

HCLU on HIV/AIDS

The spectacular development of modern medicine gave rise to the confidence that epidemics are a matter of the past. This confidence has now been seriously challenged by the HIV/AIDS epidemic. The first cases of AIDS were recorded in June, 1981 and no successful cure or vaccine has been developed ever since, although effective drugs to treat at least the symptoms of the illness have been developed.

The major high-risk groups are people who have traditionally faced poverty, ostracism and discrimination on account of their lifestyles. This has made it inevitable for public health officials to re-examine measures traditionally used to combat infectious diseases while taking into account three internationally recognized principles, namely

- informational privacy;
- the right to be free from discrimination;
- equal access to health care.

The main focus of this Policy Paper is on the question how human rights can be and are in effect protected in the public health domain.

What is the Epidemiological Picture of HIV/AIDS Today?

WORLDWIDE

The number of people with HIV/AIDS is about 42 million worldwide. According to a UN estimate, another 5 million contracted the epidemics in 2002 alone. With 3,1 million AIDS-related deaths during the same year, HIV/AIDS definitively challenges the notion

that modern medicine is capable of eliminating infectious disease epidemics. The HIV/AIDS epidemic began in North America in the early 1980s and spread quickly to the rest of the world during the decade. The first diagnosis of HIV/AIDS in Eastern Europe and Central Asia was recorded at the end of the 1980s. The areas which are most affected are in developing countries, in regions such as Sub-Saharan Africa, with has a prevalence rate of 8.4% –

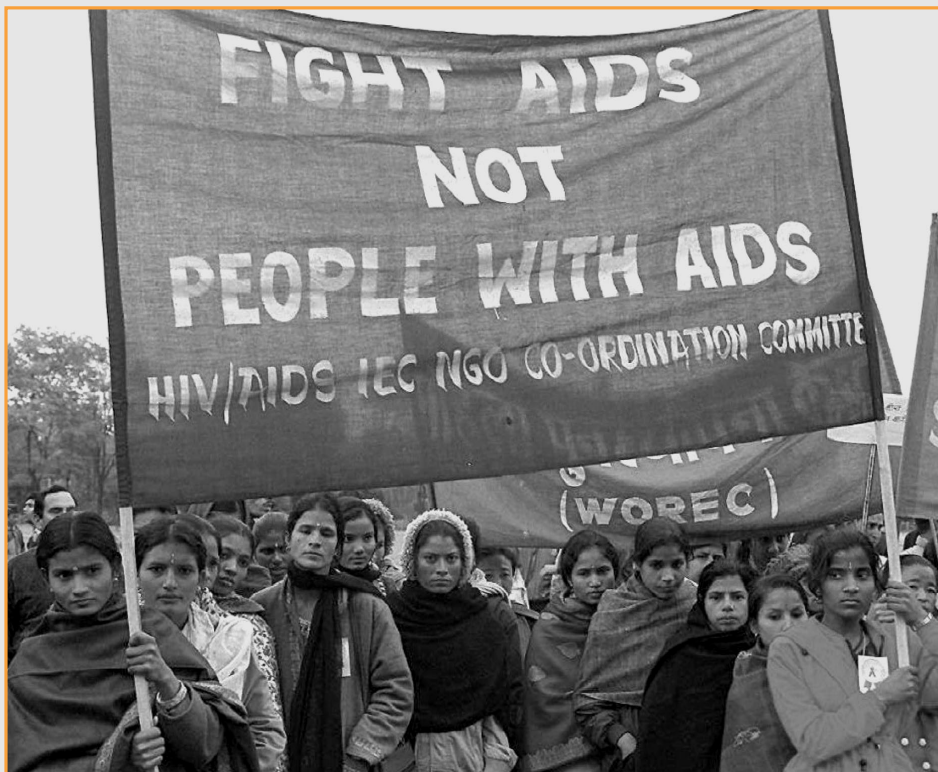


Photo: MTI

in some of the countries 30% of the population is infected by the HIV virus, the workforce is shrinking, and experts fear of a complete social and economic breakdown. The major high-risk groups have slowly evolved from being primarily Men who have Sex with Men to include heterosexual couples (the latter currently making up 80% of infections) and Intravenous Drug Users (IDUs). In Sub-Saharan Africa for example, the most common mode of transmission is heterosexual relations, and in Eastern Europe and Central Asia, the majority of the 1,2 million people living with HIV got infected through intravenous drug use.

