

WORLD HEALTH ORGANIZATION
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WELTGESUNDHEITSORGANISATION
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ORGANISATION MONDIALE DE LA SANTÉ
BUREAU RÉGIONAL DE L'EUROPE

ВСЕМИРНАЯ ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ
ЕВРОПЕЙСКОЕ РЕГИОНАЛЬНОЕ БЮРО

6543

Meeting on AIDS diagnosis and control:
current situation

Munich, 16-18 March 1987

ICP/CDS 026/9
1960G
10 March 1987
ORIGINAL: ENGLISH

SOCIAL, ECONOMICAL, PSYCHOLOGICAL ASPECTS OF AIDS

by

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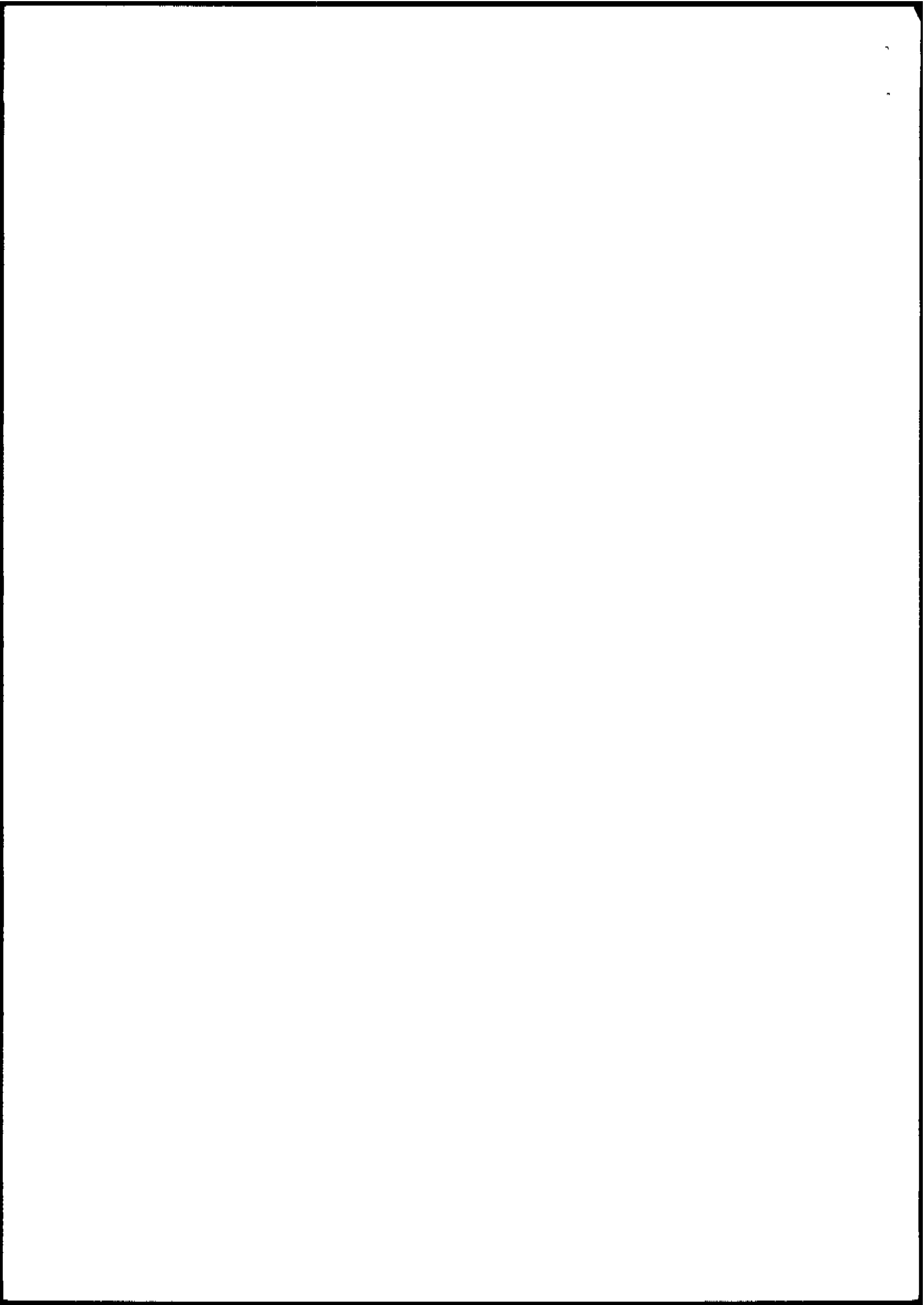


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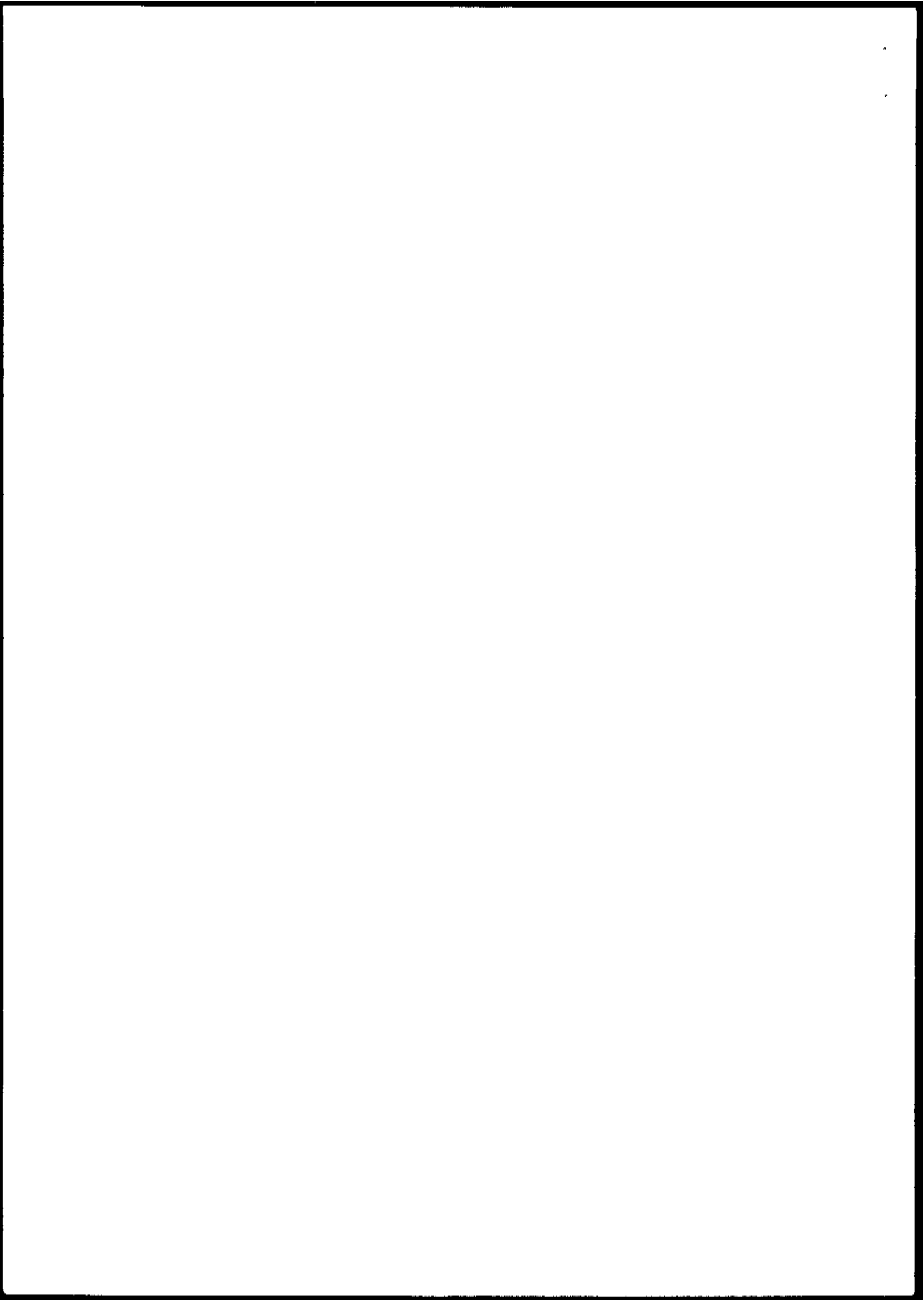


