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AIDS and Preventive Health Policy

by

Rolf Rosenbrock

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Steinplatz 2, D 1000 Berlin 12
030/313 40 81

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Abstract

The infectious disease Acquired Immune Definciency Syndrome (AIDS), which has so far been unrestrained, is the subject of extensive public attention, as well as the source of strong fears and hopes. The fears are due to a further expansion within and outside of those risk groups which had first been identified (homosexuals, intravenous drug users and prostitutes). The hopes are formed in the area of pharmaceutical development of effective vaccines and therapeutic drugs. The following contribution illustrates the possibilities of preventing the disease, a fact which has hardly been taken into consideration so far, especially in the area of non-medical prevent!on.

- The dynamics of pharmaceutical research on immunization and therapy lead to a low priority of exactly those special fields and questions of research which can provide important information for primary prevention (preventing the transmission situation) and secondary prevention (preventing manifestation of the disease after viral contact).

- The scope of information and education campaigns is too small in regard to the target group and too wide in regard to the risk situation: what we need is a specific and widely available information for the entire non-monogamous population and a precisely defined catalogue of risk factors which could then be considerably reduced from their present 1evel .

- Information, education and prevention will become more efficient and effective if they are carried out in decentralized, non-governmental operations, organized in small groups (e.g. AIDS-help organization).

- The efficiency and effectiveness of such strategies require the maintenance or creation of a series of material and general poTitical conditions by government agencies and the medical system.

- An essential condition for effective prevention is to return the virus antibody test to the medical task it was designed for which means to secure blood supplies and transplants, a direct use in diagnostics and the professional use in reputable epidemiological research. The test is not an instrument of prevention; on the contrary: rather its use in screening can increase the level of illness while preventing effective measures.

The problems in achieving an AIDS policy aimed at prevention are happening in an environment of a deeply seated volatile response to the disease.

The following text summarizes the results of a book which the author published in October 1986 "AIDS can be defeated faster - Health policy exemplified by an infectious disease", (AIDS kann schneller besiegt werden - Gesundheitspolitik am Beispiel einer Infektionskrankheit"), Hamburg, VSA-Verlag, ISBN 3-87975-389-X.

I. AIDS as a Problem of Health Policy

AIDS is transmitted by the HIV-virus which puts the immune system out of action. No medical treatment has been discovered so far; it is fatal in most cases. In fact a considerable "levelling off" as to the rate of increase of newly infected persons can be noted - at least in Western Europe and the USA. Nevertheless, the world will have to live with this infectious immune deficiency (AIDS) beyond the year 2000. Perhaps this disease will never be entirely eradicated which has been the case with almost all epidemics up to now. The only exception to this sad fact in the past few centuries has been smallpox.

In the case of a favourable - and probable - development, AIDS will at some future date occupy an unassuming spot in the statistics on illness and the causes of death, possibly ranking below tuberculosis, for example. A hundred years ago this disease caused a similar panic as AIDS does today. It cost millions their lives. The causative agent, the tubercular bacteria, discovered by Robert Koch in 1882, could never be eradicated. This pathogen can still be found everywhere in our environment (it is ubiquitous). As housing, working, living as well as hygiene conditions have been improved and since medical progress in immunization and therapy was made, a contact with the pathogen today only seldom leads to infection and the disease seldom to death. For this reason, tuberculosis is by now rightfully considered as being defeated - at least in Central Europe. Nevertheless, since the appearance of this new disease more than twenty times more people in the Federal Republic of Germany have died of tuberculosis than of AIDS (over 5,500 as opposed to approximately 250 victims).

Contrary to the prevailing perception in the public and amongst politicians, the continuing development of the disease does not only and probably not even primarily depend on a success in pharmaceutical research in the search for new vaccines or therapeutical drugs.

The decisive possibilities, for today as well as for the foreseeable future, for favourably or unfavourably influencing the number of new cases lie in the health policy (this means in the control and regulation of research, non-medical prevention and the reaction of the medical system) as well as in the emphasis which the health policy receives in comparison to other political areas, e.g. minorities, drugs, vice and moral policies.

Every disease appearing for the first time represents a challenge to health policy and involves two tasks both of which must be resolved quickly and efficiently to the same extent: restraining the spread of the disease and improving immunization and therapy. Despite numerous positive results, the previous developments and presently foreseeable ones in dealing with AIDS also reveal deficits and inappropriate regulatory procedures. Their corrective adjustment could reduce the personal catastrophes and social dangers connected with the disease to a considerable extent.