WOMEN AND HIV

All over the world children and young people are among those most affected by HIV/AIDS. Women are more vulnerable to infection than men, owing to a mixture of biological and cultural factors. Today women account for at least 50% of new infections, largely as a result of increased drug use by women, sexual trafficking and open borders. The UN General Assembly Declaration of Commitment

acknowledges the dangerous dynamic played out between traditional male dominance and female HIV infection. Article 61 states that by 2005, national strategies shall have been developed that "promote and protect women's full enjoyment of all human rights and reduce their vulnerability to HIV/AIDS through the elimination of all forms of discrimination as well as violence against women and girls". Also, new public health strategies need to be developed that reach out specifically to women, making early detection and treatment possible.

Nearly all HIV-infected children below the age of 10 acquired HIV from their mothers – either during pregnancy, birth, or breast-feeding – and live in developing countries. Drugs have been developed which dramatically reduce the risk of mother-to-child transmission: a simple antiretroviral medication can save an infant born to an HIV-infected mother. As antiretroviral drugs became increasingly available in pregnancy care in North America and Europe, mother-to-child transmission in these parts of the world declined greatly. By contrast, not a single poor country in the developing world is in the position to offer antiretroviral drugs

routinely to prevent mother-to-child transmission outside the private sector.

INTRAVENOUS DRUG USERS

IDUs are the largest group at risk in the countries of the former Soviet Union. In this region the HIV infection is spreading exponentially in countries which were hardly affected only a few years ago. Rapidly growing numbers have been reported: in 1999, the number of infected people added up to 420 000, while only one year later a conservative estimate put the figure at 700 000, and the number of those infected by the HIV-virus continues to increase at a very high speed. In the Spring of 2003, people using drugs through injection still accounted for more than 90% of HIV cases reported in the countries of the FSU.

The spread of HIV is not due to the drugs themselves, but is a result of the practice of sharing needles. Strict drug laws that prohibit the sale of needles and syringes, or even the possession of such 'works', because they are considered to be drug paraphernalia, limit the drug user's chances of using intravenous (IV) drugs safely. They result in the practice known as syringe-mediated-drug-sharing (SMDS), a simple arrangement for injecting drugs which also becomes established as a social norm within the IDU culture. Some governments protect themselves against this phenomenon by a strict ban on selling and possessing needles. Such procedures do not contain the practice of intravenous drug use, but they limit the chances of the drug users to a safe intravenous administering of drugs.

In consideration of this some countries have re-examined their drug laws and have adopted a harm reduction drug approach. Harm reduction policies accept the fact that people do use and will continue using drugs. Instead of criminalizing drug users, harm reduction aims at creating an environment in which they can pursue their practices safely, with the further aim of decreasing the amount of harm they inflict on themselves and others. Examples of harm reduction policies are needle exchange and substitution schemes. Needle exchange schemes attempt to stop HIV infection where it actually happens. It offers IDUs the opportunity to receive sterile needles in exchange for used ones. Substitution clinics seek to get drug users off the illegal drugs, which they use via injection, and to replace them with oral pharmaceuticals that are less harmful. Harm reduction schemes focus on what individuals do rather than on the individuals themselves. They have been endorsed both by the United Nations and the World Health Organization as an effective way to prevent the spread of HIV.

Declaration of Commitment on HIV/AIDS: Global Crisis – Global Action (UN 2001). Prevention, Article 52: "By 2005, ensure: that a wide range of prevention programmes ... is available in all countries ... including information, education and communication ... aimed at reducing risk-taking behavior ... including ... access to ... sterile injecting equipment, harm reduction efforts related to drug use, expanded access to voluntary and confidential counseling and testing."

The Progress Report issued by UNAIDS in 2003 states that "[b]ased on the assessment of progress made to date in implementing the targets outlined in the Declaration of Commitment, it is apparent that many countries risk falling short of full compliance". The aims of the Declaration can be met only if a comprehensive set of measures is introduced in all the countries affected by HIV/AIDS. If such a progress would be made before 2010, the epidemic could be rolled back, and 29 million new infections could be prevented.

Principles for Preventing HIV Infection among Drug Users (WHO, 1997): "The total and immediate elimination of drug injecting is ... unlikely to be an achievable goal. Alternative approaches can and should be employed to help reducing HIV transmission among those who continue to inject drugs. No evidence has been found to support the fear that such measures will promote drug-injecting practices."

How are Nations Fighting the HIV/AIDS Epidemic?

There are two major paradigms that define a country's HIV/AIDS policy. The traditional public health model is based on a coercive approach, at the cost of private rights, while its philosophy makes appeal to concerns of public safety. By contrast, the new public health approach argues that only in protecting private rights can a state achieve genuine public awareness and safety. The new public health model takes a voluntary approach toward preventing the spread of the HIV/AIDS epidemic.

CAN THE TRADITIONAL PUBLIC HEALTH PARADIGM BE APPLIED TO THE HIV/AIDS EPIDEMIC?