AIDS as a Social Phenomenon

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Introduction

On 20th November, 1986, the Director General of the World Health Organization announced that WHO considered the Acquired Immuno Deficiency Syndrome (AIDS) to be an unprecedented challenge to public health. "AIDS is a global health problem of paramount international importance and the action, we take now, may have a more profound impact on the history of the AIDS epidemic than actions taken at any later time. We are present at the historic moment, the beginning of a major pandemic. Since the beginning of the AIDS epidemic, approximately 100.000 AIDS cases have occurred worldwide. In addition, from 5 to 10 million persons are currently infected with the AIDS virus. One can expect from 500.000 to 3 million additional AIDS cases during the next 5 years, occurring among the millions of persons already infected. In addition to the medical problem and the cost of AIDS, the psychosocial dimension of the problem including alienation, abandonment and adverse effects on families, groups and nations must be taken into account. When all these impacts are considered, AIDS represents a global problem of tragic proportions" (1).

As the epidemic evolved in the Americas, Africa and Europe, the AIDS problem has been repeatedly characterized with some licence as "less a medical than a social-psychological and a social-political problem", and it was maintained that "the overall social consequences will be even more catastrophic than the disease itself" (2). Whatever the merits of this argument are, they should not detract from the fact that AIDS is in the first instance a dangerous infectious disease. All social, ethical, moral, psychological and financial consequences cannot yet be assessed, but they must be taken seriously. Many of the above stem from objective problems vis-à-vis a new disease the knowledge of which has only gradually been emerging, but is as yet not complete, and some stem from the fact that society and authorities have for the first time to take note of some twilight zone minorities identified as the main risk groups: homosexuals, prostitutes, and drug addicts. They have not found an adequate institutional response throughout history to deal with.

This paper is the continuation of the previous one (Uelinirovic,3) in which some of the social dilemmas and ethical problems involved have been discussed in detail.

Social influences in the spread of the disease

Through the numbers of people involved (diseased, ill or infected) mode of transmission and by the impact and reactions it provoked in the society, AIDS can be called a "social disease" even more than alcoholism, tuberculosis or the classical sexually transmitted diseases. The ambiguities in the definition of the term "social" remain, the emphasis is wider than only the communication and transmissibility from person to person in a sexual act or otherwise. It implies all phenomena of the presence (togetherness in the community) of the disease and diseased along with the rest of the population, with all manifestations of physical illness and psychic disturbances, behaviour, attitudes, fears, conflicts, illusions, concerns, crisis in confidence, denial, overreaction etc. There is no doubt that AIDS has high relevance to sociability and social work, from the reaction of individuals to the institutional response in terms of support services and responsibility toward the sick. With increasing numbers and changes of the epidemiological picture the social dimension of AIDS cannot but grow in the future. Many of the questions posed are new to social research on medical problems, both for professionals and the policy makers. The issues of AIDS can be viewed from different perspectives, but they all relate to each other in a rather intricate way. As a social phenomenon it touches not only the health profession, but as well the public, the mass media, politicians, administration, social workers etc., and above all the victims themselves. There is an implicit tension between the groups mentioned above. This in turn depends on the social location of the groups, their economic and political power or the lack of it, and on a general social definition of situations. As example one can examine two opposite positions of the social scale: the homosexual and drugabuse groups, the strategies and tactics used by those who want to change public image of special riskgroups, in order to gain support for them, to bridge the distance between special groups and the public at large. This can be best exemplified on the case of the homosexuals. While the image of

this special groups will not change as to make public more sympathetic "social marketing", can bring about a better understanding of the special measures which are to be taken in favour of a better social support to the infected or diseased.

Programmed Conflicts

We have discussed the phenomenon fear and "discrimination" elsewhere (Uelimirovic, 3) and they will not be repeated in this article, which limits itself to some new aspects of behaviour of the risk groups likely to remain for years the main epidemiological reservoir for AIDS. Although legal provisions to eliminate discrimination have been enacted in most countries, the fear of the main risk groups and of the public has remained, often by enhanced superficial press reports and reactions of some activists of risk groups concerned with the possibility of more restrictive public health measures, experienced as fight against liberality and social freedom. The main problem is that there is and will be confusion about what discrimination is, and the danger that sound epidemiological measures might be perceived as discrimination. So f. ex. the proposal of the federal health officials in the USA in 1987 to recommend much wider HIU blood testing, including tests for all applicants for marriage licences and for every one hospitalized, in pregnancy, and those treated with sexually transmitted diseases has generated controversy from those who believe that this could violate personal rights and frighten potentially infected people away from medical facilities. The clash over control strategies, over attempts to protect civil liberties as opposed to protecting public health is bound to continue as the epidemic develops. "The time is ripe to discuss these ideas in an open forum to make certain we do not overlook any possible way to curb the epidemic. "This is a consensus building and a multiple process". Children are intended to be the beneficiaries of premarital and prenatal testing to detect the infection. Most children whose tests are positive for AIDS at birth have some manifestations of the disease within a few years" (4) . The knowledge of the infection would provide an opportunity for counselling and for protecting the noninfected potential partner as well as future children. Testing for AIDS when people are admitted to a hospital would provide the physician with information

that may directly relate to the way he cares for the patient". "The person who benefits from a test is the individual and the contact of that individual"(5).