Serious deficits and inappropriate regulatory procedures in dealing with AIDS can be seen in all important sub-areas of applicable health policies. In their structure they are all not AIDS-related, but can be found, in different forms, in the health policies involved with all important contemporary diseases.

Meanwhile, these inappropriate health policy controls have assumed forms of institutionalization and stable resource distribution and have in part become firmly established. The appearance of a new kind of disease, however, also provides an opportunity to develop an innovative and progressive start to a health policy. Even the volatile socio-psychological response caused by AIDS is no convincing reason for exclusively solving the problem in the usual deficit health policy manner.

Basically the central task of health policy for the entire population consists in reducing to a minimum the probability of acquiring a disease. In this point health policy differs from medical treatment of the individual, which is necessarily concentrated on each single case and its knowledge and possibilities of therapy supply one essential aspect for the creation of an efficient health policy. Other, aspects such as particular circumstances affecting disease risk, determined greatly by social conditions and psychic constitution, play an at least equivalent role.

The maximum reduction in the probability of catching a disease is the objective, not only for chronic degenerative cases, which make up approximately 90% of the illnesses and deaths in industrial countries, but also for the infectious diseases which occasionally emerge anew.

This objective' is valid for both medical and non-medical intervention. The potential in health-maintenance, especially of non-medical prevention, represents the largely unused productivity reserves of health policy - not only with AIDS. Activating them is generally easier to accomplish with infectious diseases such as AIDS than with common, non-transmittable diseases because they normally do not have to be enacted in face of strong political and economic interest groups and because the number and various constellations of risk-creating factors are easier to see in most case and thus easier to influence.

There is no evidence for a genetic determination for AIDS, neither in epidemiological nor virological research. It can be said that the virus is transmitted almost exclusively from sperm to blood and blood to blood contacts. Meanwhile we know from the many thousands of cumulative years of experience which were made in handling AIDS-patients in clinics, families and prisons, that even a close contact with the sick does not carry any danger. The only documented case worldwide is that of an English nurse who accidentally infected herself in a

clinic with blood taken from an AIDS patient, whereupon HIV-antibodies developed in her blood. Two thousand other injuries involving injection needles among nursing personnel who have dealt with AIDS patients have been investigated. Those persons concerned, without exception, remained sero-negative. There is no known case of transmission within families or inside prisons without their having been high risk sexual intercourse although, for example, non-infected family members even shared in some cases razors and toothbrushes with full-blown AIDS patients.

There is no single case worldwide of an absolutely definite virus transmission occuring from saliva, tears, perspiration, sebum, mucus, earwax, dandruff, urine or excrement. Worldwide there are two cases of unsolved infection mechanisms: a husband infected with blood products who infected his wife although a transmission through sexual intercourse can be excluded due to the husband's impotence as.well as a four-year-old boy infected by a blood transfusion who passed on the infection to his older brother.

We can therefore conclude, with a safety factor going well beyond average health protection measures, that close, even intimate body contact with sero-positive persons represent no danger of infection when the known risk situations are avoided.

In regard to preventive measures, the struggle against AIDS has an objective which is easy to formulate: to reduce to a minimum the number of transmission situations amongst the population. These risk situations are identifiable and only arise when individuals consciously enter into them.

For this reason AIDS prevention is - at least at the present level of knowledge - a permanent and effective behavioural control in potentially high risk situations.

AIDS has produced the objective necessity for an effective change in, or limitation of, personal sexual activities for all those persons who risk transmission by having sexual intercourse with differing partners.

Research and health policy thus have three priority tasks:

- to identify the transmission situations exactly and if need be, to further delimit the identification;

- to prepare and realize prevention strategies which reduce the number of high risk situations as much as possible while taking into consideration their respective importance in the life-styles of those likely affected;

- to refrain from doing anything that could socially and individually hinder the effectiveness of such strategies.

II. Five Areas of Intervention in Health Policy Control

The following summarized package of five politically practical measures all aim at the development and use of possibilities for the prevention of AIDS. At the present state of knowledge about medical immunization and therapy of the disease, the touch upon the only field of intervention in which health policy could now have a direct effect. However, with the proven suitability of medically effective vaccines and/or therapeutic drugs the importance of non-medical prevention would never shrink to zero. The victories of health policy over the great "old" infectious diseases were always based on a combination of behavioural changes finding acceptance and impetus in society, and the effective weapons of medicine which, in, most cases, were developed later.