The traditional public health model was developed in the late 1800s and early 1900s to combat venereal diseases, tuberculosis, smallpox epidemics, etc. in the newly industrialized societies. Its components are:

- identification of cases of infection through screening or testing;
- reporting of known cases;

- isolation of identified cases; and
- contact tracing.

This approach assumes a disease with a short incubation period, spreading through ordinary contacts and the availability of an effective treatment. People identified as infected are cured of their disease, and rendered non-infectious.

1. Public Health Laws

The laws on communicable diseases were designed to control traditional contagions through means which fail to even address the social and institutional issues raised by HIV/AIDS. Even today, public health laws often use outdated scientific and legal standards, which fail to respond to either the contemporary understanding of diseases and medical interventions or the requirements set by individual rights as these are interpreted in the modern world.

Assessment is needed to balance the public health benefits of a policy against its costs in terms of human rights. Measures involving a clear restriction of an individual right without significant evidence of benefits to public health fall below the standards of constitutional doctrine.

Legitimate public health measures must stand in a reasonable relationship with the aim of protecting public health, and be free of unnecessary discrimination against persons with HIV/AIDS.

2. Why not include HIV?

When applied to the AIDS epidemic, classic public health responses to infectious disease are rather problematic. HIV surveillance differs from the surveillance of other diseases because of

- the specific nature of the patterns of its transmission;
- the long latency period characteristic of it;
- the lack of affordable treatment and cure; and
- the social stigma associated with HIV infection.

3. Coercive measures

Non-voluntary testing:

Testing is non-voluntary if

- a test is performed as a prerequisite for someone's receiving a job or some benefit (e.g., a life insurance);



- persons in closed institutions such as the military or the prison system are subjected to it;
- individuals arrested, charged or convicted of a rape or some other sexual offense are subjected to it;
- blood or organ donors are screened.

Mandatory HIV-testing infringes upon the right to integrity and informed consent. According to UNAIDS, WHO and international experiences as well public health itself is best served by voluntary testing and prevention education. Efforts are needed to encourage high risk groups to cooperate with counseling/testing sites and health care facilities. The only legitimate exception to non voluntary testing is the routine testing of blood and organ donors.

Named reporting

In many countries, it is a statutory requirement that every positive HIV test result be reported by physicians, laboratories and hospitals to the public health authorities. The test results, together with a personal identifier of the persons who have tested positive for HIV, are officially registered.

Such a rule infringes upon the privacy rights of the infected individual. Besides meeting the requirements of privacy, impersonal epidemiological research methods are also superior to named reporting as a more reliable means of understanding disease prevalence in a population.

Contact tracing

The physician notifies public health officials who, in their turn, meet the infected patient and ask for the names of his sexual partners. Then the latter are contacted and given information about their past exposure to the HIV virus. A test is offered to, or imposed coercively on, them. Even if the warning is made without disclosing the patient's name, circumstances usually lead to revealing his identity to the target person in the end.

Isolation

Where the law traditionally authorizes measures such as isolation for "communicable diseases", there has been controversy over whether or not HIV meets the criteria stipulated by the definition. Public health authorities do not order "general isolation" on the basis of health status (isolate everyone who is infected with HIV): they order isolation on the basis of behavior. The purpose of this measure is to

subject to restriction individuals who engage in dangerous activities.

Involuntary confinement (in a hospital or in a special institution) constitutes a significant deprivation of liberty, which requires protection by due process. The individual who faces a loss of liberty is entitled to a public hearing, a decision by a court passed in the presence of a legal representative. Public health statutes often fail to provide for such procedural safeguards.

To take stock: the traditional public health model gives priority to the danger posed by the spread of a contagious disease over the voluntary cooperation of the infected. However, the efficacy of this approach is seriously reduced by the fact that the coercive threats discourage members of risk groups from seeking testing or treatment. Public health authorities should rather encourage and assist voluntary changes of behavior by providing education and easily accessible and confidential services.

IS THERE A BETTER APPROACH?

As HIV/AIDS keeps spreading, most countries come to recognize that the traditional public health model is inadequate to the task of dealing with the circumstances of HIV infection and transmission. The environment in which HIV is transmitted, as well as the high risk groups, presents public health officials with the problem of finding ways to reach out to those groups most at risk which often harbor a deep-seated suspicion towards the state – e.g. gays, sex workers and IDUs. This difficulty made public health officials realize the need to adopt a new approach to AIDS pre-

vention which is premised on voluntary participation and education.