The political director of the "National Gay and Lesbian Task Force" in Washington believes that debate on HIV testing had "laudable public health objectives", but "in ignoring the social consequences it undermines its public health value". If the government combines testing with a major counselling programme, a general education programme, antidiscrimination protection and dealing with the health insurance issue, then I think we could begin to talk" (6). The American Civil Liberties Union and few others were critical. Obviously, everybody agrees that the best weapon against ignorance and discrimination, and the spread of the disease itself is education. But is it sufficient? Control of the AIDS epidemic ultimately will depend on breaking the cycle of disease transmission "It is important to remember that whatever epidemiological utility there has been in the initial ascription of behaviour to groups, continued singular reliance on these is fast becoming untenable. The groups both interact and overlap in ways that provide innumerable pathways for the spread of infection to the population at large". One must recognize that changes in behaviour cut across the total community" (7). The Association of State and Territorial Health Officers (1986) advocates to actively seek those at greatest risk. It is unlikely that voluntary reporting and surveillance alone will be sufficient to stem the AIDS epidemic. AIDS patients should be interviewed to obtain their heterosexual contacts for serological testing. All contacts that are positive would be counselled and educated about the nature of AIDS and its transmission, and their contacts would in turn be tested (8). Some doubt the value of this approach without further expansion of surveillance and case follow-back to all identified infected individuals (9). Furthermore, since substantial but as yet unknown numbers of antibody positive individuals are known to be virus positive and theoretically capable of transmitting the virus, it is critical that we follow groups of antibody and virus positive persons over time to determine the natural history of those two states. Similarly, the long-term clinical implications of those with AIDS-related conditions are unknown. Only by follow-up over time can the utility of the

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antibody test and the ramifications of the AIDS related clinical manifestations be assessed. This requires repeated contacts with surveillance and research subjects which in turn requires the ability to identify and to locate these individuals. Longitudinal studies of new seroconversion in differing population must therefore be the major component of the overall control strategy. There must be substantive and convincing assurance of confidentiality (10). So far the approach was based upon research and on education and counselling specifically targeted to groups at risk of spreading or contracting the disease. The commitment to education in the case of AIDS occurs against a background of controversy about the efficacy of efforts to achieve the modification of personal behavior by health-promotion campaigns(11). The choices are not easy and the rational path tragically narrow, and consensus will be difficult to reach.

Risk Groups

One of the foremost problems is the one of risk behaviour. Although we only reluctantly speak of risk groups or risk subpopulations, they are grosso modo identifiable. It is of no help to deny the concept of risk groups: homosexuals and bisexuals, drug addicts, prisoners, male and female prostitutes or other promiscuous individuals. These terms have been objected to as artificial. Obviously the group membership status can be misleading and imprecise, the groups overlap and interact, not all homosexuals are promiscuous and not all drugabusers are sharing needles, nor are all prisoners involved in either. Certainly in the risk group of haemophiliacs there is no behaviour component involved in acquiring infection, however, being a victim of transfusion or blood product, (hopefully now eliminated) has also grave social aspects and the behavioural risk to the sexual partner remains. Nevertheless in the USA and Europe AIDS still is predominant in defined risk groups and only 3 - 7 % of cases in the USA and up to 19 % are so far found in Europe among nonrisk population. Presently information on competing risks and their relative weight in the developing of disease is either lacking or hypothetical. Neither the term "high risk" nor "low risk" is reliable. How low is "low risk"? Taking into account instead of risk groups the risk gradients and individual factors

particularly of those who do not choose to identify themselves as members of riskgroups, but who nevertheless belong to one by virtue of their behaviour (12), may be one of the pressing issues in risk assessment for understanding variations in individual response and clinical manifestations and for evaluation of the recommendations made.

Promiscuity, hetero- or homosexual, has been recognized as a significant individual behavioural risk factor. It is common epidemiological knowledge that: "if a population is divided into relatively isolated subpopulations, with low rates of interaction within each network, a disseminated disease entering the population would be confined mainly to one subpopulation and be likely to spread slowly, if at all"(13). With high rates of interaction and large numbers of network linkages rapid and extensive spread is possible. The probability of contracting venereal diseases is unequivocally determined by the pattern of sexual behaviour. Influencing sexual behaviour is, as experience has shown, not easy. To deny promiscuity ("how many partners is promiscuity?") as was often heard in the context of AIDS is irresponsible (see consequences to AIDS in Africa). The attitudes prevailing in the society and the group sanctions will of course greatly vary. Research in this social field, based on empirical data, is only beginning.

In spite of the sexual revolution of the 1970's and of new pluralism of sexual behaviour (see WHO ICD-Revision below) it is unavoidable that the question of some forms of behaviour, considered as deviant from the point of view of the public arises. Even if tolerated and legally accepted they are likely to remain considered by the majority as a personality disorders.

This means: Evidence that the individual's characteristic and enduring patterns of inner experience and behaviour deviate markedly as a whole from the culturally expected and accepted range (or "norm"). Such deviation must be manifest in more than one of the following areas:

- cognition (i.e. ways of perceiving and interpreting things, people and events; forming attitudes and images of oneself and others);
- affectivity (range, intensity and appropriateness of emotional arousal and response);
- control over impulses and need gratification;
- relations to others and manner of handling interpersonal situations.

The personality disorders (formerly) deviation must be pervasive in the sense of manifesting itself as behaviour that is inflexible, maladaptive, or otherwise dysfunctional across a broad range of personal and social situations (i.e. not being limited to one specific "triggering" stimulus or situation). There is personal distress in, or adverse impact on the social environment, or both, clearly attributable to the behaviour referred to above (14).

In fact, the social tendency of involved groups is to achieve legitimacy and recognition that some behaviour may be accepted as normal choice of life, a matter of individual preference, rather than deviant behaviour. In the context of AIDS the problem becomes actual in the discussion of "risk" and in relation to Public Health Law and constitutional law that require the individual's interest in liberty and privacy to be balanced against the public's interest in health and safety.

Homosexuality

It is well known that repression of social behaviour brings about a considerable degree of solidarity among the repressed groups. Traditionally the emergence of a minority group is always related to certain cultural stresses and social strains. The grouping process provides a type of safeguard for the preservation of emotional and behavioural characteristics as well as contact opportunities (distinctive style, press, leisure, own vocabulary, concentration in certain parts of the city or occupations) and applies to the homosexual minority with the liberalization of legislation and the sexual revolution in the 70's and an open identity with complete dissociation from traditional moralistic codes. This development

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was not without social costs: high prevalence of hepatitis A and B, herpes, syphilis, pharyngeal and rectal gonorrhoea, venereal warts, chlamydia, Epstein-Barr virus and Cytomegalovirus infections, amoebiasis, giardiasis, shigellosis and a few other diseases and now AIDS.

Two major characteristics mark the social situation of homosexuals today (or in recent past). The first is the acceptance of sexual plurality in modern society. This is best exemplified by the elimination by the WHO of homosexuality from the "List of Diseases", (which will in turn be followed by changes in respective national lists). The "Gay Liberation Movement" originated in 1969 in Greenwich village, New York. The North American Conference of Homophile Organizations proclaimed that there is a moral right to be homosexual and to live out one's homosexuality fully, freely and openly; free of pressures to convert to the prevailing heterosexuality, and free of penalties, disabilities, or disadvantages of any kind, public or private, official or unofficial, for his nonconformity (15). The stand of the Gay Liberation Movement that homosexuality is not pathological and does not belong in the realm of the psychiatrist and psychologist, was supported 1973 by the American Psychiatric Association: "Surely the time has come for psychiatry to give up the archaic practice of classifying the millions of men and women who accept or prefer homosexual object choices as being, by virtue of that fact alone, mentally ill. The fact that their alternative life-style happens to be out of favour with current cultural conventions must not be a basis in itself for a diagnosis of pathology" (16). The homosexual person therefore is no longer classified as being mentally ill but merely having a sexual-orientation disturbance. The International Classification of Diseases (ICD)-9 used to classify homosexuality under the "Sexual Deviations and Disorders" defined as (code number 302): Abnormal sexual inclinations or behaviour which are part of a referral problem. The limits and features of normal sexual inclination and behaviour have not been stated absolutely in different societies and cultures but are broadly such as serve approved social and biological purposes. The sexual activity of affected persons is directed primarily either towards people not of the opposite sex, or towards sexual acts not associated with coitus normally, or towards