The low priority given to non-medical forms of intervention in health policy, not just present day and not only to be seen with AIDS, justifies the thesis that, with a minimum of effort, a relatively high rate of health and, considering the volatile social response to AIDS, social gain can be achieved with the changes in health policy control suggested here.

1. AIDS research must not simply be expanded, subsidized more and de-bureaucratized. This, of course, must also be done because it is a neck-to-neck race against time between life and death. From the point of view of disease prevention, however, it seems much more important to expand the thematic and systematic research into AIDS. Equipped with equal rights, the involvement of the social sciences, social-epidemiology, sexology, and ethnology as well as the expertise out of the high risk groups, could considerably help to specify the planning and realization of preventive strategies and thus make it much more efficient.

Besides that, the experiences gained from the struggle against the "old" infectious diseases at least point out that important information on immunization and therapy can also be gained by observing systematically the path of the virus into the blood stream and the circumstances of the transition between the different potential early stages of the disease (viral contact, formation of anti-bodies, latent stage, and finally ARC-symptoms).

Research for effective vaccines and/for therapeutic drugs is evidently pushed ahead by the ever reliable profit motive of the corporations involved, the career and reputation structures of the medical profession, and a health policy which is still, to a great and continuous extent, fixed on the natural science area of the health sciences. It is obvious that the struggle against the AIDS virus will bring the first and most important inroads into human genetic engineering, whilst in this process, even more animals will have to die. All this raises problems which go far beyond AIDS as an infectious disease.

It is of decisive importance in the struggle against AIDS that this research thinking does not reduce the essential questions regarding prevention to the level of scientific inquisitiveness. Five research question, receiving little consideration worldwide, can concretely be formulated:

a) What is the distribution of risks within the population? Which individuals and what groups, and in what contexts, let themselves enter into situations today where an associated risk of transmission exists? How can these groups be described socially, sexually, regionally, and ethnically?

In order to avoid impairment to one's health on a psycho-sociological level, today the question must also be posed the other way round: What groups today because of disinformation

and fear, impose upon themselved barriers in every day life and in their sexual patterns which cannot realistically be justified by the danger of AIDS?

Answers to these questions are above all important for the creation of specific information and prevention measures for target groups. A definite benefit would be gained from the creation and perfection of campaigns towards prevention, above all in the area of socio-epidemiological counselling, which would expediently lie in the hands of the organizations affected.

b) How does the virus enter the bloodstream? How great is the viral "critical mass" of different bodily secretions containing viruses? What consists a point of entry for the virus? Are lesions necessary or does the contact of virus-containing body secretions with tissue of the mucous membrane suffice? How can the differences in the resorption probabilities, which amount to differences of up to factors of ten and even possible exclusion of risk, between the mucous membranes of the rectum, vagina, and mouth be explained?

c) Under what social, psychological, and acute conditions does an "effective" virus contact result from a sufficiently large virus inoculation into the bloodstreams? Epidemiology provides indications that some people, despite considerable viral contact, have never formed antibodies nor become sick. What are the distinguishing characteristics of these people and their living conditions that differ from those with whom the same virus attack was "successful"?

d) Do conditions exist under which the virus can be eliminated or permanently neutralized in time by attacking antibodies, i.e. before the RNA/DNA transcription in the infected cells?

e) Under what conditions does a sero-positive person turn into an ARC or AIDS patient? All the indications are that these conditions do not only lie in the physiology of the people af-

fected. The fate of millions of people worldwide, for whom both of these characteristics (sero-positive and healthy) apply, depends on the answering of this question..

2. Education and prevention campaigns are imperative and necessary for all high risk groups. They must present the essential warnings clearly and precisely. The less clearly defined they are and especially the more extraneious facts (which are not related to AIDS) that are mixed in, the more this message will become hampered. Consequently, the basic conditions for AIDS prevention are improving due to the latest research results (predominantly form descriptive epidemiology), most recently presented at the international AIDS congress held in Paris at the end of June 1986, which permit a more detailed determination of dangerous practices.

a) In addition to intravenous drug users the target group comprises the entire active, non-monogamous heterosexual population because generally common sexual practices are connected with risks ranging from considerable to catastrophic.

From the point of view of AIDS prevention, a differentiation between heterosexuals and homosexuals, as well as between prostitutes of both sexes, as to the degree of risk cannot be accepted - though expedient when conveying the message to the specific target group (see below).

