Back in Thailand, my AIDS doctor referred me to a liver doctor—AIDS doctors in Thailand do not have much co-infection experience—but this can take months in our health system. Once I was able to see a liver doctor, he said the cost for the viral load and subtype tests is about 7,000 baht (US\$170). I am still waiting for my test results, but have already learned that the cost of treatment would be between 300,000-400,000 baht per year (as much as US\$9,800, considerably more than the average annual income in Thailand), an amount I cannot afford. The Thai government's universal health care scheme covers every disease except HIV and chronic liver disease. A separate budget exists for HIV treatment, but nothing is available for hepatitis, which affects the vast majority of drug users in Thailand.

Hopefully some of these problems will change with the huge expansion of Thailand's AIDS treatment system that is now being developed. Currently, the AIDS Division of the Ministry of Public Health oversees treatment provision. The policy is to provide 70,000 people with ART by 2005 (primarily funded by the Thai government, with a portion paid through Global Fund grants). The plan is to provide ART at all 800 government hospitals, through new "Continuum of Care Centers (CCCs)," 200 of which should be established by the end of 2004. Each CCC has a team composed of a doctor, nurse, counselor, pharmacist, lab technician, and three people living with HIV/AIDS. They are trained to give information to incoming PLWHA, determine medical criteria for ART eligibility, conduct home visits for patients, and ensure their bi-monthly visits to the CCC. The involvement of people living with HIV/AIDS is crucial, and although the Thai Network of People Living with HIV/AIDS (TNP+) plays a major role with the support of the Global Fund, capacity to cover all 800 hospitals remains a significant challenge.

Currently, the fixed-dose combination, 'GPO-vir' (d4T/3TC/NVP) produced by the government pharmaceutical company is the standard first line HIV treatment, and

80% of those eligible use it at a cost to the government of 1,250 Thai Baht/month (or about US\$370 per year). The government currently imports drugs and negotiates with major pharmaceutical producers, but has also seriously considered compulsory licenses for key drugs. Under the current ART scale-up program, participants receive free cd4 counts twice a year and viral load tests once every 2 years. There are 19 cd4 flow cytometers in the country now, and 4-5 more will be purchased with Global Fund monies.

Many questions must still be worked out. Should the AIDS program be integrated into the national health care system? How can standards of treatment at private hospitals be ensured? Should procurement of medications be centralized to deal with varying demand in different parts of the country? How can we address problems of stigma, negative attitudes from doctors, and lack of awareness about treatment? How can the continuous exodus of doctors from practicing in rural areas be stopped?

The point is that Thailand now has a great opportunity to change course and develop programs that can reach drug users, decrease the number of new infections, and provide effective treatment for those who need it. To do so, drug users need much more information about how to take care of their health, and be more effectively supported by the community. We must immediately come together to develop national scale harm reduction programs in cooperation with all sectors of the health system. We urgently need to organize HIV and hepatitis treatment that IDUs can truly access, instead of pretending that our health is somehow unrelated to the rest of society. And of course if we don't address the criminal situation of drug users, who will feel safe to come for health care? What drug user will trust a health care provider if they are seen as a bad person who deserves nothing, let alone decent health care or other basic rights?

Finally, in the middle of the AIDS epidemic and the war on drugs, the only way we can survive is by trying to get more information, support our peers, and become more involved in policymaking and services. Only then will we have programs that really meet our needs on our own terms.

*The author is director of the Thai AIDS Treatment Action Group, and a founding member of the Thai Drug Users' Network.*

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The evidence from our experience in France is that adherence to HIV treatment need be no more of a problem among IDUs than in other categories of patients, provided that IDU patients receive the necessary social and medical support.

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# France: Meeting the Needs of Injecting Drug Users in HIV Care

By Michel Kazatchkine\* and France Lert\*\*

## Introduction

The HIV/AIDS epidemic has resulted in major changes in drug policy in France since the late 1980s, leading to a system of integrated drug- and HIV treatment for opiate dependent patients. In 1986-7, the first testing campaigns in prisons determined that over 50 percent of injection drug users had contracted HIV. Because the French Social Security System guarantees free-of-charge provision of the standard HIV treatment for those who need it, French patients living with HIV/AIDS have had access to HAART (Highly Active Antiretroviral Therapy) since 1996. At the same time, beginning in February 1996, buprenorphine became available in pharmacies under the commercial brand of Subutex and general practitioners obtained permission to prescribe it for use in drug maintenance treatment (DMT). Buprenorphine has since become established as the primary drug maintenance treatment medication in France, with an estimated 84,000 patients on buprenorphine treatment and 9,600 people in methadone programs (OFDT, 2003).

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## Drug Maintenance Treatment in France

In the late 1980s, a few general practitioners (GPs) started to prescribe low-dosage buprenorphine and slow-release morphine sulphate to heroin-dependent users—a practice bordering on illegal. AIDS activism, coupled with pressure from drug users on GPs to obtain substitution therapy, and in conjunction with international advocacy in support of harm reduction, led to this new treatment approach. The first attempts to increase the supply of methadone substitution for up to 1,000 patients began in 1994. This capacity of supply was not initially utilized, however, largely because of stringent conditions imposed on patients in order to be admitted to most drug treatment centers.

Following the approval of high-dosage buprenorphine in March 1995, two different regimens for buprenorphine and methadone were instituted. Since then, the French situation regarding the supply of substitution treatment has differed from other countries in three respects: i) buprenorphine rather than methadone has become the standard treatment, ii) GPs play a major role, and iii) patients under opiate substitution may be registered in the program anonymously.

Buprenorphine has been available since February 1996 under the brand name Subutex with three dosages (0.4 mg, 2mg, or 8mg) in a seven tablet box. Naloxone (an opiate antagonist) is not added to the buprenorphine. Subutex may be prescribed either in a drug treatment center or in family practice, and is dispensed in pharmacies for home use. Urine tests are not required at admission or during treatment. The maximum possible length for prescription and dispensing was 28 days. Since 1999, however, dispensation has been restricted to a seven-day period because Subutex was being diverted into the black market.

## France's Drug Treatment Network: Centers, General Practitioners, and Prisons

Substitution treatment is supplied in drug treatment centers (DTC), family health practices, prison health services and from methadone buses in Paris (since 1998) and Marseilles (since 2000). Drug treatment centers may prescribe Subutex which is dispensed by pharmacies. The centers also offer psychosocial care to clients. Services provided by drug treatment centers are free and may be anonymous at the patient's request.

Any general practitioner is allowed to prescribe buprenorphine and methadone following a patient's intake and stabilisation at a DTC. Consultations are provided on a fee-for-service basis, and prescribed drugs are covered totally or in part by health insurance. Thus, a large proportion of drug users can receive medical care and prescription drugs free of charge. A small amount of public funding was made available to encourage GPs

to establish drug treatment networks supporting a multidisciplinary approach to drug treatment. Such networks aim to improve training for clinicians, treatment accessibility, and quality of treatment.

The 1994 law on health care in prison states that medical and psychiatric care are to be accessible to prisoners as well as to the general population. Health care services in prison are now part of local general hospitals and are therefore independent of prison administration. According to this principle, substitution treatment, as with any other medical treatment, is not to be discontinued upon entry into prison. Dependent drug users are to be offered either drug-free treatment or substitution therapy with buprenorphine or methadone. Upon release, individuals under substitution therapy are to be given their medication for the next three days.

## An Integrated Approach to HIV Treatment for Injecting Drug Users

The model we have implemented in the Hôpital Européen Georges Pompidou in Paris and in other programs which offer HIV care for IDUs integrates elements of care specific to injecting drug users within an HIV program, rather than integrating HIV care into IDU programs. The key principles of this approach are as follows:

- ▶ having a physician who is capable of prescribing substitution therapy as part of the medical team in the clinic, and ensuring their collaboration with HIV/AIDS specialists on issues related to management of patients receiving both antiretroviral treatment and drug maintenance therapy;
- ▶ availability of the maximum possible number of high-priority services in one location (including, for example, dermatologists, psychologists, nurses specialising in adherence support, NGO volunteers);
- ▶ adjusting the operating hours of outpatient clinics to allow for maximum accessibility, for example by having regular evening hours.