coitus performed under abnormal circumstances. If the anomalous behaviour becomes manifest only during psychosis or other mental illness the condition should be classified under the major illness. It is common for more than one anomaly to occur together in the same individual; in that case the predominant deviation is classified. It is preferable not to include in this category individuals who perform deviant sexual acts when normal sexual outlets are not available to them. Code 302 further defines homosexuality: "Exclusive or predominant sexual attraction for persons of the same sex with or without physical relationship under which homosexuality was coded whether or not considered as a mental disorder. Lesbianism is also included here but it excludes homosexual paedophilia (302.2) defined as "sexual deviations in which an adult engages in sexual activity with a child of the same or opposite sex" (17).

WHO is proposing now not to identify homosexuality as such in ICD-10 due in 1988 (14). Rather, under the rubric "Psychological and behavioural problems associated with sexual development and orientation", chapter "Mental Disorders", section on personality disorders, five types of sexual orientation (hetero-, homo-, bisexual, uncertain and prepubertal) are listed to qualify for the following categories: (F66)

- Maturation crisis
- Ego-dystonic sexual orientation
- Relationship problems
- Other problems or reasons for referral.

Ego-dystonic sexual orientation, be it homo-, bi-, or heterosexual, is only diagnosed if the individual concerned wishes his/her sexual orientation were different and seeks treatment in order to change it. Thus the following variations of sexual development or orientation may or may not be problematic for the individual: heterosexual, bisexual (only to be used when there is clear evidence of sexual attraction to members of both sexes and uncertain or prepubertal). Homosexuality has been thus eliminated from the list of mental illnesses under the heading: Abnormalities of sexual preferences. While even under the old ICD liberal choice it had

been left to the physician to consider homosexuality or not as mental disorder, the New Classification tries to be even less specific, avoid the emotionalized response and social stigmatization by putting sexual orientation disturbances along all other sexual orientations only if the person facultatively seeks treatment *).

The second characteristic in contrast to the drug abusers and/or prostitutes is the high position and acceptance of homosexuals in the cultural and economic basis stratification in spite of the fact that the behaviour of both groups is contrary to the dominant values of the society and in spite of their minority status. Homosexuals (although not higher than 4 - 6 %) are an articulated politically significant group of voters, with high visibility in the society through relatively large numbers in artistic, literary and fashion fields. The most important objective brought by the advocates of homosexual rights is the symbolic message that homosexual practices are protected by the highest authorities, and that those practices are as deserving of respect (and possibly encouragement) as heterosexual practices. Denial of this message of approval is seen symbolically by some (18) from the epidemiological point of view as contributing to the development of attitudes that will help fight the spread of AIDS. States taking this view rely less on the (unlikely) prospect of punishment as a deterrent than on the inhibiting power of publicly proclaimed community norms. It is at present unclear how the future social response might develop in the public health crisis caused by AIDS, which is likely to be influenced by the widening scope of the present epidemiological crisis.

Although the AIDS epidemic has tragically affected homosexual population and although it is not possible to predict further

*) In this list then remain fetishism, fetishistic transvestism, exhibitionism, voyeurism, paedophilia, sado-masochism, multiple abnormalities of sexual preferences and other abnormalities of sexual preference.

changes in its social position, it does not seem that this will be radically endangered. Given ability to organize and establish support groups, to develop protective strategies, and given their predominance among both AIDS-victims (cases) and among infected, they have suggested themselves as the most appropriate channel of communication to speak on behalf of infected and about various AIDS problems in general. From the initial position of spreaders of infection a change through a delicate interplay of socioeconomic, psychological and political factors has evolved to innocent victims of a new virus. One hears today that society has to be thankful to homosexuals for by being pioneers who have taken upon themselves the brunt of the dangers of an unknown disease for the benefit of the rest of the community.

Homosexuals are far from being a homogenous group. Such subsectors who were willing to cooperate with the medical establishment (similarly to their cooperation in testing hepatitis B vaccine) have helped in elucidating a number of initial epidemiological questions, and may eventually do it with the future AIDS vaccines.

Drug addicts

Drug addicts came to special attention only after 1984, when it became apparent that drugs use is more frequent in homosexuals. A high rate of HIV-positivity was found in prisons and therapy centers and in prostitutes which have often frequent connection to the drug subculture. Since then a marked increase in cases and HIV-positivity was observed wherever targeted examinations were undertaken (19). The spread of infection in drug abusers has been rapid. In the USA the number of drug abusers has been conservatively estimated at about 750.100 who use i.v. drugs regularly and about the same number of those who use them occasionally (recreationally)*. Heterosexual i.v. drug users comprised (end of 1986) 17 % of all cases (15 % of male cases and 51 % female cases). In the USA homosexual or bisexual i.v. drug users comprised 8 % of all cases (20). In New York the percentage of HIV-positives among drug abusers reached 87 % (29). The number of i.v. drug abusers in Europe is estimated at between 560000 and 650000 (about 158-183/ 100000) In Italy and Spain this group represented 57 % and 50 % of all AIDS

cases respectively (22). In total drug addicts represented 14 % of all know AIDS-cases in Europe, mostly selfselected individuals who come for examination or from examinations in prisons. The rapid development of seropositivity and clinical cases in this group is alarming, and prevention programmes for this group is seen as a major priority.

Drug users are an isolated desintegrated yet important risk group without group-like qualities, needing risk-reduction education. As persecuted individuals per definitionem they are not easily reached by Health Authorities and are least responsive to public health education: it is thus most difficult to assess awareness and knowledge of AIDS risk and preventive efforts. In contrast to homosexuals they do not have their own advocacy organization and supportive counselling or systematic educational exposure, except in the therapeutic or correcting setting, which encompasses only a small number and might not be the most propitious environment anyhow (3).

There is no lack of general recommendations that the effective, social, legal, financial and educational efforts to deal with the drug problem should be adopted. But how this should effectively be done is not elaborated. The free distribution of syringes and education is not likely to stop transmission, although it has relaxed somewhat the legal constraints in respect to drug abusers. The cost of injection is negligible in comparsion the cost of 1 gramm of heroin. Society does not want to admit that it has no effective means to deal with drug addiction. Perhaps it is time to review the whole strategy and not only in respect of therapheutic centers, which are in danger of becoming primarily places of AIDS concentration and also possible infection places, but in a wider perspective. This would mean taking into consideration the unsocial acts into which addicts are forced by their drug dependence including theft, violence and prostitution. Except one article on

*> Some reports put the number of all drug addicts at 2,5 million.

the benefit of legalizing heroin presented in Lancet as a point of view (23) and formerly by T.Szasz, (24) no advocates in favour of radical changes in approach have come forward, to "demonstrate our concern for addicts more practically than we do at present through driving them into criminality" (23) and in final consequences facilitating in final the risk of AIDS.