Especially when one, in clear intellectual coolness, directs the preventive considerations towards the numerical minimization of AIDS cases, it becomes evident that even the "advantage" of transmission probability of heterosexual intercourse over homosecual intercourse, lower by factor of, for example, twentyfive, would be very quickly cancelled by the approximately forty-fold greater size of the heterosexual population.

b) As opposed to earlier attempts made with preventive guidelines, primarily "safer sex", dangerous practices can be defined more precisely and restricted accordingly.

Obviously the most dangerous are the practices of anal intercourse without the use of condoms and the use of unsterile injection needles. A relevant danger evidently.also exists with vaginal intercourse without condom and blood vessel-damaging practices, especially in the area of sado-masochism (S & M).

If <u>these and only these</u> techniques were avoided within the high risk goups, then the infectious disease would lose its dynamics of expansion. It must be kept in mind, however, that the prevention of viral contacts today will determine the number of cases of illness in three to five years.

Epidemiológica studies conducted in the USA and Canada arrive at the same results, namely, that the risk of viral transmission through other sexual practices, above all oral sex, is lower by at least several factors of ten ("no detectable risk for oral receptive intercourse"). Since research into the "outer" mechanism of transmission of the virus is being disregarded worldwide, one cannot presently, with certainty, explain how this difference arises and wither or not the virus can be transmitted in this way at all. Contrary to the danger of especially unprotected anal intercourse, the not yet entirely excluded possible dangers such as the ripping of the condom, transmission through oral sex, or accidents in sexual intercourse, lie below other epidemiological risks to health and life such as continual stress on the job or cigarette smoking. If these limited rules for safer sex are observed, then intercourse with HIV-antibody-positive partners is free of the risk of transmission. There is no justification on health grounds for the creation of a new ghetto for "tested sero-positive persons". By compliance with the rules of safer sex, the importance of promiscuity as a risk of transmission clearly loses weight.

3. The special nature of respective topics in prevention (promiscuous sexuality, homosexuality, prostitution, and addiction) as well as the extreme position in society of three of these four fringe groups requires particular forms and agencies for providing communication and prevention.

In this respect the beginnings of self-help (AIDS-help organizations, which came about for the most part spontaneously in the homosexual risk groups) would provide a solution. Only these AIDS-help groups have a sufficiently decentralized organization as well as adequate knowledge and capability at their disposal in regard to the relevant risk situations, their social background and needs, as well as the possible ways of conveying a message suitable to the risk groups. And above all, their work rests on a solid base of trust among high risk groups. Their organization and the financing of these beginnings, taking into account sub-groups and specific "science" characteristics, must be expanded for all four groups.

They can only contribute specifically towards prevention when they make relatively autonomous use of their situational proximity and competency within the prevailing law structure. They must have the possibility of acting within the risk groups specifically and exclusively from the perspective of AIDS prevention. A burdening with other topics will endanger the substance of their success. Safer sex for the non-monogamous population and disposible syringes for intravenous drug users are the message of this prevention. According to all the experiences acquired from attempts to influence health-related behaviour, lasting success with such efforts can be achieved best when the acceptance of the "necessity" factor ist maximized and the "anxiety" factor (in contrary to the "fear" factor) is minimized.

As difficult as this insight may be for some individuals in positions of responsibility: He who wants to combat AIDS must first accept the sexual behaviour and the intravenous drug use

as a fact and on this basis look for possiblities to intervene. He who aims "lower", i.e. considers the change of drive and addiction behaviour a suitable starting point in the struggle against AIDS; or he who aims "higher" and thinks he could solve the prob1erne by creating a general atmosphere of fear and police repression, will - in the end - achieve the contrary of what he is trying or alleging to do.

Consequently, successful prevention cannot be controlled by the logic of official administration. Also an inclusion of such campaigns in the area of "public morality", which attempts to adhere to the exclusiveness of models of society such as monogamy and drug-free, endangers the essence of the contained health policy in these measures. If the actual social development of sexual behaviour and the danger to life connected with AIDS are taken into account, then the protection of the family guaranteed by constitution (Art. 6 Grundgesetz, German Constitutional Law) certainly also leaves enough room for action.

When and where these conditions are given, AIDS-help can become a model case for the performance and structure policies, decentralized and close to the problem, in health care, the importance of which will point far beyond the reach of the infectious disease AIDS. Furthermore, an essential innovation in regard to the necessary preventive reorientation of health policy could be made here.

For years, campaigns for prevention have been conducted in the USA primarily by organization representing the main group affected. Their success can be seen in the observance of the rules for safer sex by sixty to eighty percent of risk group members. Such rates lie far beyond the usual success levels of health information campaigns. With appropriate actions and suitable conditions, they could be increased and stabilized even more.