One of the most important things is to have regular meetings of the whole team including medical professionals, nurses, and NGO volunteers working in the clinic with representatives of harm reduction teams and representatives of IDU groups. Frequent interaction and discussion is necessary in order to address the obstacles for effective HIV care for IDUs and for better understanding of the needs of these patients.

The evening clinic at Hôpital Européen Georges Pompidou opened in 1988, at a time of high levels of discrimination against people with HIV/AIDS. The aim was to

provide asymptomatic patients the opportunity to see their physician without disrupting their normal schedule (and thus without having to justify their absence from work for daytime appointments). The price the patients had to pay for this convenience was that everyone in the waiting room would know that everyone else there was HIV-infected. And also, somehow, in the frenetic activity of the hospital during the day, the trauma of being seropositive is more “diluted” than in the silence and isolation of the evening clinic. Even so, the evening clinic has grown. From 6 p.m. to about 11 p.m., four or five physicians work with one ophthalmologist, one psychologist, and one dermatologist. There is also a nurse, a secretary, and two to three volunteers. These volunteers from the NGO AIDES—one of Europe’s largest AIDS service organizations—have been present since the very beginning and offer valuable support to the patients. The medical professionals do not receive extra pay for their work in the evening clinic—it is understood and accepted as a normal commitment of working in an HIV department.

## Supporting Adherence to HAART: The Role of Buprenorphine Maintenance Treatment

The experience of the clinic has shown that that drug maintenance treatment plays an important role in effective delivery of medical care for IDUs and is a critical factor in their compliance with medical treatment and social and psychological rehabilitation. A high level of treatment adherence has been observed in patients with HIV receiving zidovudine and antituberculosis prophylaxis while being on methadone treatment. A number of trials have shown that methadone maintenance treatment is a key element of the adherence support for effective HAART utilization in IDU patients.

Use of buprenorphine that could be easily prescribed and monitored in out-patient care in France, compared with more strictly regulated methadone, has a number of potential benefits. The MANIF study (2000) assessed the effect of DMT with buprenorphine on adherence to HAART of IDU patients. Good adherence was evaluated as taking 80 percent of the prescribed medications during the week prior to a clinic visit. Among 164 patients infected through injecting drug use, 107 (65 percent) were shown to be adherent to HAART—a rate comparable to the general population in France of people living with HIV/AIDS and receiving antiretroviral therapy. Contrary to stereotypes existing among medical professionals, IDUs participating in a buprenorphine programme have shown very similar levels of adherence when compared to ex-IDUs who do not present continued opiate dependence (see Table 1).

**Table 1.** Non-Adherence to HAART in the MANIF 2000 cohort (n=164)

	Total N=164	Non-adherent N=57 {1}	Adherent {2} N=107	OR (95% CI) {1} vs. {2}
Drug use and DMT		%	%	
On buprenorphine DMT	32	21.9	78.1	1.0
Ex-IDU	113	34.5	65.5	1.9 (0.7 - 5.28)
Active IDU not on DMT	19	57.9	42.1	4.9 (1.2-20.8)

The main reasons for non-adherence have not been identified as specifically linked to illicit drug use alone, but instead to a variety of social and economic factors, including absence of financial resources, legal problems, housing status, youth, and alcohol consumption. This reveals the need to adequately address the material and social environment of IDUs as an important factor of their adherence to medical HIV care.

## Conclusion

The evidence from our experience in France is that adherence to HIV treatment need be no more of a problem among IDUs than in other categories of patients, provided that IDU patients receive the necessary social and medical support including substitution therapy. Thus, there is no reason to use adherence as an *a priori* alibi to reject access to life-saving therapy for IDU patients.

Buprenorphine therapy has been shown to be a useful tool for effective utilization of HAART in IDU patients and for supporting their adherence to a prescribed therapeutic regimen. Although the relatively high rate of buprenorphine diversion into the black market brings into question its use as standard treatment, methadone is often viewed both by patients and physicians alike as a less desirable option to be pursued after buprenorphine failure.

AIDS care facilities should be designed in order to meet the demands of IDU patients and to establish outreach infrastructures to which HIV-positive IDUs can come with the full confidence that they will have access to the most needed services (including a full spectrum of HIV care, substitution therapy, psychological counselling, and support as well as adequate referral to social services). A motivated and committed team

of medical doctors, nurses, psychologists, and peer counsellors is needed for effective work with IDUs in order to break the barrier of stigma and discrimination that is usually associated with medical institutions within the IDU community.

Expansion of comprehensive care is also needed: liaison work is required to improve psychiatric care for users with dual diagnosis. Social work both at the individual and the community levels are needed to assist in providing access to housing and employment for drug users.

Harm reduction policy has been effective in addressing the challenges of opiate addiction and the needs of drug-users with HIV/AIDS. Further improvements are still necessary—better quality of prevention and treatment services, continuous adjustment to changes in drug subculture, and the implementation of innovative policies to address the interests and rights of both the community at large and drug users.

Personalizing healthcare interventions based on the needs of IDU patients, the effective use of substitution treatment for opiate users receiving HAART, ensuring flexibility and a user-friendly approach in the healthcare setting—in particular through the involvement of peer counsellors and educators—are the most important elements of effective delivery of HIV care to drug dependent patients. Questions of adherence are not, therefore, in and of themselves an acceptable excuse for denial of HIV treatment for drug users.

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Success rates in using our intensive adherence promotion program in a patient population with high levels of poverty, substance abuse, and a range of psychosocial problems suggest that such services should be considered as part of routine care.

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# New York: Antiretroviral Treatment for Multiproblem Patients

By Jay Franklin Dobkin, M.D.\*

## Introduction

This paper describes a “Jumpstart” treatment program initiated in an urban clinic, Columbia-Presbyterian Medical Center in New York. The program’s hallmarks are a specific focus on intensive support for and education of the patient in terms of adherence to antiretroviral therapy. The program mainly targeted marginalized patients, including substance users who have undertaken therapy for diseases such as HIV and TB.

The clinical patient case below illustrates some of the critical issues facing Jumpstart clients and care providers. It also indicates the potential solutions that emerge when substance users and others with major psycho-social challenges initiate HIV therapy.

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## A Jumpstart Case Study

DA is a man in his fifties with a long history of substance abuse problems. He was an active heroin injector for over 20 years, which probably led to his HIV infection. He was in methadone maintenance treatment for a number of years and was able to keep a moderately high skilled job. In his forties, DA began using cocaine in various forms and drinking alcohol excessively. This was associated with several episodes of domestic violence leading to imprisonment and eventually loss of his job. His course in the HIV clinic was one of erratic attendance and poor treatment response. Eventually he was referred to the Jumpstart adherence program where a careful assessment was done by a health educator and a series of educational sessions were conducted by a peer educator. DA was assessed as intelligent, knowledgeable and motivated to take advantage of the opportunity to treat his disease. He was also, however, insistent that his ongoing cocaine and alcohol use was not a problem and that he could “handle it.” During his enrollment in the adherence program, which required him to return to the clinic weekly to pick up a pre-filled pillbox, he was often several days late and there were many longer lapses in his treatment that he either refused to explain or blamed on his wife or others. Then he disappeared for several months. Upon his return he reported that he had been jailed for domestic violence but hadn’t informed the prison health system of his status for fear of discrimination. He reentered the adherence program but developed an opportunistic infection and was hospitalized. On this occasion he agreed that his substance abuse was a major contributor to his medical and other problems and agreed to enter a residential drug treatment program as a condition of restarting his HIV therapy. His subsequent course has been dramatically different with excellent control of his HIV infection reflected in viral load values below 50 copies for over two years even though he reports at least occasional usage of cocaine and alcohol.

DA's case highlights how important it is for a patient to recognize that substance abuse was creating major problems in their life. DA's willingness to struggle with this problem and to accept help in doing so appears to have allowed him to control his addictions enough to maintain adequate HIV medication adherence. Since he was closely supervised during the time his behavior was most erratic, it appears that he avoided acquiring high level multi-drug resistance which might have precluded a good response when he later achieved high level adherence.