The proposals of separation of positives from negatives (25) are still meeting with violent opposition, although both therapeutic institutions and prison authorities agree that those are neither drug free nor that the sexual contacts between positives and negatives can be curtailed. This poses ethical problems of where the priority lies in the protection of non-infected (constitutional duty of the state) or in the individual right to continue with risk behaviour. The basic question remains, what is the task of society and of the individual vis-à-vis the carriers of the virus, to drug addicts and HIV-positive drug addicts in particular (25). This cannot be solved by the therapeutic communities themselves without corresponding legal instruments, which the society chooses not to use. The question of motivation is crucial but not resolved. How far can one expect that the drug addict can be on upon to understand the full reach of consequences of risk behaviour, and how far can one appeal to the ethical responsibility in the context of a priory irrational behaviour such as drug abuse? There may be the sign of messages penetrating this group, but nobody knows how farreaching this is or how lasting the compliance will be.

Prostitution

The initially doubted and emotionally discussed role of prostitution in the spread of AIDS has in the meantime been unequivocally demonstrated. The infection rates in prostitutes and epidemiological studies have shown that bidirectional heterosexual transmission is the dominant mode for spread in Central Africa and the relative importance is increasing elsewhere (Europe). When the first cases appeared in Europe and the USA, the assumption was that the infection occurred through drug abuse, which is no doubt present in a segment of the professional prostitution. The new AIDS cases in men and women acquired through heterosexual contact will increase

from 1.100 in 1986 in the USA to almost 7.000 in 1991, still a very small proportion in comparison with Africa (26). As a social phenomenon, prostitution has flourished throughout human history despite the innumerable attempts of violent suppression. Contempt and reprehension have now given way to tolerance. It has come to be considered a necessary evil and sometime as having a useful social function. There were striking changes in prostitution in the contemporary world where poverty, social hopelessness and lack of elementary education do not play a role anymore in entering prostitution. The industrial world has created new status and opportunities to make a living without the stigma and low self-esteem attached of confirmed prostitution as a profession which operate under other labels: hostesses, masseuses, models, escorts, call-girls, danseuses etc. Sex freedom has not displaced "red light" prostitution although it officially does not exist or is prohibited and clandestine by operating in many countries, but it has increased the non-registered "glamourised" forms of selling sexual favours. Even in countries where prostitution is banned it is sufficiently important to be considered "big business" of interest for organized vice. Exact estimates of such new form prostitutes is unknown. In countries where registered prostitution is tolerated, the number of the "amateur" prostitutes is thought to be 5 to 10 times more numerous than that of the official profession. The problem is further complicated by the occasional "Anschaffung" for income supplement and drug addict prostitution for the purchase of drugs. This change in the pattern of prostitution has in the context of AIDS presented the health authorities with a problem without a solution. While the registered prostitution could be regularly examined for venereal diseases including the AIDS infection, this is by definition not possible in other forms of trade. Neither is contact tracing, even if health authorities would consider it possible. Consequently no attempts are made to curb prostitution. However, they are likely to experience compulsory measures to control AIDS more harshly than any other risk group. Denial of licence usually involves only a change of residence. Even in proven cases of infection no severe sanctions have been so far instituted under the principle that the least restrictive means available should be employed to protect the community. The application of these principles is illustrated by the case of a

Florida prostitute with AIDS who was confined to her home and ordered to wear an electronic monitor that signalled the police if she strayed away more than 200 feet from her telephone (27). Assuming the facts to be as reported and recognizing that they have not yet been revived by a higher court this woman proved infectious and persevering in conduct that exposed others to infection and presented a specific danger. A form of house arrest was less restrictive than imprisonment and achieved the public interest with reasonable efficacy, although maintaining house arrest for a long period would be difficult. It is questionable how far restrictions, even if effective, would be practical for non-compliant prostitutes in general (28). Particular care is needed to avoid victimization of those individuals. In the USA, during the First World War there was a massive attempt to arrest prostitutes because it was feared that they were spreading venereal diseases to the troops. As many as 40,000 to 60,000 prostitutes were interned in camps (29).

The situation of prostitutes who by definition have no other means of subsistence, promiscuity being their trade, is particularly difficult. While there is almost general agreement that seropositive prostitutes should be deprived of the licence to their profession, there is no institutional answer to the question of how to control compliance nor of their future existence, employment, unemployment benefits, social security, etc., as in the definition of laws their occupation is not counted as work. Positive help and encouragement are needed for those wishing to abandon the trade. Social support, alternative employment or in case of disease social security provisions are imperative, although for the prostitutes, they are never experienced as satisfactory.

It is not possible to eliminate prostitution, "to get rid of it", but some changes affecting prostitution as consequence of fear and education are plausible: decline in their numbers and in the numbers of customers, decline in sex-tourism to Africa, decline in alternative and a stricter regulation of juvenile prostitution. However, increases in visits has been reported in establishments advertising that the "girls are regularly tested". There is greater awareness of danger in this group, condoms are requested and offered, desinfectant use has increased and there are self-help

initiatives for protection against AIDS in some cities. But the degree and efficiency of organization never paralleled similar initiatives of homosexuals.

Most experts believe that male homosexual prostitutes are spreading AIDS on a far larger scale than female prostitutes (high number of bisexual customers, married men who can in turn infect women). A case (1985) in Houston, where a male prostitute with AIDS persisted in his trade until entering hospital has led Texas health officials to request the authority to quarantine individuals with AIDS; not the average cases but the incorrigibles. This is refused in San Francisco as it takes a consensual act to get infected, and thus there is no rule for either AIDS-infected prostitutes or other sexually active individuals (30). Male prostitution does not officially exist in legislative dictionaries of antiepidemic laws dealing with prostitution in Europe, although such individuals are well known to the authorities and can be identified at any railway station (and other meeting places) in European cities. The laws of many countries would empower authorities to control them but there is a general reluctance to apply these laws (3).

Coping and socially incompetent behavioural style.

Coping with diseases leading unavoidably to death has been dealt with extensively in medical, social and psychological literature f. ex. cancer and cardio-vascular diseases. The stages the person goes through upon learning the AIDS diagnosis or antibody status were (somewhat schematic) postulated: shock, denial, crisis, transition, fear, depression, panic, guilt, anger, selfpity, bargaining, search for meaning, fighting, eventually the stage of sense of themselves, positive action and finally acceptance which is of course not permanent. In AIDS additionally the long and unpredictable period between the learning of own positivity to the development of overt disease extends the period in which above manifestations may take place, even with alternation and a "repeat"-programme. It is the

reaction in the state of anger, hostility and aggression which is likely to suscite widest attention. We do not know anything about the actual frequency and duration of socially incompetent behaviour beyond the well documented incidents (from reports to and from the police) but obviously extrapolations and generalization from those are not permissible. However, they will not be self-reported by the positives in the most important domain of sexual aggression. There are no instruments for measurement of those psychological reactions suitable for AIDS positives or patients. Some may be appreciated through intensive psychological follow-up to classify overt physically aggressive acts. One of many advanced category systems for rating the aggressive hostile content (they have all been developed earlier for other diseases than AIDS) recognizes following categories (32, 33).