4. The representatives of government and paragovernment health policy have by no means been released from their responsibilities by the extensive transfer of concrete -information and prevention tasks to extra-governmental representatives (AIDS-help organizations) who can carry out this task with specific regard to situation and "scene" as well as with the corresponding autonomy. Their tasks can be summarized in four points:

a) The creation and guaranteeing of the necessary room for action for AIDS-help groups as decentralized, non-government carriers of this very specific public health task. The provision of the required financial resources, organizational support, and public legitimation of the scope of action.

The relationship between government agencies and AIDS-help organizations must be considered as being analogous to an obviously legal relationship and cannot be formed according to supervisory rule of experts. The formulation of AIDS-help tasks are not compatible with attempts to blend the problems of an infectious disease with other moral, sexual, or addiction topics or even to instrumentalize AIDS-help for them.

b) The task of government agencies in preventing AIDS also lies in those areas where government regulations directly contradict the necessities of AIDS prevention, as is the case, for example, in prisons, in care for prostitutes, and in dealing with intravenous drug addicts. Access to the mass media for the safer sex message also seems to be in need of government regulation. When tabloids refuse to print safer sex advertisements by referring to "public morality", while at the same time publishing page after page of daily ads for prostitution ("hostess", "dressman"), then the double standard turns into a life-threatening perversion. In the area of paragovernment health policy, i.e. pension schemes and health insurance, it is of special importance to ward off or reverse intrusions into the solidarity principle within rehabilitation and insurance protection. In other words, the HIV-antibody test, which

in essence does not represent any kind of individual diagnosis, but solely a diagnosis of disposition with merely epidemiologically interpretable results must not become a prior condition for insurance benefits, legitimized by social welfare law. Besides that, "ostracism" by social welfare laws of a disease would have considerably adverse effect on the climate in society towards prevention of this disease.

c) Effective AIDS prevention among the four identified risk groups (promiscuous heterosexuals and homosexuals, prostitutes and intravenous drug users) presupposes that the persons bearing these risks be approached as carriers of a health risk and not as social and sexual deviates, perverts, disreputable individuals and lost souls. Effective behavioural education collides at this point with government supported "public morality", which propagates the ideal of exclusive and life-long monogamy and "delegates" addiction problems present in all of society to fringe groups, represented as being criminal elements. Part of the subsequent burdens of this schizophrenia, connected with every double standard, can be offset by the autonomous, differentiating efforts of AIDS-help groups in the specific risk groups. Above all, the necessary behavioural education in the homosexual scene presupposes that non-monogamous sexual behaviour is also accepted at large as a lifestyle for which - within the assumable framework of a given health policy - certain rules for preserving one's health and life are urgently required. If an attempt is made the other way round, i.e. to instrumentalize AIDS for restoring such models then it would first of all be less promising, secondly - and also partially - attainable only by means of massive, health damaging campaigns of fear, and thirdly at the expense of avoidable AIDS deaths.

d) A glance at the history of dealings with, not only sexually defined, minorities in Germany shows that these groups have solid reasons for harbouring suspicion towards government measures, especially when the latter are embellished with labels claiming to provide health and moral protection. The cli-

mate in all of society, which also makes up part of the climate of infection, could be considerably relaxed by "measures inspiring confidence" and the chances of AIDS prevention could thus be greatly improved.

5. The test for the HIV-antibodies (or for the virus itself with regard to advancing technology), is a necessary and helpful instrument for the safety of blood supplies and transplants.

In exclusion and differential diagnosis the test should only be employed after all less "invasive" diagnostic instruments have been used because of the often devastating to potentially fatal consequences of one's being informed of positive test results. In epidemiological research and in the research of the course of the disease, the ethical and health justification for employing the test depends on the maintenance of the usual professional standards. The present research practice of frequently testing, in a completely unsystematic manner, all attainable blood from mainly the first visible groups affected, and not always observing the basic condition of "informed consent" falls below these professional standards to a disturbing extent and thus also contributes little to our knowledge of the prevention and treatment of AIDS.