## Jumpstart: A Comprehensive Approach to Treatment

The need for strict adherence in order to achieve treatment success was not a surprise to most clinicians in the HIV field, but the challenges to achieving it remain great. In the late 1980s we were reminded by the explosion of tuberculosis cases in New York City that

multidisciplinary approaches to address such disparate issues as housing and substance abuse are an integral part of promoting successful treatment of many infectious diseases. But it was the implementation of directly observed therapy programs on a large scale that appeared to truly turn the TB tide. This experience informed the approach that was developed in our center several years later, when truly potent but complex HIV treatment regimens became available. There were obvious similarities to TB therapy: several drugs needed to be combined to assure success; like TB, the HIV virus was prone to rapid acquisition of drug resistance—especially if medicines were taken erratically or one at a time. When these TB or HIV drugs are combined and taken properly, resistance could be avoided and cure (TB) or long-term control (HIV) could be achieved.

Initially practitioners in our clinic attempted to provide the education, counseling and support their patients seemed to need. One early crucial observation made by our nurses was that some patients could not organize the profusion of pills they needed to take. Most were on three antiretroviral drugs three times a day (10-20 pills) as well as several medicines to suppress or prevent opportunistic infections (3-5 pills), and often several more for psychiatric or other illnesses. Some patients were unable to read English, some were illiterate in any language, some were developmentally or intellectually challenged such that they could not keep track of so many pills, and many were just overwhelmed by these and other demands on them.

The nurses questioned patients about their ability to organize their medications and began to offer help to those with problems. This included writing out charts that patients could use to remind them of their medication schedule and filling multi-chambered pill-boxes with all of the medicines the patient needed.

Soon two sources of grant support became available to establish a more thorough program. Through the Ryan White Care Act, a national AIDS treatment program in the United States, we were able to establish a treatment education program for patients beginning HIV therapy for the first time or experiencing difficulty with treatment adherence. Typically an HIV+ peer educator will conduct three one-hour individual sessions during which important aspects of the HIV lifecycle, human biology, drug effects and side effects, and the requirements for treatment success are reviewed. Another grant, from New York State, allowed us to incorporate these elements into a comprehensive program we call the Jumpstart Treatment Adherence Program.

Jumpstart has four elements:

- ▶ **Assessment:** Each patient referred to the program is interviewed by a health educator utilizing a structured interview protocol that focuses on identifying barriers to treatment adherence.
- ▶ **Education and Counseling:** A peer educator is matched with the patient on the bases of language, gender, and HIV risk background if possible. Three educational sessions are conducted as well as a home visit.

- ▶ **Team Evaluation:** A multidisciplinary team comprised of the Jumpstart Program staff, social workers, and nurses from the clinic meet biweekly with the clinicians to review the progress of the patient evaluation. Often obstacles are identified that may not have been apparent during routine clinical care. With the team's advice, the clinician will decide when to start antiretroviral treatment and select the regimen. In straightforward cases, this process can be completed in three to four weeks. If major obstacles are identified (such as active substance abuse, or depression) and it is felt that they represent an unacceptable risk of treatment failure, there may be prolonged delays while efforts are made to resolve these critical issues. Interventions may include referral for drug detoxification, securing stable housing, assistance and encouragement to patients as they disclose their HIV status to their relatives and close ones when necessary, or initiating psychiatric treatment.
- ▶ **Supervised Medication Dispensing:** Once patients in the Jumpstart Program begin treatment, medicines are distributed in pre-filled pillboxes on a weekly basis by members of the program staff. When patients return to pick up each new pillbox, they are counseled by a staff member, and problems with adherence or side effects are addressed. As therapy progresses, and patients are doing well, the pickup frequency is decreased to biweekly and then monthly. Eventually patients may graduate from the program.

In the last five years over two hundred patients have enrolled in the Jumpstart Program. These patients are almost equally divided between patients new to treatment and those who have failed in at least one previous treatment regimen.

Overall rates of treatment success have been quite high, as measured by the proportion of patients remaining in care and achieving sustained suppression of HIV. When compared to a cohort of historical controls, treatment-naïve patients were far more likely to achieve an undetectable viral load and to sustain it through one and two years of follow up. Among those in Jumpstart, 98 percent achieved at least one undetectable viral load during the first year of treatment, compared to 62 percent of controls who stayed in care at least temporarily. After one year all but one (41/42) of the Jumpstart group were still in active care, and 86 percent of them had viral loads that remained undetectable. In the control group only 37 of 52 were still in clinic at one year, and 28 were still on HAART. Of these 28, only 17 (61 percent) remained suppressed.

When intention to treat analysis, which assesses the original group the patient was assigned to and considers it a failure if anyone from this group stops treatment for any reason, is applied to this data, an even more striking difference is apparent: 86 percent success in the Jumpstart group compared to 33 percent among historic controls. In addition, patients in the Jumpstart program reached suppression at substantially faster rates than did the controls.

The management of patients who have already failed one or more HAART regimens is even more challenging. In addition to the factors which have contributed to treatment failure, often including poor or erratic adherence to the demanding treatment regimens required for HIV control, drug resistance is often present. This problem is compounded by the typical interaction between physicians and patients in which the patient downplays the problem of adherence and the physician is often more inclined to simply prescribe new drugs rather than investigate the reasons why the last regimen failed.

The approach of the Jumpstart Program is fundamentally different: if an initial regimen has failed there is a detailed assessment of the factors which may have contributed; when adherence barriers are identified there is a concerted effort to address and correct them. Only then is a new treatment regimen begun, and it is done so with close supervision and ongoing attention to the adherence challenges that have been identified.

Our initial results with this approach in treatment-experienced patients suggest two important points: 1) Many patients have difficulty staying involved with ongoing care and treatment necessary to achieve goals of treatment; and 2) despite the burden of psychosocial problems, including the substance abuse that characterized this group, there was a high rate of treatment success after one year on salvage therapy, which is a regimen designed for patients who have failed many previous treatment programs and have a high level of drug resistance.

The difficulty with retention in care is reflected in our experience with 97 consecutive treatment-experienced patients who entered the Jumpstart program. Nineteen dropped out of the program during the evaluation phase before the salvage regimen was begun, and 20 more left the program within one year of starting salvage HAART. Unstable housing was the only factor which predicted retention: only 5 percent of those remaining in treatment had unstable housing compared to 29 percent of those who dropped out. Injection drug use as the risk factor for HIV infection was not significantly more common in the dropouts than in the retained group (16 percent vs. 13 percent). Treatment success, defined as having an undetectable HIV viral load (<400 copies) after one year on salvage therapy, was accomplished in 66 percent of the 78 patients who remained in the program and started the salvage regimen. When an inventory of barriers to adherence was generated for each patient during the evaluation period and compared to treatment outcome, poor housing status was again a predictor of lack of success, as was active mental illness. Active substance abuse, however, did not predict a lower rate of success.

Assessing response to HIV salvage regimens is difficult since drug resistance may prevent successful suppression even when there is perfect adherence to the new regimen. Simply testing for resistance does not completely account for outcomes either, since many patients harbor HIV strains that are resistant to drugs they have received in past regimens and which may not be picked up by the standard available tests. In addition, there is heterogeneity in patients starting salvage regimens in terms of prior treatment exposure,

severity of immunodeficiency, and, perhaps, the fitness or replication capacity of the mutated virus. Nonetheless, it is clear that many—if not most—patients arrive at the stage of salvage therapy in large measure because of prior difficulty in achieving high-level adherence. Therefore aggressive remediation of adherence obstacles must be a top priority for any patient contemplating a new regimen intended to overcome prior treatment failure and drug resistance.

Our experience with salvage patients in the Jumpstart program indicates that such intensive efforts can lead to great success, possibly because many of these patients have been so erratic in their care that there may be less drug resistance than might have been expected at the point they enter the program. This is suggested by the observation that among salvage patients in Jumpstart treatment, success rates were comparable between double and triple class-experienced patients; and in the two class patients there was no difference between those who received a regimen containing a drug from the new class and those who didn't.