- 0 - no hostility
- 1 - forceful advice-giving, quarreling, feelings of anger or resentment, self-beratement, remorse or guilt
- 2 - incompetent behaviour, threatened murder or suicide
- 3 - physical attack short of murder or rape, attempted suicide
- 4 - murder, rape, or suicide

Five behavioural patterns have been identified in infected: "celibacy, denial or rejection. Celebacy with close friends while engaging in multiple anonymous sexual contacts, increased use of drugs and alcohol and development of small groups of sexual contacts" (31).

None of so far published histories on socially incompetent behaviour in AIDS elaborates sufficiently the relation to education, social class and different social context from which the person comes or in which he lived beyond the crude belonging to a risk group. And obviously there is no possibility of prediction of socially incompetent behaviour except, to some degree in suicide. The diagnosis obviously requires to adopt a new pattern of behaviour in an unexpected, incomprehensible and frustrating situation. The psychosocial support hopes to help to facilitate coping, selfcontrol, to compensate for the loss of self-esteem, to eliminate social isolation, to give the feeling of being connected, the sense

of belonging in a situation in which the sense of continuity with the past has been disrupted. "Whether one succeeds in eliciting active coping efforts depends on whether the individual believes and feels what happens to him is a result of his own behaviour or chance, accident, fate or otherwise a feeling of guilt was not common in consultation samples (35). Some of those factors may be crucial in the coming to term with a tragic definite situation of the individual and might also have epidemiological relevance in respect to curbing or passing further transmission of the disease. The most successful coping means seem to be religiosity where a priory disposition to it was preexisting or newly found, however these seem to be a minority. Notable attitude it is attempted to establish the sense of continuity (to defeat death) through pregnancy, by giving life to a child. In many cases the positives or patients reported finding a new meaning of life in positive actions of preventing the same happening to other people or by involving in AIDS self-help and care-groups. Some of the above reactions could refer not only to the affected but also to friends or lovers who might have experienced the loss of a near person.

Social factors in control strategies

The universally accepted strategy of control, lacking more effective means: as yet health education and wide information campaign including unproven efficiency of safe sex developed in the USA and transplanted without modification to Europe, has been thought the only possible way compatible with the liberal commitment to privacy, to voluntarism, and to the reluctance to employ coercive measures in the face of behaviour that occurs in the private realm (36). It is not yet possible to evaluate this strategy. It will certainly have some results. But just how much and for how long? The question has been repeatedly raised "Why do some people continue to expose themselves to extreme risk?" (37) Examples of the failure of education in general and sex-education in particular abound (teenage pregnancy, venereal disease control in the period prior to antibiotics (29), smoking, seatbelt use, alcoholism, drugs, immunization etc. Nobody today expects as was the case before AIDS that 60 % in a study of 156 relationships had sex with each other before they knew each other's names (38). The assumption underlying

the information in some campaign seemed to be that if one could sufficiently frighten persons at high risk of AIDS, they would limit themselves to safe sex or no sex. Many feel that this is wrong "Rather in response to fear arousing messages, persons continue to engage in self-destructive behaviour precisely because it has become their response to anxiety and their means of temporarily reducing anxiety" (37). Thus, as has often been reported in the gay community, an atmosphere of intense anxiety may increase, rather than decrease, promiscuous sexual activity. "The rudimentary survey of research literature currently available on AIDS indicates that whether a person engages in safe sex or reduces the number of his sexual partners is unrelated to the level of education or level of information (39). Denial of danger and giving in to the feeling of hopelessness are most characteristic of persons who have not been forced to take seriously the reality of the threat they face. Once persons acknowledge that awesome reality, they become amenable to a variety of procedures that enhance coping skills (40).

There is of course intense dispute about various ways how to communicate the messages among health education specialists. Unfortunately the time of observation is not yet sufficient for consistent evaluation and the further development may reduce the options available. One might mention examples of coping by providing false hope or false sense of efficacy, the strategies (sleep, nutrition, sport, etc. as stress reduction) based on hardly more than wishful thinking, and also the still by some held opinion that withholding the information on positivity may protect the patient from psychological harm. Although data on AIDS are still lacking several studies have previously shown that anxiety and upset were not greater in those given information about the diagnosis than in those who were not informed, and that, in fact, uncertainty may be more anxiety provoking than knowledge, even if the news is bad news (41). Withholding the information is also epidemiologically objectionable, and can lead to socially incompetent behaviour. The difference of opinion boils down to whether to rely only on education or use also other epidemiological methods. One can give as example of success virtually eliminating syphilis in Sweden before the advent of penicillin through epidemiological control, i.e., tracing out all sources of infections and subsequent contacts.

Under the Swedish law notification was mandatory for physicians and patients in order to prevent further spread of infection. On the other side in respect to health education is the example of the US Public Health Services which armed with modern drugs and with modern techniques of propoganda, inaugurated a Nation-wide anti-venereal disease campaign in July 1949 to strike the first of a series of death blows to syphilis and gonorrhoea. This was assisted by the Communication Material Center of Columbia University, with the help of slogans painted on sidewalks, billboard advertising, radio songs and announcements, television dramatization and even juke-box messages in bars and taverns. The Public Health Service hoped to reach 96,5 million persons. The general belief was "we can eradicate syphilis today with the help of penicillin is almost a foregone conclusion" (42). This was not achieved. Almost 40 years later, the CDC still reports for 1986 about 27000 cases of syphilis and about 900000 known cases of gonorrhoea a year in the USA (43) and some 20 million of Americans suffer from genital herpes.

There are also many optimistic voices. There are several possible explanations for the reported slowing down of the rate of increase in the number of repeated cases of AIDS in San Francisco and New York (change shift to safer sexual practices (39) and possible saturation of high risk susceptible susceptible population or statistical artifacts (44) and those should be closely followed up. The spread of the HIU-infection in the population as a whole may be retarded by changes in behaviour that fall short of absolute safety (safe sex, condoms, virucidal agents etc.). For the individual, compliance with a restrictive regimen may be highly unappealing. A longitudinal study conducted at the New York Blood Center however, provides a sobering antidote to such educational enthusiasm and is compatible with what we have come to expect from health promotion campaigns (45) Though, like other studies, it found a dramatic change in the extent to which gay men engage in anal receptive intercourse, just less than half of those in the study population continued to engage in that practice. If the percentage of the infected risk population has reached 50 % or more, as has been reported from San Francisco and New York, the chances of infection would be increased even if the number of partners is reduced and some practices avoided.

Social support

Need for support services and the social responsibility for the sick with AIDS has been early recognized and services have been progressively organized in various ways as the epidemic has developed, although occasionally patients could fall through the cracks in each system or the services could not have taken into account the entire spectrum of problems confronting the patients (46). Hospital care has been everywhere up to the standards and a few individual disfunctional reactions were unimportant. In addition to the medical complications associated with AIDS, patients face a host of psychosocial stressors and social problems apart from having a terminal disease, such as financial, housing, inadequate nursing home and home care, transportation, work and others. For example in Los Angeles. "Early efforts of individuals concerned with the psychosocial sequelae of AIDS were devoted to determining which services were available and putting special services for AIDS patients in place. While a number of traditional and special social services currently are available to provide psychological services to persons with AIDS, coordination among these programs and information regarding use of such services has not kept pace with their development. As a result, persons with AIDS, as well as their caretakers in the medical community, frequently were unaware of services available to persons with AIDS" (47). Study findings, to date, regarding the association of social networks, supports and AIDS have generally been to varying degree positive in terms of coping with the illness. They cannot be compared because of differences in types of actual measures, their scope and dimensions and commitment of resources, physical, personal and financial, although they have elements held in common. They have been effective in cases of selfhelp volunteer groups of homosexuals caring for the ill, when out of hospital and for the dying. Drug addicts and prostitutes have no such support systems and networks of their own. It seems that the number of social ties and the quality of those ties is the relevant factor.