The use of HIV-antibody tests on persons without symptoms clearly lies beyond the limits of professional medical ethics and health-related logic. With our present level of knowledge a positive test result means a five to thirty percent probability of acquiring AIDS or an early form of it, generally within three to seven years. At least up to the point when symptoms appear there is no possibility of specific medical intervention. A need for intervention results only, but very frequently, from psychological effects, which stretch from severe psychological disorders to suicide, of one's being informed of positive test results. In such a situation an iatrogenic induces "group of patients without symptoms" is the re-

suit. This is all the more so senseless since no consequences for the behaviour of thoses persons tested or for their environment follow from the test results. The rules of preventions (safer sex and disposible syringes) are valid for all persons connected with the high risk groups regardless of sero-status. Positive test results frequently cause panic, a withdrawal from reality or anomie.

These reactions, however, are the worst conditions for the rational behaviour indispensable for AIDS prevention. Fundamental advice for the way to live for sero-positive persons, with which the probability of an outbreak of the disease could be diminished, are unknown. That, on the other hand, the existential fear increases the disposition towards full blown AIDS and for the outbreak of infectious illness, appears to be at least plausible.

Protection from AIDS in hospitals, schools, prisons, and restaurants cannot be increased by the HIV-antibody test because there is not threat outside the well-known risk situations.

The official administration test-offer ("Who should go for the test? Anyone who thinks he has been infected.") has in reality started an ill-directed mass screening that is not compatible with criteria for early detection examinations as self-defined by medical science and medical ethics. Conducting the test on expérimentées without symptoms, outside the strictly defined research intent, amounts to medical malpractice in view of the health and behavioural effects triggered. In the face of a growing gap caused by a series of technological developments between possible medical diagnosis and the treatability of numerous diseases, the misuse of this instrument, carried out without any resistance, represents a dangerous health policy weakness.

Since the mere existence of the test also awakens and stimulates to a great extent irrational demand for it, access to the test must be made more difficult. In order for enquirers

to overcome such burdens, they must first be made cognitively and emotionally aware of the quality of the report as well as the life-altering psychological effects of positive rest results. Access can be expediently regulated in a procedure analogous to an abortion - several health and psycho-social counselling sessions at drawn out intervals with different, and not only medical, institutions.

The forseeable increase in similar, therapeutically irrelevant, tests raises the question of the sense and handling of medical Damocles swords which goes far beyond the framework of AIDS.

III. Implementation Problems of a Rational AIDS Policy

1. "Normal" Health Policy and AIDS

The one who is concerned - or generally spoken - dealing with health and sickness, knows that health policy responses correspond only in a few areas to the nature of health challenges.

This is true for the largely underused possibilities for illness prevention given in workplaces, in the environment, in transportation, at home, and in school. Many thousands of people become ill and die annually, although this could be prevented by commonly known measures. Furthermore, this is also valid for the "selection" of health problems which enter into the catchment area of the medical system: about 80% of self-detected health disorders are - luckily in the majority of cases - not treated medically. Among the remaining 20% of cases which do not receive treatment, many problems cannot be cured medically or are not of a medical nature. This can also be seen deep within the medical system with its fissured structure in which the respective individual areas (public health services, protection in the workplace, practices of established doctors, the pharmaceutical and medical equipment industries, hospitals, health insurance organizations etc.) seem to be carefully protected from significant innovations in the health care field.

If one compares the results of health policy (measures, performance, and information) to the original health problems and the possibilities provided by knowledge, technology, and money for possible preventive, care, and curative interventions, it will become obvious that the results obtained are in every respect below optimal.

In many cases they do not provide any answer at all to health problems; oftentimes they are even harmful and exacerbate the problem(s).

From this comparative point of view a glance at the dealings with AIDS does not provide any great surprises: Present health policy does not follow any concept which adequately confronts the problem. Even when the protagonists are for the most part well-meaning and also well-informed, they achieve almost always at least doubtful results.

The reasons for these policy errors in the case of AIDS are not much different from other areas:

a) The government as upholder of public health policy has in the whole only three instruments at its disposal for taking action: It can pass laws and decrees as well as define obligations and entitlements for performance, i.e. it can set standards. Furthermore, it can regulate the flow of money either directly or through establishment of required standards, in other words, it can use money to exercise control. The government can also provide information. It cannot do much more in health policy.