The use of an intensive adherence promotion program in a patient population with high levels of poverty, substance abuse, and a range of psychosocial problems suggests that such services should be considered as part of routine care, especially among similar patient populations. We have estimated that the incremental cost of such a program adds less than 10 percent to the cost of antiretroviral therapy in the first year, and is likely to pay for itself quickly in avoidable treatment failure, drug resistance, opportunistic infection treatment, and hospitalizations. The model is labor-intensive but relies almost entirely on peer educators and other non-medical personnel, and should therefore be applicable in many developing country settings. Although not designed or operated as a categorical program for substance abusers, the approach we have taken offers the intensive, multifaceted service and support vital for a client's successful enrollment, retention, and treatment.

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A comprehensive and effective strategy to confront AIDS worldwide necessitates both prevention and treatment, and respect for public health priorities and the human rights of the most vulnerable individuals and populations.

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# Argentina: Developing Quality HIV Treatment for Injection Drug Users

By Mario Pecheny\*

*These drugs [for hepatitis] give great results, I mean I always go for the best; I used to say, for instance, so, what's the hippest club? I always wanted to be in, so... you know, with drugs, it's the same: so, who's got the best drugs? ... I do the same with my disease. To get well I say: so, what's the best place?*

—Marcos, 31, drug user, former IDU, HIV negative, who successfully completed HCV and HBV treatments

## Introduction

The introduction of Highly Active Antiretroviral Therapies (HAART) in 1996 was a turning point for people with AIDS. In 2002, the World Health Organization (WHO) estimated that some 6 million people in middle- and low-income countries were in need of HAART. However, only 230,000 had such access at that time, and 170,000 of them were in Latin America.<sup>1</sup>

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Through a variety of means, some South American countries have been providing free and universal HAART for over half a decade; notably Brazil, Uruguay and Argentina. From the government perspective there are at least two arguments in favor of this policy: first, the impact of HAART in reducing deaths, and second, its impact in substantially reducing hospital admissions and treatment costs associated with opportunistic diseases. Furthermore, HAART treatment can drastically reduce mother-to-child transmission, and lowered viral load may also reduce horizontal transmission.<sup>2</sup>

## HIV and Drugs

The Pan American Health Organization (PAHO) estimates that 34.3 percent of the total cumulative AIDS cases in the Southern Cone (Argentina, Chile, Paraguay, Uruguay) and 23.7 percent of the cases in Brazil are among injection drug users.<sup>3</sup> After Brazil and Mexico, Argentina has the third highest AIDS figures in Latin America, with 27,000 cases, 36.3 percent among IDUs.<sup>4</sup> In Argentina, prevalence of HIV infection is very high among IDUs, ranging from 27 percent to 80 percent.<sup>5</sup> Co-infection, particularly with the hepatitis C virus (HCV), is extremely high, ranging from 80 percent to 92.3 percent of HIV positive IDUs.<sup>6</sup>

During the 1990s, injection drug users accounted for the majority of AIDS cases, leading NGOs and public health officials in South America to finally face the reality of the epidemic. The contexts of drug use in the region, however, are not homogeneous. Different uses, users, and generations of users have unique problems and needs.

In Argentina, the possession of illegal drugs is punishable by law. Since there is a stigma attached to taking drugs, drug users are liable to face a dual ostracism, for engaging in unlawful behavior and also for failing to conform to prevailing social norms. Although it is strict, Argentinean law can also be ambiguous. For example, those found in possession of illegal drugs are liable to be arrested, even for the possession of small amounts for personal use. However, they can opt for a temporary alternative to prison by admitting that they are drug addicts or have drug-related health or psychological problems.<sup>7</sup>

The stigma related to drug use is extensive. Drug users experience social rejection—even by health professionals—and prejudice against the physical attributes associated with drug taking. Sometimes users themselves think that these views are fair: for example, out of 400 IDUs interviewed, 70 percent agreed that they were “the main group responsible for spreading the HIV virus.”<sup>8</sup>

According to this study, 80 percent of IDUs reported that they had shared syringes, although 94 percent knew that this practice carried a high risk of contracting HIV. There is clearly a gulf between theoretical knowledge and concern on the one hand, and

actually taking precautions in risky situations on the other. Discrimination and exclusion actually increase the probability that drug users will behave in a way that endangers both their health and the health of others.

During the 1990s, the number of AIDS cases steadily increased in Argentina. At the same time, the government implemented a policy based exclusively on a “curative approach.” Few NGOs and local governments developed prevention programs focused on the most vulnerable populations. By the end of the decade, however, a solution was reached that put the Ministry of Health largely in charge of treatment while NGOs and other organizations were charged with prevention.

During the 1980s and 1990s, policies on drugs became even more repressive and extensive. In the face of the AIDS epidemic, the necessity of redefining Argentina’s predominantly curative and abstentionist paradigm and its repressive drug policies became evident.<sup>9</sup> Reforms to drug policy had to be made in order to open the door to a harm reduction approach.

## Harm Reduction

In Argentina, harm reduction programs proved effective in reaching IDUs in urban centers. First carried out by NGOs, they mainly targeted drug injectors who were practically or completely out of touch with medical and social services. Progressively, public health officials in cities such Buenos Aires, Rosario, and Santa Fe have endorsed harm reduction programs as a key element of their AIDS policies.<sup>10</sup> Finally, in 2003, the Ministry of Health itself launched a program on harm reduction and AIDS prevention.

Public health officials and governments in Argentina and throughout South America are generally not supportive of legalization of drugs or other radical measures. However, epidemiological data, pragmatic considerations, and the early results of harm reduction programs have made them enthusiastic supporters of this preventive approach towards IDUs. Besides health messages related to drug use, AIDS, or hepatitis, NGOs and public health officials often offer drug users information and advice on legislation and drug users’ rights.

Just as important as the interventions themselves are the gestures and attitudes from the practitioners who staff these programs. Drug users have consistently experienced negative treatment from every civic institution (e.g. the police, the prison system, the health service), and are comforted when they meet professionals who treat them as human beings worthy of respect. Thus, in spite of the challenges of such work, practitioners and peers working in harm reduction programs frequently remark on how rewarding their task is because of the expressions of gratitude they receive from the program’s beneficiaries.<sup>11</sup>

Drug users may be capable of responding rationally to information and public health services. Ethnographic and sociological research has shown that drug users are fully aware of the risks and harms related to IDU, including death (Pecheny et al 2002; Epele 2003).<sup>12</sup> The responsibility of the individual user to make an informed decision when the option to prevent harm related to of his or her drug use is available, must therefore be recognized. Behaviors of self-care and care for others are common among drug users, for example, by women taking contraceptives and undergoing prenatal care, by IDUs who complete a course of vaccinations against hepatitis B, and by those who pick up the results of their HIV tests (in Jorrat et al 2004's sample, 91 percent of 209 IDUs did so).<sup>13</sup>

Users and former users often work in outreach activities, peer education and counseling, equipment exchange and distribution, condom distribution, and even in more technical tasks like monitoring and evaluation. Using the "local knowledge" of the programs' beneficiaries has been crucial to their success, an aspect that should be taken into account when developing adherence programs. Users' involvement is, in itself, an instrument of social reintegration, and for some it can be an acceptable way of making a living.

## Prevention and Treatment

20 years of the AIDS epidemic have proven that prevention and treatment are inseparable.<sup>14</sup> In Argentina, since new treatments became available universal distribution of anti-retroviral (ARV) drugs has been implemented with the support of the National AIDS Program and other sectors of the health system (i.e. social security and prepaid insurance). Specific laws provide for the free and universal provision of treatment for people with HIV/AIDS, without discrimination as to the method of transmission.<sup>15</sup> In 2003, approximately 23,000 people were receiving HAART in Argentina, most of them through the National AIDS Program. Active and former users, their partners, and their children, constitute an important proportion of HAART recipients.

The following is a summary of two texts related to ARV for IDUs in Latin America. The first is a sociological study I conducted in Buenos Aires about the management of illness among people living with HIV/AIDS and/or hepatitis C. The second is a hospital-based study, conducted by prestigious health professionals in Buenos Aires, on their experience in treating HIV infection in IDUs. These studies illustrate that drug use may be a key factor affecting management and treatment of HIV.