In the AIDS Project/Los Angeles volunteer organization two full-time staff social workers facilitate the work of 150 professional and nonprofessional volunteers who assist 250 clients. Services provided

include psychosocial evaluations, crisis, individual, couples, group and grief therapy, advocacy with social services, practical assistance in the home, day care, transportation, food and shelter, legal, financial and insurance services, recreation and a selfcare manual. Provision of such diverse services are dependent upon the contribution of large numbers of professional volunteers including physicians, psychiatrists, lawyers, psychologists and social workers. Over two years, the attrition rate for volunteers remained low due to support mechanisms such as a telephone networking and formal acknowledgement of contributions as one method of positive reinforcement. The education provided in conjunction with the interactions of volunteers and peer pressure was suggested as a preventive measure for AIDS (48). Although the above example indicates sources and needs, the evaluation is not yet available due to variation in the target groups, stages of illness and the multidimensionality of the support structures. Is the presence of a confidant friend who provides acceptance and understanding more important to material aid? Finally the cost of the support services is not yet evaluated.

Financial aspects

At this stage it is not yet possible to overview the cost of AIDS. No attempt has been made to detail the cost of AIDS to the community, which are growing from year to year. The total funds allocated to the Centers for Disease Control in the USA for all AIDS education and public health measures are estimated to have been US-Dollar 64,9 million in the fiscal year 1986 (26). The Public Health Service budget request to the US-Department of Health and Human Services for 1988 includes US-Dollar 68,8 million for all AIDS public health and education efforts within a total request of US-Dollar 471,1 million for AIDS-related activities. Expenditures by states for AIDS prevention for only five states (California, New York, Florida, New Jersey, and Massachusetts) account for 85 percent of the total spent since July 1, 1983 (US-Dollar 117,3 million) with California and New York jointly accounting for 66 percent. Current annual state expenditures for AIDS-prevention efforts in California average 65 cents per capita, and in San Francisco such expenditures approximate US-Dollar 5 per capita. Extra polated on a population

basis for the entire United States, these figures would amount to state expenditures nationwide of approximately US-Dollar 150 million and US-Dollar 1 billion, respectively. Thus is a need for approximately US-Dollar 1 billion annually for education and other public health expenditure by 1990 is proposed. (26) It is envisaged however, that this amount will not be sufficient to stem increases in the prevalence of infection. Despite the expenditures noted above, the infection continues to spread in areas such as San Francisco, though at a reduced rate. The average total cost for in-patient care from the time of diagnosis until death ranges from about US-Dollar 50.000 to US-Dollar 150.000. The difference in the figures derive largely from differences in the numbers of hospital days used, the type of care, readmission (average 3,3 hospitalizations per year and patient and between 18,4-21,8 ambulatory visits) and the disease manifestation. Lower amounts of about have been advanced (from Massachusetts) 91 % of these expenditure 38.702-46.505 related to use of inpatient services (49) and even less (in San Francisco) for all hospital in patient and outpatient care ranging from \$ 7026 to \$ 23.425. rp. \$ 23.571 (50).

The Public Health Service has estimated that the direct cost of care for 174000 AIDS patients projected to be alive during the year 1991 will be US-Dollar 8 billion to US-Dollar 16 billion in that year alone. Because this estimate does not include the care of ARC patients and seropositive individuals, and because it does not take into account the costs associated with experimental therapies or lengthened survival times, it significantly underestimates the total annual direct costs for HIV infection in that year. The costs for care of ARC patients and seropositives - of whom there are many more than there are AIDS patients - and the care of newly recognized AIDS dementia, the costs will certainly be higher. No attempts have been made so far to estimate indirect costs associated with the loss of wages for sick persons, the loss of future earnings for persons who are permanently incapacitated or die because of illness and the cost of infection control in the course of other health services such as dental care. With 9500 patients, at that time, the loss of productivity costs were estimated at exceeding US-Dollar 4 billion over the course of what would normally be the rest of patients' lives. (51) The cost of antibody-test, performed about 80000 times

per working day in the USA, is about 3,2 million a day. (26)
Demonstration of the virus costs about \$ 300.

The recommendation of the National Academy of Science in the USA (1986) was an increase for research toward a level of US-Dollar 1 billion annually by 1990. In addition, it recommends that there be a significant federal contribution toward the US-Dollar 1 billion annually required for the total costs of education and public health measures.

The future costs in Europe are not known, they are likely to be lower due to different ways of financing health care, both preventive and curative and will depend on innovative approaches to care. In Germany the costs were calculated at 150000 DM per patient (52) indirect costs at about 330000 DM, in the UK about US-Dollar 36000 for medical care per case (52). The disease has created a new pool of recipients of public assistance, because of patients' lack of ability to continue employment as the disease progresses.

All those cost projections exclude costs which will be spent on church-related voluntary agencies and private foundations. Curiously enough, in Europe there were no reports of funds collected at bars or memorial donations made in honour of those who died. The World Health Organization has planned an expenditure of 1,5 billion a year by the start of the 1990s for a massive global public-health programme. This would represent three times the current annual budget, and would dwarf the US-\$ 100 million WHO has spent over 10 years to eradicate small pox.

Research in the economy of health care for AIDS patients, monitoring of effectiveness of various modes of financing and of total expenditure is needed. There is no doubt that AIDS has become a most expensive disease and the costs cannot but increase. The full range of obligations is not yet clear (blood screening, therapy, counselling, education, research).

Social epiphenomena

As with any other disease for which there is no effective therapy

AIDS has brought about a gray market for non serious healers and "wonder" drugs. This is sad but not a new phenomenon. Already from the plague epidemics in middle ages there are reports of sellers of patent drugs (and at attempts to control it). In Germany the healers, prohibited to treat any infectious disease are allowed to treat AIDS. Recently a paper recommending treacle based on snake flesh has been submitted for publication (and refused) in a serious medical journal by a homeopathic physician, and cure of AIDS has been advertised in the newspapers. The legislation preventing financial exploitation of AIDS patients is lacking in many countries.