The AIDS problem because of the psychological "nature of the problem" and society's response cannot be achieved by forcing a set of government standards. The government can indeed make research and prevention possible with money, but cannot carry them out itself. In order to get prevention and research moving optimally - with money -, it must back off from the usual routine of bureaucratic hierarchy, of orientation towards medicine, and of administrative behaviour - things which are hard to do in government. Despite obvious progress, the government is still blocking its own path in regard to general information on AIDS. When government representatives understand themselves as guarantors of the "upper levels" of society's double standard, then they are hardly able to conduct

any education on AIDS since such education should presuppose an affirmative response to non-monogamous kind of relationships.

b) The medical system functions and develops largely on the basis of the problem awareness of the individual medical profession together with the tangible material interests of the doctors, the pharmaceutical and medical equipment industries and some other economic branches. Among other things they posses the common tendency to integrate more and more health and sickness problems into their catchment and market areas. Thus the medical system is aimed at expansion - against all health and economic understanding. Organizational and procedural form which aim at activating one's own and "layman's" expertise are only accepted reluctantly and with difficulty. Even prevention as part of society's organized prophylaxis is often misleading titled as "preventive medicine" and therefore declared to be the role of the medical profession.

Attempts at concentrating and limiting the millions of benefical efforts of the medical system to those problems which can indeed provide better solutions than other existing or at least feasible organizational and intervention forms, have, without exception, failed so far. The medical system resists the government's power to set standards primarily by knowing how to secure for itself a real monopoly on defining the problems of government health policy.

In the case of AIDS this has until today - despite undoubtedly positive beginnings - led to a systematic, and for an unkown number of persons, fatal underemphasis of the possibilities for prevention outside the medical system.

An essential part of the reasons for the mass and senseless administering of the antibody test can be found here. Since immunological and therapeutical possibilities are in reality not available, but the medical system is "responsible" for sickness problems in society, then something else has to hap-

pen ("ut aliquit fiat") - even if it is the use of a "diagnostic" method which certainly causes much more harm than benefit to expérimentées without symptoms. The interest of the pharmaceutical corporations in selling their tests and thus preparing the market for coming vaccines and therapeutic drugs is another factor.

The medical monopoly for defining health and sickness problems leads to an undervaluation of other sources of knowledge and an intake for other problems which cannot be factually justified. This is expressed in the low estimation of "layman's" expertise and the understanding of other scientific disciplines also concerned with health. In the contribution of "layman's" expertise - as is the case with AIDS - from the groups affected has to be included for pressing reasons, then their questions will at best only be responded to incidentally by medical research.

Questions, methods and sources of knowledge from other disciplines can only find their way gradually into the design and the realization of health policy strategies including the preliminary formulation which is controlled by research policies. This also to the detriment of prevention.

In this power-play of government and medical system as well as the respective political and material interest, AIDS has no better chance for being treated than the many thousand times more common national health problems such as heart attacks, cancer, rheumatism, bronchitis, alcoholism, etc..

Those who are interested in an effective struggle against AIDS will be forced to deal with such "old" health policy topics and will have to examine both proven and failed reform strategies for their suitability to this problem.

2. AIDS as a Special Problem in Health Policy

Referring to health policy as a whole does *not* mean playing down the social volatility which surrounds AIDS; it is real and dangerous. The mixture consists of elements of the physiological nature of the problem (veneral disease, extremely long latency periods, a great degree of uncertainty concerning an outbreak, generally fatal end of the disease), also its mysterious and exotic origin and the fringe position in society of the groups concerned with AIDS who were incidentally first identified, namely gays, addicts and hookers; indeed a real unique human constellation that can mobilize atavistic fears, desires, and prejudices. We are dealing with a combination of sex, sex for sale, perversions, orgies, addiction, invisible enemies and death, all in one topic.

For this reason it is no wonder, that the mass media, oriented towards marketability, just had to jump at this topic. Frank Ruhmann reported in his book, AIDS - A Disease and its Consequences, published in 1985 - on numerous upsetting ..examples of irresponsible cheap sensationalism. If one takes into consideration that, in regard to AIDS, the especially aggressive trashy publications and the large tabloids are still the most widely read printed material in the Federal Republic of Germany, then the latent danger becomes obvious: there are wide segments of population whose image of AIDS and the groups it has affected is fed almost exclusively from such counter-educational (regressive) reporting. But even such magazines regardes as serious, as for example DER SPIEGEL (published in Hamburg) have exhibited, and still exhibit, malicious aberations.

It is also no wonder that style and contents, controlled more by the market than by ethics, of the public treatment of AIDS especially produces fear amongst the groups most affected - not only an irrational fear of AIDS, but also fear of a recurrence of repression. Both forms of fear represent a definite obstacle for rationally and sensibly dealing with AIDS

and its prevention. However, little is known - and not only when dealing with AIDS - about the effects of such counter-education in concert with other sources of- information on moods, attitudes, and actions amongst the population as well as among the health policy decisionmakers. This does not at all reduce the threatening aspect of the problem.. ,One must not, however, diagnose an extremely defensive situation for the groups affected just because of the negative media reports.