## Daily Life with HIV/AIDS and/or Hepatitis C

In 2001-2002, at the University of Buenos Aires, I conducted a study on everyday life with HIV/AIDS and/or hepatitis C virus (HCV).<sup>16</sup> I interviewed adults who tested positive for HIV, HCV or both infections, including different categories of transmission.<sup>17</sup> In relation to the subject of this book, we found that once patients start treatment they have similar attitudes and problems with adherence and other aspects of therapy, irrespective of whether they were infected via sexual intercourse or drug injection.

### Diagnosis

Every person we interviewed, at the time of diagnosis, had a fairly well rounded knowledge of AIDS while practically none had information about hepatitis C. HIV and HCV positives learn of their diagnoses within similar contexts. Most of the subjects found they were infected when they or their partners presented symptoms, or when partners tested positive. Some women learned they were infected during or after a pregnancy. Others discovered they were infected during a treatment for a different affliction or while at an addiction recovery center. Coinfected interviewees first discovered their HIV status and only from subsequent tests, sometimes several years later, did they learn of their HCV infection.

Subjects infected by HIV, HCV or both reacted differently to test results. The initial reactions of HIV positive individuals are associated with death and feelings of guilt. Although attitudes toward the epidemic have changed over the years, most still seem to equate AIDS with inescapable death, hopelessness, fear, and discrimination, and it is within this atmosphere that an HIV positive person receives his or her diagnosis. Nevertheless, interviewees noted a change in their perceptions and attitudes once they gained access to information about treatment. For them, it was essential to modify the initial association of the disease with death. Otherwise undertaking any kind of life projects—personal or professional—seemed unthinkable. On the other hand, when faced with their HCV diagnosis, subjects were commonly perplexed and said they were unfamiliar with the disease. Access to information and treatment led to a more complete understanding of hepatitis C (as distinct from hepatitis A) and sometimes resulted in feelings of despair.

All the subjects that had been infected by HIV or co-infected with HIV/HCV through IDU had—prior to being tested—some idea that they could be infected. The same was true of partners of IDUs who became infected through sexual intercourse. Conversely, active and former IDUs who were infected only with HCV were surprised by their diagnosis. This is probably due to the relative lack of information of HCV as compared to HIV. AIDS is, among injection drug users, something to be expected, but this is not the case for hepatitis C. Test results came as a surprise to those non-drug users who were infected

via heterosexual sex with non-drug users, and to the one interviewee who received a blood transfusion. Among homosexuals there was no common response.

After diagnosis, HIV and HIV/HCV co-infected individuals spent some time in denial but eventually sought medical attention. Some who delayed getting medical attention went through a period of behaving recklessly, spurred by the diagnosis. Others did not believe treatment was necessary until visible symptoms appeared.

### **Treatments**

In Argentina, ARV is available through different sub-sectors of the health system. Although there are sporadic interruptions and logistical difficulties, people who need ARV receive it for free. We have studied how treatments become embedded within a person's daily routine, in line with their personal circumstances. In most cases, diagnosis does not drive people to seek treatment directly, but rather they wait until initial symptoms begin to appear, more or less visibly. The few who do begin treatment before symptoms appear are the ones who have better access to information about available treatments. Knowledge is not related to their level of education, but rather to firsthand observation of the disease—acquaintances living with HIV, friends or family in health services, or contacts at specialized NGOs. Access to groups familiar with the disease had a more powerful influence on the decision to initiate treatment than any abstract knowledge of the topic did. The circumstances under which a person decides to seek treatment are usually marked by acceptance and “owning” the infection. This acceptance may be linked to changes in drug habits and/or concern about children. In cases of co-infection, HIV/AIDS is the disease that receives the most attention and concern, while hepatitis C is addressed later for patients in drug rehabilitation.

We found very few cases where subjects had suspended treatment once they had begun. In general, when patients “own up to” or become aware of the disease, they are highly likely to adhere to their treatment program. According to the patients, the relationship they have with their physician is the key factor in promoting adherence. Once they find a professional who treats them “like a human being” and “really listens,” they are diligent in taking medication, doing blood tests, and carrying out other recommended treatments. Furthermore, some of the interviewees specified that there was a certain gender empathy with the professional treating them, typically mentioning among their doctor's virtues that, “as a man” or “as a woman”, the physician understands them. Once patients find someone they feel comfortable with, the relationship becomes compassionate. Information about more- or less- friendly professionals and services is widely circulated among networks of people living with HIV and AIDS, especially among drug users, gays, and transgender people.

From the testimonies in our study, we concluded that adherence to treatment is possible in spite of ongoing drug use. Adherence itself may contribute to reducing the risks

associated with drug use and sometimes leads to giving up drug use altogether. Yet despite this, most of the health professionals we interviewed in the second phase of our research perceived IDUs as non-adherents, even though they made up a substantial proportion of their patients.

Health professionals perceive drug users as conflicted and aggressive patients. They will say that most of their colleagues are reluctant to work with drug users, and complain also about their own lack of specific skills related to offering care to drug users. One of the key issues, according to our interviewees, is the alleged inability of drug users to follow rules. This perceived irresponsibility is part of the stereotype of drug users—who, as a result, may conform to such behavioral expectations.

The preliminary results of this phase of our study show heterogeneous attitudes among health professionals. Attitudes differ depending on job (doctors, nurses, social workers, pharmacists, administrative personnel), generation, and experience working with clients living with AIDS and/or clients who are drug users. Younger, better-trained professionals recognize the different uses of illicit drugs and the legal, social, and cultural ramifications of drug use (cf. preliminary results in Alonso et al 2003).<sup>18</sup>

Other clinical results show that drug users may be as adherent to treatments as non-users in similar socioeconomic conditions.<sup>19</sup> As a result of these findings, some services launched programs to train health professionals in dealing with drug users and overcoming their own prejudices toward working with this population.<sup>20</sup>

Stress and side effects were the most frequently stated factors for interrupting treatment—usually for short periods of time. The motivation to adhere to treatment came first and foremost from the trust developed with the doctor and second from achieving visible results. If treatment seems to work, this convinces the patient that it is worthwhile continuing to take the medication. Favorable results, however, can also prompt a less positive outcome: patients coming to believe that discontinuing treatment is viable, especially after many years of taking medication. This seems to apply to every person living with HIV or AIDS, regardless of the way in which the disease was contracted.

Finally, patients complained about the frequent interruptions in the provision of drugs (the government sporadically interrupted the provision of some drugs, due to financial and logistical difficulties; in these cases, social mobilization and individual lawsuits helped bring about governmental commitment to stabilize ARV provision). In fact, interruption in the provision of drugs is one of the major obstacles for adherence in Argentina. Also, patients must deal with frustrating administrative and bureaucratic situations in order to get their medications. These organizational factors result in difficulty in adhering to treatment.

### **Patient “expertization”**

In terms of the relationship with the doctor, the expertise that the patient develops about his or her condition leads to an important degree of empowerment for him or her. Individuals belong to social networks of persons directly or indirectly affected by AIDS, i.e. networks of gay people, former or current drug users, and people living with the disease, have a greater sense of autonomy.

Expertization means that the patients learn more about their own disease. This learning process encompasses many areas, including symptoms, test results, treatments, medication, usage of medical terminology, information about laboratories, legal rights, the reactions of other people (including health care professionals), and ingenuity in accessing supplies, institutions and professionals. Patients may even learn nursing techniques: performing some care procedures at home reduces the number of disruptions and allows people living with HIV and AIDS to lead more “normal” lives.

Former drug users have special skills they can bring to bear in implementing treatment—for example injecting their anti-hepatitis C drugs. Drug users have a certain *savoir-faire* (“smarts”) around syringes, needles, and substances. However, some have expressed mixed feelings about utilizing “*la Terumo*”—the same syringe they had used to inject cocaine. Claiming that she felt unable to face this challenge, one interviewee discontinued her treatment for hepatitis C.

Familiarity with the medication means knowing its quality, effects, contraindications, manner of employment, prices and how to obtain it and/or pay as little as possible for it. Medical terminology finds its way into everyday language. The people we interviewed claimed they kept abreast of scientific progress and developments in medical techniques. Furthermore, ingenuity in obtaining access to treatment and medication is key to improving one’s quality of life.