The new public health paradigm takes human rights seriously as a necessary component of any effective public health strategy. It is based on the principle of the least restrictive alternative, which requires public health officials to choose from the set of available policy options the one that is expected to achieve the policy aim at the lowest cost in terms of human rights infringements. Let us take a closer look at the elements of the new paradigm:

1. Prevention

Preventive education targets those people who are in danger of infection with the aim of reducing the incidence of high-risk behavior among them. Society must accept norms of safer behavior – safer sex and drug use. "Free sex" and, particularly, same-sex relations and drug use, however, tend to trigger off social contempt and rejection. In order to get the free distribution of condoms and needle exchange schemes for high-risk people accepted by society, it is necessary that the public should come to accept the facts of atypical sexual practices and drug use. It must be understood that the distribution of condoms does not aim at encouraging atypical sex and that needle exchange schemes do not lead to any rise in drug use.

2. Voluntary HIV Testing

The aim of a general policy of voluntariness and of non-disclosure is to encourage high

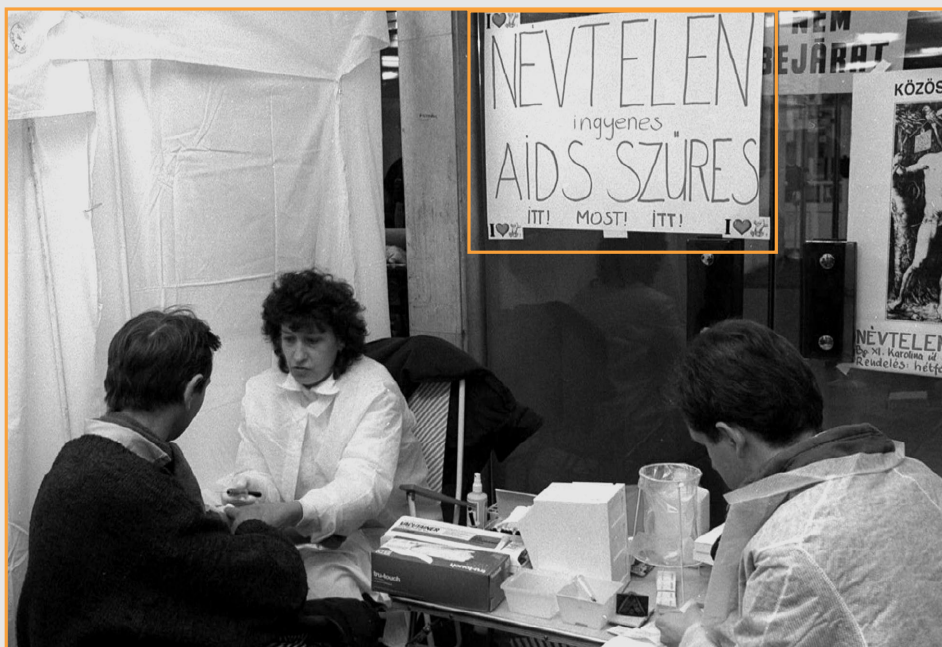


Photo: MTI

risk individuals to seek testing, and to promote access to voluntary testing. Media campaigns need to be started to encourage testing through raising individual awareness of the benefits of knowing HIV status.

The Policy on identification

- Anonymous testing,

Testers do not ask for the patient's name. This method prevents even accidental disclosure of personal and health data.

- Confidential testing,

Testers ask for the patient's name but do not disclose it to third parties, unless strict confidentiality rules allow for this.

Informed consent

It is now generally accepted that the individual must be able to decide whether he or she wants to be tested. The physician is bound to seek express consent to testing. Testing as a routine part of a medical examination is against the requirement of informed consent. Routine testing is justified from a public health perspective only when it applies to individuals who donate blood or organs. The consent is valid only if it was given specifically to HIV testing, not as a blanket consent to a general medical examination.

Pre-test counseling

Actual testing is preceded by a counseling process in the course of which the patient receives help in recognizing those forms of behavior that involve high risks of contracting the virus and those behavioral changes that help to reduce the danger of infection.

Post-test counseling

The disclosure of the test results to the patient is accompanied by a second counseling process in the course of which he receives information on how to live with his HIV infection, on medical treatment, on possible ways to avoid infecting others, and on dealing with the psychological trauma.

3. Unlinked reporting

The most common method of HIV/AIDS surveillance consists in reporting new cases and deaths.