AIDS has also been perceived as means for upgrading status and self interest of various nonmedical or nonprofessional aspirations, filling the market gaps, particularly self styled and more often than not biased sexual scientists". Under the wings of recognized needs of counselling, care, protection or under the umbrella of a friendly society (and subsidies), the question to be asked is not only who acts on behalf of whom but also why? (3)

Social Science Research Needs

The general tenor of scientists (medical and others) has been that there is no adequate financing for social science research. One has also become aware of how little we know about various aspects of sexual behaviour in the society in general, f.ex. the precise degree to which current sexual behaviour differs from that of the past, how it reflect the drifts of social changes about the frequency with which homosexuality occurs f.ex. in Africa, about the pattern of heterosexual behaviour in Africa, of behaviour of bisexuals, use of protective practices and reasons why some members of the homosexual group continue to expose themselves to extreme risk, what degree of risks is dependent on what kind of behaviour, (oral behaviour for example) the relative frequency etc. Research in these fields is only beginning and it is likely to increase. What then are the areas where social research can be seen as most effective today? Perhaps it can help develop effective education programmes to encourage changes in behaviour that will break the chain of HIV transmission. It can contribute to the design of policies that reduce public's

fear of AIDS and that help eliminate discriminatory practices toward AIDS patients, and shape establishment of the best form of health care and social services adequate for AIDS patients. (26) One of the priorities is to understand the social dynamics related to HIV infection, to develop means to reach people at risk, to find the most appropriate language and communication among various population groups. Social science can find what social support is most convenient and what kind of staff is best suited for various groups and stages of infections, what type of settings, such as open homes, joint housing, communities oriented care and hospices in which AIDS patients can spend their last days. It can show what are the most common social problems to be dealt with in various ecological conditions, which will vary from country to country and specific subpopulation. Perhaps social science studies could also, by watching a constantly changing situation of individual and collective values, discern the rifts and dichotomies which might occur and endanger the social structure, values and the social order of our societies.

In the long run (next decades) social science could watch multifaceted consequences of AIDS, f.ex. changes in contemporary codes of sexual behaviour, ("the swinging time is over") and effects on demography, or contraception as product of wide spread use of condoms, trends in teenage pregnancy and the like. AIDS reduction and the possible development of a new morality begin with separate premises and a separate frame of reference, they are intimately related to the human sexual behaviour. Although Nothing so far points to radical trends toward a return to the ascetic ideal of the Christian church, swept away by the Industrial Revolution, the development of political individualism and technology, it is conceivable that AIDS will be a significant factor in shaping and conditioning future sexual and social codes.

Among the major recommendations of the National Academic of Science, Direction for Research (26) it is inter alia stated: "Begin substantial, long-term, and comprehensive programmes of research in the biomedical and social sciences intended to prevent HIV infection and to treat the disease caused by it.

Concluding observations

After years of successful control of infectious diseases, society finds itself in a situation characterized by objective limits to control, the impossibility to offer as it did over the past half century in the series of other diseases the "magic bullets" of vaccines and antibiotics. Modern man of the 20th century has forgotten about lethal infections and he expects instant effective solutions. Until better means are available the options will remain limited and are causing division among physicians who have lost to politicians, advocacy groups, lobbies, journalists etc. the authority over the problem and the primary right to influence control strategies.

The risk of embracing the promise of education is that the politically attractive will be confused with the socially efficacious (29). Nobody speaks today about stopping, controlling, eliminating AIDS but only about slowing its spread until medicaments for therapy or vaccine for prevention are hopefully developed, or wishfully, some mutation in the virus brings about its loss of pathogenicity or some herd immunity. This is of course an unsatisfactory prospect. "We are hostage to the advances of virology and immunology and will be so for many years. As the AIDS-associated toll mounts, so too will the level of social distress. If this protracted encounter with a microparasitic threat, it will be critical to preserve a social capacity for reasoned analysis and public discourse". (11) That is a capacity that may be subverted by those who would generate hysteria and repressive moves as well as by those whose fears of such a turn result in irrational charges of "totalitarianism" at the very mention of public health (53, 54, 55). It has been pointed out that the failure to take appropriate public health measures could produce the popular basis for more drastic action (11). Concentrating on fear of "Labelling", fear of being blindly activist, alarmistic, restrictive, infringing the rights of individuals has already brought charges of timidity and capitulation to political pressure of interest-groups (56). There are reasons to believe that public health officials have been too reassuring about the modes of transmission, the proportion of infected and about the rate of development of overt diseases. The

health authorities tread on the narrow path between extremes of voluntarism and regulationism. "If the recognition of disease implies both a phenomenon and its social perception, it also involves policy. And that policy inevitably reflects phenomenon and perception. If an ailment is socially defined as real and nothing is done, then that too is a policy decision" (57).

Starr (1986) has pointed out that when rights to individual privacy demonstrably conflict with collective rights to survival, some hierarchy of values will be involved. So the use of serological testing as an epidemiological - medical tool for community survival must be separated in law from its misuse for unrelated purposes against individuals in housing, employment and insurance. While strengthening the moral compulsion for being tested, he would strengthen legal guarantees of those fundamental rights of the infected, since their exercise poses no reasonable threat to the community (58).

Until the natural history of AIDS is definitely known one could only speculate what social consequences will the pandemic ultimately have. No doubt a disease predicted to kill millions of people cannot but profoundly influence demography, culture, politics, morality and sexual norms, the pattern of economy and trade, tourism, the attitudes to diseases and death way of living and the fabric of social organization. It will also affect the ways of provision of medical care and the views on the philosophy of medicine itself. The importance of AIDS has not, perhaps could not have been, initially rightly assessed. The Director of the World Health Organization has admitted that he has underestimated the AIDS importance. Most national authorities did not admit it yet. The politicization of AIDS is in progress influenced by various ideologies and group interest and impede calm search for best answers.

The National Academy of Science in the USA concludes in its 1986 Directions for Public Health, Health Care and Research: "No single approach - whether education and other public health measures, vaccination, or therapy - is likely to be wholly successful in combating all the problems posed by HIV infection" (26). In view of the number of people now infected, it is extremely unlikely that the

rising incidence of AIDS will soon reverse itself. Disease and death resulting from HIV infection are likely to be increasing 5-10 years from now and probably into the next century" (26). In the field of medicosocial science the work is only beginning, perhaps taking the form of a new branch of medical behavioural anthropology as suggested by Gorman (59).

Summary

AIDS is an infectious but also a social disease. Next to the major epidemiological question on the natural history of AIDS, important problems are posed in various fields of social, political ethical and legal areas extending far beyond the traditional medical interest. They are bringing polarisation among public, politicians, press and also among physicians. As the situation changes, the gravity of the disease has become more prominent and consensus on effectiveness of means used and proposed is not yet achieved. Social phenomena depend on the societal values, perception of the fear and menace of the disease to the individuals versus perception of the collectivity. In the major risk groups this fear influenced by various ideologies and societal goals is more pronounced than the response of the society warrant. It is not one of condemnation but one of tolerance, and sympathy and has been directed not toward deterring people in engaging in certain kinds of sexual behaviour, but toward doing this with minimum risk possible. The conflict between the perception of rights (individual versus collective) is bound to grow (testing f.ex.) although it is easy to separate in law legitimate epidemiological needs from their possible misuse.

Present position of the main risk groups is changing in various ways. The reluctance of the society to address openly issues of sexual behaviour has disappeared. There is rapidly accumulating knowledge on the social influence in the spread of the disease, but as yet, scant information on the influence of social factors on the control efforts and effectiveness of the preventive behavioural strategies (ei education, safe sex). Effects AIDS will have on the complex social structures in general, on health structures in particular, and on the problems which might shape future attitudes, values and codes can not be defined with any degree of precision but only vaguely guessed as the disease progresses now and into the next century.

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