A core issue in expertization research is the role of networks of people with the same pathology and/or situation (former or current drug users, gays), before and/or after diagnosis. NGOs and self-help groups play an important part in the process of expertization, generally providing their support between the crisis point of the diagnosis itself and the “normalization” that comes later.

When families are affected by the same pathology this seems to speed up the process of normalization. When our subjects need to talk about personal matters or require help with disease management, most turn to a family member. This bond changes as a patient’s personal history with the disease progresses. Our subjects described various transformations of the relationship; at the moment of diagnosis, they occasionally faced accusations and feelings of guilt, but most eventually received concrete aid from their families. Support generally comes from mothers, siblings, and close friends who become involved in the patient’s world of medication, treatment, and care. Often times these relatives serve

as a voice of restraint when their relative living with the disease has a crisis or wants to suspend treatment.

In some cases people did not find emotional support in their close relatives. Some had a history of drug use and the fact that they became infected did not change the already tense relationship with their families. For emotional support during their illness these subjects usually turned to friends and professionals. Nevertheless, some IDUs experienced a turning point with their HIV diagnosis, causing them to reopen channels of communication with families that had, up to that moment, been estranged or excluded from their lives. In these cases the interviewees said that infection had its “good side” because they quit their destructive behavior and became more integrated in their families. Our subjects stated that their groups of friends, many of whom were infected themselves, occupied a major role in their lives.

Most received emotional support but few received economic support. Those who did receive such support were, in general, upper-middle class, while those who did not were mostly lower class. Since 2001, several local AIDS programs have distributed food or food vouchers to the needy. These programs improve adherence and the quality of life of people with HIV/AIDS. People with hepatitis C and who are HIV-negative do not have access to such programs.

The above findings support the idea that people who use or have used drugs are able to follow treatment providing they are able to take responsibility for their situation and find the resources to cope with the extremely difficult social conditions and personal problems associated with the diagnosis. However, current social and economic climates are still too challenging for most drug users to overcome.<sup>21</sup>

In order to face what are frequently difficult situations, a comprehensive treatment approach should be put in place. Personal and social conditions—including drug use—must be taken into account in the design of treatment programs. Health professionals know that this is not an easy task, especially in such resource-limited settings as Latin American public hospitals. However, some successful examples do exist.

## A Study of Drug Users in a Buenos Aires Hospital

Doctors Graciela Moscatello, Patricia Campello, and Jorge A. Benetucci, work at the Dr. F. J. Muñoz Hospital of Infectious Diseases, an important public hospital that treats AIDS in Argentina. The following is a summary of an article they published (2003) describing their experiences in treating IDUs and the positive results of their comprehensive approach.

From 1983 through 2001, a total of 12,292 people attended their HIV infection unit at the Hospital for HIV testing. Of these, 27 percent (3319 individuals) were IDUs.

The most frequently diagnosed complications were blood borne infections, sexually transmitted diseases, and tuberculosis. The prevalences were as follows: HIV 80 percent, HCV 92 percent, and HBV 73 percent. Of 1472 clinical events that occurred in the unit's patients during that period, 65 percent (957) involved IDUs. Thirty five percent (515 of 957 events) of these events were diagnosed as tuberculosis (TB).

In response to the historic exclusion of IDUs from the public health system, Moscatello et al. implemented "a strategic and integral frame of investigational actions" that would allow them to diagnose the emergencies associated with drug consumption, thus allowing proper therapies to be applied. The study lasted 21 months (April 2000-December 2001) and 108 HIV-infected IDUs were enrolled (73 men and 35 women).

The authors classified patients into 4 four stages (A to D) of increasing gravity of drug abuse called a TMSP score that allowed for individualization of the therapeutic priorities demanded by each patient, the choice of specific treatments, medical follow-up, and clinical examinations during their evolution.

Stage A examined the age at which patients began using drugs (56 percent between 11 and 15 years old, 26 percent between 16 and 20, 11 percent between 21 and 25, and 7.5 percent at age >26); and the duration of use of injection equipment (46 percent for >10 years, 26 percent for 6-10 years, and 25 percent for <6 years). This stage also revealed that the most frequently used or combined drugs were cocaine, benzodiazepines, and marijuana, and severe alcohol consumption was common among patients. Eighty one percent of patients had criminal records.

Stage B examined medical follow up and showed that 56 percent were already aware of their HIV status. However, they had not had any medical follow-up or received any kind of treatment. Thirty eight percent of the patients had sporadic or discontinued medical follow-up visits, but they had not been tested for HBV or HCV. During the study, 60 percent of the patients had positive results for HBV, 81 percent for HCV, and 43 percent for TB (only 1 case of multi-drug resistant TB).

Stage C examined the family and social situation. Joblessness was high among the patients, with 55 percent unemployed, and only 12 percent holding steady jobs. About one-third of the patients worked sporadically and were not supported by social security. In terms of housing, 29 percent had permanent homes, 56 percent lived in marginal areas, 12 percent lived in the streets, and just under 3 percent were in prison. Sixty three percent of the patients had pending or ongoing trials, and 28 percent of the patients had served jail time for robbery.

Stage D provided a psychiatric evaluation and found that 70 percent of the patients had not had any significant alterations in personality; moderate alterations were observed in 23 percent of the patients; and 6 percent had significant personality alterations.

At the beginning of the study, only 7 of 108 patients were in a low gravity stage related to drug abuse, whereas 40 patients were in the low gravity stage by the end of

the 21-months study ( $p < .0001$ ). See the following table on the initial and final distribution of patients in the study cohort according to TMSP gravity of drug abuse stage (p. S345):

<i>Stage</i>	<i>At beginning of study</i>	<i>At end of study</i>
A (low)	7	40
B	58	40
C	33	18
D (high)	10	10

According to the authors, “of 40 patients who eventually arrived at stage A [low gravity stage], 30 were indicated to begin antiretroviral therapy according to the criteria existing at that moment. Patients began antiretroviral therapies and maintained good levels of adherence, with a parallel stabilization of virologic and immunologic parameters of infection. However, they continued to consume psychoactive drugs, to a lesser extent than before” (S345).

Of the 91 patients initially classified in drug-abuse gravities [intermediate] stages B and C, 33 (31 percent of the total enrolled) lowered their score and switched to stage A. This was a significant improvement, especially compared with their previous situation of exclusion from the health system. This benefit was achieved by working on social situation factors. A high rate of unemployment, a lack of income and housing, and involvement with the judicial system made it very difficult for them to maintain a stable relationship with the health care centers. Nevertheless, they found evidence to refute the idea that IDUs should first reach substance abstinence before beginning treatment. Instead, the main objective has always been to help IDUs tackle the social circumstances that facilitate drug consumption.

“The combination of both major factors, that is, improvement in dealing with social problems and the absence of pressure to attempt drug abstinence, permits diminishment of the magnitude of health-risk for these patients. This means that they can achieve a reduction in harm to their health while being connected with the hospital without being pressured to quit drugs” (S345). These findings are consistent with the people with aids (PWA)’s and drug users’ perceptions, analyzed by the ethnographic and sociological studies.

Professionals at this unit used a variety of resources to resolve the multiple problems that IDUs face:

- ▶ They tried to find free accommodation for homeless IDUs, with the support of the Buenos Aires local authorities.
- ▶ They connected those persons in need of food with different community food providers, social service organizations, etc.
- ▶ They obtained free access to public transport for IDUs, thus enabling them to reach the hospital (cost of transportation is one of the main barriers for access to health care).
- ▶ They completed the complicated administrative formalities to include these IDUs in the National AIDS Program, which offers the chance to access HAART, prophylactic medicines for opportunistic infections, viral load measurements and CD4 cell counts.

The authors conclude that “both the support to deal with social matters and the softening of pressure to achieve substance abstinence, which is hard to achieve rapidly and in a voluntary fashion, can significantly improve the relationship between IDUs and the health care system, thus contributing to improved care of their clinical condition as well as a reduction in harm for them and for their partners. Parallel to this improvement, a decrease in personal, familial, and social violence was also observed.” Many in Argentina would share these conclusions.