The main epidemiological tools for monitoring trends in HIV infection suggested by WHO include:

- Data provision (passive data collection). New cases of infection and of AIDS related deaths are reported to the authorities without personal identifiers. Data collected on the occasion of anonymous testing are forwarded anonymously but grouped according to age, gender, and the likely way of contracting the disease. The reliability of the statistical data based on such sources is limited, given that the data basis is self-selective: it is restricted to those voluntarily asking for a HIV test. This distortion can be eliminated with the help of
- Targeted data collection (active data collection). Some population groups are subjected to blood test independently of HIV/AIDS polls (e.g., blood is taken from pregnant women at gynecological clinics or from people who may carry venereal diseases at venereal disease centers). The epidemiological authority makes use of such institutions as "observation stations". The blood is deprived of personal identifiers, and in this state it is subjected to a HIV test. The anonymous results so obtained are used exclusively for epidemiological aims. They serve as a good indicator for the rate of infection in the rest of the population too. This is a reliable procedure to assess the rate of HIV infection of the risk groups.

A combined use of passive reporting and of active sentinel surveillance respects the principle of informational privacy and, at the

same time, provides for a more precise representation of the facts than passive reporting alone. The problem with the latter is that it requires all health care providers to be well educated about HIV/AIDS and to be able to recognize the manifestations of the virus. Passive reporting is also premised on the assumption that all HIV positive persons are in fact part of the health care system, which may not always be the case. Reporting tends to be a passive process; health providers are required to report the number of cases and deaths to epidemiological centers. In contrast, other surveillance methods encompass fieldwork, requiring epidemiologists to actively gather information about population groups, the number of cases, and to analyze behavior patterns associated with HIV infection. The European Union has adopted a programme of community action on the prevention of AIDS and certain other communicable disease within the framework for action in the field of public health (Decision No. 647/96/EC, it was extended in 2001 with Decision No. 521/2001/EC).

HIV Policy and Informational Privacy

Informational privacy is a basic right which needs strong legal safeguards, such as strict limits on the use of identifiable data. Safeguards for privacy protect individuals from the unauthorized disclosure of their health data. Breaches of privacy can lead to individual discrimination in employment, education, health care, and insurance. Individ-



Photo: MTI



uals concerned about privacy invasions may avoid HIV testing and treatment. If they can control their intimate health information, they will be more willing to participate in health schemes.

The disclosure of identifiable personal data to individuals other than public health officers – for example employers, insurers, family members – exposes patients to a considerable risk of discrimination. Protected health data may not be disclosed without the informed consent of the person they are about, except under special circumstances which are defined very narrowly. Unlawful disclosure by public health officials constitutes a ground for initiating criminal proceedings and/or a civil suit against them.

Public health agencies shall only require identifiable health information that

- relates directly to a legitimate public health purpose; and
- is reasonably likely to achieve such a purpose.

Laws concerning public health information often fail to define narrowly enough the range of persons entitled to have access to such data. Not less frequently, they fail to require such persons to demonstrate why they need access to identifiable data and give them rather broad powers to have access to them.

THE DUTY TO WARN A THIRD PARTY

When it comes to the question of informing those put to a risk exposure by a HIV infected person, the physician has to proceed according to the International Guidelines issued by the expert bodies of the UN:

- counsel and educate the patient to refrain from practices which involve a risk of transmitting the virus, and
- empower the patient to warn his partner himself;
- avoid directly to address the partner unless the patient refuses to do so himself, against all attempts to convince him.

The physician should proceed to warn the partner only if the patient cannot be brought to cooperate in partner notification.

EUROPEAN NORMS ON PRIVACY PROTECTION

The primary legal instrument that protects people's right to privacy is Article 8 of the European Convention of Human Rights (ECHR, Council of Europe 1950). "Everyone has the right to respect for his private and family life, his home and his correspondence. There shall be no interference by a public

UN Commission on Human Rights

HIV/AIDS related stigma and discrimination reinforces existing social stereotypes and inequalities: inequalities linked to gender, to drug use, to race. The UN Commission on Human Rights (Resolution 2001/51), has stated that the term "or other status" in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS, and has confirmed that "discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards".

UN Special Session

In July 2001 the UN General Assembly held a Special Session on HIV/AIDS. At the end of the meeting delegates endorsed a Declaration of Commitment on HIV/AIDS which commits member states to dramatically increasing the level of funds available for fighting HIV/AIDS, as well as to achieving specific targets in HIV prevention and care.

The Assembly called upon states to enact regulations to eliminate all forms of discrimination against people living with HIV and members of vulnerable groups, and to ensure their access to treatment, while respecting their privacy and the requirement of confidentiality. The Declaration called upon states to ensure by 2003 the development and implementation of multi-sector national strategies for combating HIV/AIDS:

- Confront stigma, silence and denial;
- Address gender and age-based dimensions of the epidemic;
- Eliminate discrimination;
- Involve civil society, people with HIV and vulnerable groups.

authority with the exercise of this right." Although this article does not specifically mention HIV/AIDS, case history shows that it can and will be applied to cases involving violations of privacy.