In Buenos Aires, doctors Ben Linas and Marcelo E. Vila, in a publication of the AIDS Coordination of Buenos Aires, ask “Is it possible to treat drug users with HAART?” Their answer is “yes.” AIDS Coordination, together with public hospitals and NGOs, has been promoting both harm reduction programs and access to treatment.

According to Linas and Vila,<sup>22</sup> “A variety of social and behavioral factors affect adherence to HAART. Therefore, it is important to identify and understand them before starting the therapy. It is also important to understand factors other than drug use. The notion that drug users do not adhere to therapy disregards the effects of marginalization, poverty, domestic violence, psychiatric disorders, and the poor doctor-patient relationship in the lives of most drug users. Moreover, not all drug users lead chaotic or disorganized lives. If we reduce the barriers to medical care, we can improve IDUs adherence to chronic anti-retroviral regimes. Specific interventions to enhance adherence in health centers, training of pharmacists, nurses, and health personnel, peer counseling, medical supervision, and patient’s own initiatives relating to adherence are beneficial strategies.” IDUs are interested in improving their health, if access is facilitated. In one of their studies, for example, out of 174 active IDUs having received voluntary counseling and testing on HIV and hepatitis, 90 percent picked up test results and 80 percent completed the three doses of HBV vaccine.<sup>23</sup>

The AIDS Coordination study<sup>24</sup> offers the following conclusions:

- ▶ Many drug users can adhere to antiretroviral therapies.
- ▶ Drug users living with HIV who initiate treatment and continue it with a qualified health team obtain clinical results similar to other patients.
- ▶ Social and individual factors impact adherence to antiretrovirals.
- ▶ It is impossible to isolate a single factor as a defined predictor of low adherence.
- ▶ Programs specifically designed to address the most vulnerable populations improve the adherence in those populations.
- ▶ It is important to consider the medical and social context of the patient before starting or postponing HAART.

In Rosario, a study conducted by the Municipal Program on AIDS<sup>25</sup> reaches similar conclusions:

- ▶ Tailored and friendly services are well accepted by drug users, who tend to improve their attitude about health when given the proper information, means, and support.
- ▶ If health care workers are correctly trained, their aim in treating drug users can evolve from abstinence to harm reduction.
- ▶ Relationships among drug users and health care workers can and should be moderated by trained health care promoters.
- ▶ Many young male and female users of drugs expect pregnancy, so the role of the condom as a contraceptive device needs to be addressed as a part of effective counseling.

## Conclusion

These discussions about access to HIV treatment for IDUs are familiar to us. They are similar to the discussions that have been held about access to HIV treatment for poor people in poor countries, and the prejudices are the same. The lessons are also the same: a comprehensive and effective strategy to confront AIDS worldwide necessitates both prevention and treatment, and respect for public health priorities and human rights of the most vulnerable individuals and populations.

Experiences from Latin American<sup>26</sup> show that “under the right circumstances and with sufficient political commitment, developing countries can provide quality care for PWA. Whereas coverage in the region is far from complete, Brazil and other countries in the Latin American and the Caribbean region have made the case for antiretroviral therapy being *available to all people living with HIV/AIDS*. The challenge remains to build

on the example and make antiretroviral therapy *available to those in need*, regardless of where they live. By providing antiretroviral to those in need, people are more willing to be tested, links are built to vulnerable and marginalized populations, and the stigma and denial that often hinder the fight against HIV/AIDS are reduced. The challenge remains to expand these benefits, which until now have been reserved for a few.”

# Notes

## Introduction

1. According to HIV/AIDS Surveillance in Europe. European Centre for the Epidemiological Monitoring of AIDS. December 2002. [http://www.eurohiv.org/reports/report\\_68/pdf/report\\_eurohiv\\_68.pdf](http://www.eurohiv.org/reports/report_68/pdf/report_eurohiv_68.pdf). IDUs represent 90 percent of registered HIV-positive cases in Russia and from 60-80 percent in the Baltic states, Central Asian nations, Malaysia, Ukraine, Vietnam, and parts of India. (See Reid, G. and G. Costigan. 2002. *Revisiting the 'hidden epidemic': a situation assessment of drug use in Asia in the context of HIV/AIDS*. Fairfield, Australia, The Centre for Harm Reduction at the Burnet Institute.)

2. Similar trends are found elsewhere in the region. For example, according to *HIV and Human Development in Central and Eastern Europe and the Commonwealth of Independent States: Reversing the Epidemic—Facts and Policy Options*, a UN Development Programme report released in February 2004, the number of people living with HIV in Estonia increased from eight in 1996 to 3,400 in 2001, and 84 percent of current HIV cases in Estonia are attributed to injection drug use. Also, in Kyrgyzstan, some 80 percent of all injection drug users were estimated to be HIV positive by the end of 2003, an increase of 50 percentage points from two years before.

3. UNAIDS. 2002. *Report on the Global HIV/AIDS Epidemic*. Geneva, The Joint United Nations Program on HIV/AIDS.

4. Significant funding for HIV treatment has been raised, pledged, or allocated in recent years by The Global Fund to Fight AIDS, Tuberculosis, and Malaria; the World Health Organization's 3 by 5 initiative (which aims to provide ARV access to 3 million people in the developing world by the end of 2005); the Gates Foundation; and the U.S. government (through its PEPFAR initiative), among others. Other organizations, notably the Clinton Foundation, have helped broker deals lowering the price of antiretroviral (ARV) drugs and are assisting national governments in the design and implementation of treatment plans.

5. Even drug users who have already sought out harm reduction services may have few ties to health services if institutional barriers remain to their access. A survey by the Central and Eastern European Harm Reduction Network (CEEHRN) found that 73% of IDUs had no access to basic health care from any source. See CEEHRN, 2002. *Injecting Drug Users, HIV/AIDS Treatment and Primary Care in Central and Eastern Europe and the Former Soviet Union*. Vilnius, Central and Eastern European Harm Reduction Network.)

6. CEEHRN 2002.

7. Wolfe, Daniel; Malinowska-Sempruch, Kasia. 2004. *Illicit Drug Policies and the Global HIV Epidemic: Effects of UN and National Government Approaches*. New York, Open Society Institute.

8. CEEHRN 2002.

9. Gray, Ronald H., M. Wawer, et al. 2001. "Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda." *Lancet* 357:1149-53.

10. Berkman, A. 2001. "Confronting global AIDS: Prevention and treatment". *American Journal of Public Health* 91(9): 1348-9; Orrell, C., D. Bansberg, et al. 2003. "Adherence is not a barrier to successful ARV therapy in South Africa". *AIDS* 17(9): 1369-75.

11. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC). "Hepatitis C Virus and HIV Coinfection," September 2002; online: [http://www.cdc.gov/idu/hepatitis/hepc\\_and\\_hiv\\_co.pdf](http://www.cdc.gov/idu/hepatitis/hepc_and_hiv_co.pdf).

12. Altice et al have shown that from the cohort of IDUs receiving ARV treatment from a mobile needle exchange point, 70% reached effective clinical outcome in six months (25% CD4 increase and viral load <400 copies) compared to 40% in the group of IDUs that did not attend the needle exchange van. (Altice et al, 2nd IAS 2003. Paris, France; abstract 40).

13. Data on drug users and HIV are considered difficult to obtain for several reasons. For example, political sensitivities make many governments reluctant to collect or report information about HIV, drug users, or both; in addi-

tion, drug users frequently avoid testing or treatment settings for fear of incarceration or stigmatization. Registered HIV cases therefore tend to include only those drug users who have been incarcerated or tested against their will by prisons, hospitals, and other institutions that may be hostile toward drug users. Health ministries and assessments by outside epidemiologists suggest that such samples may underestimate actual cases by anywhere from two-to tenfold. (See, for example: USAID. 2002. *The HIV/AIDS epidemic in Central Asia*. Online: [http://usaid.gov/locations/europe\\_eurasia/car/hib\\_aids/htm](http://usaid.gov/locations/europe_eurasia/car/hib_aids/htm).; Hing, P.M. 2003. *The HIV/AIDS Situation in Vietnam in 2002*. International Harm Reduction Association, Bangkok; Human Rights Watch. 2003. *Fanning the flames: How human rights abuses are fueling the HIV epidemic in Kazakhstan*. New York, Human Rights Watch; U.S. Russia Working Group. 2003. *On the frontline of an epidemic*. New York/Moscow, Transatlantic Partners Against AIDS/East-West Institute.