Here are two cases to exemplify how Article 8 of the ECHR is applied to the protection of persons infected with HIV.

1. *X v. Commission of the European Communities (Case C-404/92 P)*

X, in his application to the Commission for temporary employment, was subjected to an HIV antibody test without his informed consent. Based on the results of this test, he was subsequently denied employment. The European Court of Human Rights argued that testing an individual without informed consent violates the right to privacy. "Although the pre-

recruitment examination serves a legitimate interest of the institution, that interest does not justify the carrying out of a medical test against the will of the person concerned." Article 8 was applied because a person has the right to keep his state of health secret.

2. *Z v. Finland (Application No.22009/93)*

This case brought up two issues: 1) the duration of keeping the court transcripts confidential and 2) the possible publication of personal data in the judgment. The Court concluded that keeping the transcripts confidential for the duration of 10 years "would, if implemented, constitute a violation of Article 8". Secondly the court decided "unanimously that the disclosure of the applicant's identity and medical condition by the Helsinki Court of Appeals constituted a breach of Article 8". In addition, the court reviewed the impact such publicity may have on other persons who suspect they are HIV positive, pointing out that "it may also discourage persons from seeking diagnosis or treatment and thus undermine any preventive efforts by the community to contain the pandemic". Both decisions affirm that individuals with HIV/AIDS are protected under Article 8 of the ECHR.

Non-discrimination as a Public Health Rationale

People with HIV are stigmatized by the rest of society primarily as a result of a wide-spread ignorance of modes of transmission. Some people are worried that they will receive the virus through casual contact with a person and thus do not want to share an employment environment with, or provide housing to, HIV positive persons. A second aspect of discrimination arises from the lifestyles traditionally associated with HIV/AIDS. HIV infection being usually associated with sexual promiscuity or illegal drugs, people who have HIV/AIDS are victims of a double discrimination, one arising from the disease itself and the second from assumptions about their life-style.

Fighting the discrimination that afflicts high-risk groups and people with HIV is not solely an approach recommended by the human rights principle, but also a sound public health policy. Relying on field experiences, WHO declared that combating discrimination towards those affected by the disease is a crucial element of any global strategy for preventing and controlling HIV/AIDS. Coercion and discrimination toward people with HIV had turned out to undermine and reduce the efficacy of HIV prevention schemes.



AIDS quilt

Photo: Archives of the Foundation Mások

quate to control transmission of the virus. Excluding patients with HIV, in addition to being discriminatory, is also irrational. It cannot protect the physician against contacting infected people, because the fact of infection may be unknown to the virus carrier himself or the latter may be driven by the policy of exclusion to hide his illness.

Health care providers need to receive proper training about the real risks of virus transmission involved in treating patients with HIV, about the practices which can effectively prevent infection during health care delivery and about the legal requirement to provide people with HIV with health care.

2. Inequality in access to HIV treatment

Since 1996, a combination antiretroviral therapy has been available. Combination HIV therapy has most dramatic effects on mortality. Infected individuals in care live longer, some of them may have a normal life expectancy. The quality of the life of individuals with HIV has improved substantially, although the side effects of the drug can be troublesome or may even involve a life hazard. People with HIV should be identified as early as possible so that HIV-related infections can be prevented and treatment can be initiated at the appropriate time.

The stigmatization of population groups affected by HIV can impede the implementation of sound public health policies. Socially and economically disadvantaged populations are disproportionately affected by the HIV infection. A further source of social inequalities is inequitable access to HIV treatment.

Combination HIV therapies are complex as well as costly. Regimens may involve multiple doses of 5-8 different medications with precise scheduling and nutritional requirements. Medical benefits are highly dependent on the strict observance of treatment regimens. Barriers to care are numerous: lack of financial means, lack of information about new HIV therapies, the presumptive judgments of health service providers about the patient's ability to adhere to medical regimens. Unequal access to new therapies enhances the inequalities of infection already encoded in the distribution of infections among population groups.

At a time of the availability of effective medication, the most serious challenge to health care authorities is posed by unequal access to HIV combination therapy. Every effort has to be made to ensure access for all who might benefit.

How to Provide Equal Access to Health Care?

The chances of people with HIV for survival and the quality of their lives depend on the level of health care they are provided with. This includes, beyond access to efficient drugs, equal access to all forms of medical service and the equal right of self-determination during treatment. Admittedly, access to effective but costly drug treatment is restricted mainly by financial constraints, but it is also restricted by prejudice and stigmatization. Anti-discrimination legislation is needed to overcome the effects of such negative attitudes.

In most countries there are laws that prohibit discrimination against people with disabilities in providing health care. The question is whether people with HIV are considered to be disabled under these regulations and are therefore protected.