14. UNDP. 2004. *Reversing the Epidemic: Facts and Policy Options*. Geneva, United Nations Development Programme.

15. USAID Central Asia Infectious Disease Network. "HIV/AIDS in Central Asia." Online: [http://www.usaid.gov/locations/europe\\_eurasia/car/hiv\\_aids/hiv/hivproj.htm](http://www.usaid.gov/locations/europe_eurasia/car/hiv_aids/hiv/hivproj.htm). Accessed June 8, 2004.

16. Reid and Costigan 2002.

17. Transatlantic Partners Against AIDS. "Russia reaches 250,000 registered cases of HIV infection." Online: [http://www.tpaa.net/articles/reg\\_091203\\_hiv.html](http://www.tpaa.net/articles/reg_091203_hiv.html). Accessed June 8, 2004.

18. According to estimates provided by the Chinese government, more than 1 million people are already infected, 60 percent of whom contracted the disease through injection drug use. Wolfe, Daniel. "Condemned to Death," *The Nation*, April 26, 2004. p. 4.

19. Reid and Costigan 2002; Kamarulzaman 2003.

20. Haring, S. 1991. "Death, drugs, and development: Malaysia's mandatory death sentence for traffickers and the international war on drugs". *Columbia Journal of Transnational Law* 29(2): 368-405; UNAIDS/UNODCCP. 2000. *Drug use and HIV vulnerability*. Geneva/Vienna, Joint United Nations Programme on HIV/AIDS / United Nations Office for Drug Control and Crime Prevention.

21. PRC Ministry of Foreign Affairs. 2002. *Constantly strengthening drug control legislation*. <http://www.fmprc.gov.cn/eng/4519>. Accessed June 27, 2003.

22. UNAIDS/UNODCCP 2000; Reid and Costigan 2002; Human Rights Watch 2003; U.S. State Department 2002.

23. Wolfe 2004.

24. Vu Doan Trang, 2001; Higgs 2003.

25. UNAIDS/UNODCCP, 2000

26. 17 See, e.g., Human Rights Watch, "Abusing the user: Police misconduct, harm reduction and HIV/AIDS in Vancouver" (New York, May 2003), pp. 8-14; Human Rights Watch, "Injecting reason: human rights and HIV prevention for injection drug users" (New York, September 2003), pp. 28-30.

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## Brazil

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institutes (4 studies), the prevalence was 48.1%; among 136 hospitalized patients (2 studies), the prevalence was 49.5%; among 2708 IDUs receiving drug treatment (7 studies), the prevalence was 39.0% (27.0-63.0); and among 26 female sex workers (2 studies), the prevalence was 47%.

6. In 2001, 63% of 200 IDUs interviewed by Kornblit et al (Kornblit A et al. 2004. *Nuevos estudios sobre drogadicción. Consumo e identidad*. Biblos, Buenos Aires) said they had been tested for HIV and 59.8% of them were HIV positive; 41.5% had been tested for HCV and 70.8% of them had hepatitis C; 80% of the HIV positive were co-infected with HCV. These results are consistent with prevalence studies. In 1999, 58.5% of 484 people living with HIV were co-infected with HCV, and 92.3% of IDUs living with HIV were co-infected with HCV (Fainboim H. et al. 1999. "Prevalence of hepatitis viruses in an anti-human immunodeficiency virus-positive population from Argentina. A multi-centre study", *Journal of Viral Hepatitis*, 6, 53-57). In 2003, a study conducted with 174 street-recruited IDUs from Buenos Aires, presented the following results: only 37% had no viral infections, whereas 63% were infected with 1 or more viruses. Seroprevalences were 44.3% for HIV, 54.6% for HCV, and 42.5% for HBV. Among the 77 HIV-infected persons, only 5 persons were not coinfected with other viruses; 88.3% were coinfected with HCV and 68.8% were coinfected with HBV (Weissenbacher et al. 2003. "High Seroprevalence of Bloodborne Viruses among Street-Recruited Injection Drug Users from Buenos Aires, Argentina", *Clinical Infectious Diseases*, 37 (Suppl 5): S348-52.).

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11. In the barrio of Avellaneda, NGO Intercambios directs a program financed by UNAIDS in which users take care of their peers. Juan tells a story: "I was working outreach, in a corridor, handing out condoms and needles. At ten-o'clock at night a person came up to me and said, 'I do not have a needle.' At that time of night a syringe is more expensive than a packet of cocaine, and that is why there is so much needle sharing. The person said to me, 'how much does it cost?' and I said to him, 'nothing, take this pamphlet, some condoms, and the syringe.'" Irma adds that she is happy because "I am helping people to not share so that they will not be as stupid as we were, because before, we did not educate ourselves." Diego summarizes his experience, "Before, when I injected, I never used to wash my hands. Now, when I inject I hear the voice of Paula telling me to wash. They didn't come preaching 'don't use drugs,' they said 'take care of yourself too.'" (Melamed. 2000. "Sida y drogas: Cómo conjugar el verbo 'prevenir'", *La Nación*, Buenos Aires, October 15.)

12. Pecheny M et al. 2002. *Vida cotidiana con VIH/sida y/o con hepatitis C: diagnóstico, tratamiento y proceso de expertización*. Buenos Aires, CEDES; Epele M. 2003. "Changing Cocaine Use Practices: Neo-liberalism, HIV-AIDS, and Death in an Argentina Shantytown", *Substance Use & Misuse* 38 (9), 1189-1216. As Epele (2003: 1203) points out, "it became clear that young drug users and some long-term drug users thought of it [suicide] within a variety of deaths suffered by HIV-infected people who used to inject cocaine: deaths from AIDS, people killed by police, deaths by overdoses, and killing among gangs outside or inside jail."

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17. The intentional sample was made up of 27 adults: 13 infected with HIV, 5 infected with HCV and 9 who were co-infected with both HIV and HCV. Ten interviewees were infected through heterosexual sex, 9 by IDU, 7 men by sex with men, and 1 by blood transfusion.
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21. In this sense, based on her experience in a shantytown, Maria Epele points out that the main factor related to access to treatment and adherence is not to be found exclusively in the drug use, but in the extremely difficult living conditions. The main variables are the extreme poverty, the lack of access to services, the precariousness of life: drug abuse and AIDS are grave problems in a long list of grave problems. "ARV therapy in IDUs is no different from therapy for other HIV patients. Maybe, in some cases, it is better to use formulas with fewer pills, every 12 hours so as to simplify treatment and improve adherence. Some substances such as morphine (whose use is rare) may interfere with ARV. It is important to keep in mind that most IDUs that are still alive knew of their HIV status from one of their periods spent in prison. Even though testing in prisons should be consensual, this is the most frequent way they learn of their serostatus. They generally start therapy there; they are taken to a health service by penitentiary agents and receive antiretroviral drugs. Once released, few continue treatment, irregularly at best. Most stop injecting and start inhaling – in general, because of the current bad quality of cocaine, a spontaneous strategy of harm reduction. Besides, there are some occasional injecting users with high use of different drugs and alcohol, whose adherence seems very low, especially among the poorest, hardcore cocaine users. They come to hospital emergency rooms, due to opportunistic infections or other reasons, are hospitalized and often die quickly. Some take medication only rarely, so they frequently have opportunistic infections like brain toxoplasmosis, pneumonia, or tuberculosis. But they can't even afford bus fare, and they face a high level of discrimination in their neighborhoods. The central issue here is decentralizing and sophisticating care and assistance: it is necessary to go where the people's needs are, follow-up, get therapies to people; extreme social exclusion makes very difficult to them to follow a "normal" pattern. Finally, each case must be considered individually: some people want to be treated and do not have access; some other people do not want to be treated and are forced to; and most of them have other, more urgent priorities" (Maria Epele, personal communication).
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