The Americans with Disabilities Act (ADA) is one of the most comprehensive bodies of legislation which can be appealed to on behalf of people with HIV. The ADA defines disabilities in terms of an impairment of some major life activity. The question is whether people with HIV are considered to be disabled under these regulations, and therefore protected by them. The applicability of the ADA to HIV positive people was tested in *Bragdon v. Abbot* (First Circuit Court of Appeals, case No. 96-1643, 1997). *Bragdon* was a dentist who refused to treat his patient, *Abbot*, on the ground that she was HIV positive. *Abbot* sued the dentist on the basis of ADA, and the case

was brought before the First Circuit Court of Appeals. In a highly circumspect decision, the Court tended to affirm *Abbot's* position that HIV should count as a disability. To be sure, people with HIV do not display any symptoms of an illness, the Court observed. Nevertheless, the definition of "a person with a disability" provided by the ADA does apply to them. This is because one of the criteria for disabilities is that they seriously limit the subject in conducting some important life activity. And there is at least one important life activity in which a person with HIV is seriously limited, namely, reproductive activity. Reproduction "which is both the source of all life and one of life's most important activities", easily qualifies as a major activity. Therefore, denying treatment on the basis of HIV status counts as disability-based discrimination.

HEALTH CARE DISCRIMINATION AGAINST PEOPLE WITH HIV/AIDS

1. Refusal to treat:

- refusal by a doctor to treat a person with HIV in the doctor's office;
- refusal to admit people with HIV to hospital, extensive treatment, nursing homes, etc because of fear of HIV infection.

Physicians have an obligation to treat people with HIV. Standard procedures for controlling infection in the health care setting are ade-



3. *Non-compliance with informed consent standards*

Non-voluntary or routine HIV testing violates the requirements of informed consent.

Before treatment, the patient has to receive information about the alternative options so that he will be able to choose the one that most fits in with his values and goals. If a person with HIV is registered and treated, according to the rules of the laws on communicable diseases, in a facility to which he is assigned, not in one of his own choice, then the shared decision-making of the patient and his physician is replaced by orders from public health authorities.

Sometimes, in order to make the relevant decision autonomously, the patient needs to have the opportunity to make an advance directive. Advance directives are not possible, however, unless the law

- authorizes the patient to make such a document;
- stipulates rules and procedures for making it; and
- requires hospitals and physicians to follow its instructions.

Deficits in advance care planning leave many patients and their physician unprepared for decisions about end-of-life care. Communication with HIV patients about end-of-life preferences and advance directives are called for. Advance care planning interventions must be included in clinical HIV schemes.

The Hungarian Scene

Like other post-Communist countries, Hungary has inherited traditional public health practices which involve compulsory screening for certain groups of the population, personal registration and contact tracing.

A number of testing facilities run on a voluntary and anonymous basis were introduced in the early 1990s, partly with the aim of adapting national practices to the recommendations of WHO. Testing facilities of this kind have also been installed in Ukraine, Lithuania, Russia and Georgia, but Hungary is special in that here voluntary HIV testing and education appeared at an early stage. Far from reinforcing this tendency, however, the political transformation that began in 1989 was instrumental in slowing it down, partly even in reversing it. The first anonymous testing site was installed in the Capital, in the last few years of Communist government. Preventive

and educational programs, mainly funded from Western sources, were started by civil associations. These programs targeted convicts, sex workers and gays. Despite these promising developments, the official public health system was unable to move away from its accustomed practices of non-voluntary HIV testing, contact tracing and reporting.

The old Health Care Act, originating from the early 1970s, was replaced by a new one in 1997. The only part of the old Act to survive comprehensive amendments was the chapter on epidemic diseases. The new Act as well as the Ministry of Health Decree issued in 1998 to complement it, classed HIV/AIDS with infectious diseases. The Act on the Handling of Health-Related Data, adopted in 1997, completely abrogated anonymity in HIV testing. According to this Act, positive test results on the first occasion could only be followed by the second test, which is necessary for confirming the results first obtained, if the patient disclosed his/her personal data; that is, in effect, one could not get reliable test results under conditions of anonymity.

In June 2002, the Constitutional Court struck down a legal provision which had been the only one relating specifically to HIV/AIDS, thereby laying an obligation on Parliament to make a new law. Thanks to determined campaigning on the part of civil associations and the express support of the Parliamentary Commissioner of Data Protection, it was made the main rule that HIV testing has to be voluntary and may be conducted under conditions of anonymity at the request of the person tested, and this applies to both tests, the first as well as the confirmatory second. The circle of persons subject to compulsory screening was reduced, and compulsory contact tracing was abrogated. Since January 1, 2003, convicts, drug users, persons carrying or suspected of carrying some venereal disease, the sexual partners of HIV positive persons and persons "suspected" of HIV infection have had the right to give their consent to, or withhold it from, being screened. The only obligation left is that of offering them the opportunity for testing.

On the other hand, the groups selected for compulsory testing by the Act include some for which the idea of compulsory screening is poorly supported by reasons and violates the human rights of the persons involved, e.g. persons in certain kinds of jobs, persons suspected or accused of certain criminal acts, and donors of mother's milk. Another source of concern is the fact that the changes ushered in by the Constitutional Court's deci-

sion have been restricted to amendments to the Health Care Act and the introduction of a new ministerial decree, but have not extended to a number of other legal documents with provisions on HIV/AIDS. For instance, no changes have been made to the Act on Health-Related Data, the 1998 Decree on infectious diseases, or the legal rules on immigration or on the order of penitential establishments. These legal documents continue to allow the personalized registration of HIV positive persons and prescribe compulsory screening for the inmates of penitential establishments.

The official immigration policy is based on a concept of public health which hinges, as it were, on compulsory screening and possible exclusion. Since 1994, foreigners applying for a longer-term stay or for a residency permit have to submit to compulsory HIV testing. Positive test results count as sufficient ground for refusal. Since early 2002 applicants for a residency permit have to be refused permission if they have tested HIV positive, without any consideration of their reasons for applying.

The number of the HIV infected registered between 1985 and 2002 was 1044, the number of those of them who died of AIDS in the same period was 247. The presence of the virus has not so far reached proportions in any social group which could be reasonably called 'epidemic'. A reasonable public health policy could still forestall an outbreak of the epidemic.

In order for the community to be able to do this, however, a network of anonymous testing facilities ought to be established so that testing and counseling would become available all over the country. It is important to make testing facilities attractive and easy to reach for the members of endangered groups – such as intravenous drug users – who are rejected by the society at large. There is one single independent anonymous testing center which offers its services free of charge and on a voluntary basis, in the capital, but its continuous functioning is increasingly endangered by financial difficulties and the insecurity of other factors.

Another shortcoming of HIV/AIDS policy in this country is the lack of comprehensive campaigns to provide the population with information and to raise interest in testing. The Public Health Program recently adopted for ten years devotes one single chapter to HIV/AIDS, and the scarcity of the funds allotted to the area shows that the Hungarian government has not yet come to recognize the dangers latent in the present situation, and to

take the attitude needed to prevent these factors from becoming active. The National AIDS Committee, once abolished in 2001, has been reinstated, but it has no funds allotted to it, and Hungary still has no national AIDS strategy.

By contrast, advances have been made in the area of harm reduction drug policy: there are several needle exchange and methadone programs being carried out all over the country, and the first needle exchange machine has recently been installed in the streets of Budapest.

Up-to-date medicaments are available to everyone free of charge, but there is only one establishment in the entire country entitled to treat HIV positive patients.

The Equal Opportunity Act is now in the pipeline towards getting adopted by the Parliament. It contains no explicit reference to HIV/AIDS, but the discrimination based on HIV status will be banned by it as a case in health-related discrimination.

The Hungarian Civil Liberties Union is a law reform and legal defence organization created in 1994. It works independently of the Government and of any political parties. HCLU's aim is to promote in Hungary the case of fundamental rights and principles laid down by the Constitution and by international conventions. The following topics are in the focus of our attention:

- patients rights
- harm reduction drug policy
- protection of personal data
- access to public information
- freedom of expression

Issues already published in the Policy Papers serie:

HCLU on Abortion
HCLU on Euthanasia
HCLU on the Rights of Patients
HCLU on Freedom of Expression
HCLU on the Police
HCLU on the Protection of Personal Data
HCLU on Freedom of Information
HCLU on Disability Rights
HCLU on Capital Punishment
HCLU on Harm Reduction Drug Policy
HCLU on Prohibitionist Drug Policy

HCLU'S Proposals in the Area of HIV/AIDS Policy

- efforts to prevent and fight back HIV/AIDS must not include traditional epidemiological methods;
- action plans must be based on principles of human rights, so that the health interests of society are served in the spirit of due respect for personal liberty, privacy and informational self-determination;
- testing sites must be established where persons are tested for HIV free of charge, on a voluntary basis, and without personal registration;
- equal access to health care services must be secured for the HIV infected and AIDS patients;
- special risk groups must be targeted with the help of services offering useful information;
- harm reduction methods must be made widely accessible;
- at the social level, an approach must be worked out which aims primarily to uncover social circumstances which enhance the likelihood of HIV infection, and measures to stop HIV/AIDS from spreading must be elaborated at the same social level.

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