3. Health Policy, Repression - in how far?

On the health policy level the effects of the socio-psychologically explosive embedment of AIDS can plausibly be assumed everywhere where political dealings with this disease deviate downward from the "normally bad" course of health policy and are connected with discrimination against AIDS patients or high risk minorities. These are the points where an AIDS-related health policy deteriorates to a repressive sex and drug policy. AIDS is then instrumentalized for other aims, although the health goal (especially the one of prevention) is thus endangered, i.e. it becomes a counter-productive health policy.

Such policy weakness can be named. They do not permit, however, conclusions as to a clear trend, particularly because numerous positive examples can be presented on the other hand.

a) Points of weakness can be found everywhere where po1icy thinking is more dominant than health thinking. At present, concrete examples can be found in concentrated form especially in Munich and Frankfurt. In other cities, e.g. Hamburg, health departments offer the owners of gay bars support against counter-productive interference from other local public officials.

b) Points of weakness can also be found in institutions regulated by the government. For example, when HIV-positive persons (more or less tested voluntarily) are not employed in prison

kitchens for reasons not based on health criteria, but "exclusively for psychological reasons", then a health-related psychology cannot be intended. The use of, for example, flaming red gloves when dealing with sero-positive persons certainly also does not correspond to sensible health thinking.

Whether the Bundeswehr (the German Army) would still reject the HIV-antibody test for all recruits if they only had to test volunteers and not entire age-groups of military conscripts, can only be speculated upon.

c) The situation is unclear in the field of social welfare law. AIDS as a great health risk is indeed included completely unchallenged, under the insurance provisions of the public health insurance system (as opposed to practice in the U.S.A.). The introduction of an HIV-antibody test as a condition for insurance cover, for example for care benefits from the federal insurance institution for salaried employees (BfA) as well as from the individual regional social insurances (LVA) and regional health insurances (AOK) would without doubt represent an action hostile to AIDS prevention. Whether or not this regulation would be made if the affected persons were "respectable citizens" and not members of society's fringe groups appears questionable. In view of the explosive potential that such testing would have beyond the AIDS-question itself, which would endanger social welfare principles, an apparent reflection on the part of these institutions on the principles of solidarity and health protection, which forms the basis of their work, at least do not appear improbable.

d) Despite partly hysterical exeptions, the institutions for medical curative treatment have - on the whole - done well in regard to the care and treatment of sero-positive individuals and AIDS patients and have not so far succumbed to the temptation to treat patients repressively.

The directing of research resources past the needs and requirements of prevention can be found in the entire health research field and is not an AIDS-specific problem alone. A similar situation exists in connection with the less problematic area in relation to AIDS of the medical profession in cooperating with AIDS-concerned persons and organizations on an equal basis.

The contributions of epidemiology and especially socio-epidemiology have remained far below their potential in shedding light on the origins and the course of AIDS. However, these research weaknesses are also not specific to AIDS but can be found in the investigations of all diseases, including the more common ones. The health policy question also posed here is: Why and under what conditions do people remain healthy? A question concerning the individual: How many people will become ill and what can we do for them?

Up to now and despite all kinds of wandering extrapolations, medical statistics have been incapable of contributing relevantly to explanations and half-way dimensioned estimates of risk. The undifferentiated addition and accumulation of new cases of the ill and the deceased over many years as well as the methodically unjustifiable statements of a "doubling of AIDS every eight months" etc. (revised in the meantime, but the public has hardly become aware of it) have undoubtly had an hysterical effect and are - as a consequence - also damaging to health. It would be premature, however, to attribute this to a conscious or unconscious discrimination of minorities: It is understandable that in the beginning when an entirely new disease appears, the incidence, prevalence, and mortality are not compiled according to periods or qualifying dates, but are simply added up. When the forms of representation, introduced decades ago and which now makes comparison possible, cannot be returned to when dealing with this new disease, then the reasons indeed lie in the medical system to a certain extent but have only partly to do with the discrimination of minorities: AIDS researchers need and want money,

including government subsidies, but they would not be doing themselves a favour, with the given structure of research promotion, if they did not represent the problem- they are investigating to be as great as possible. That these figures are then picked up by the press, interested in an additional quantitative exaggeration for market reasons, can surely not be answered by epidemiology alone. Areas in the medical profession have surely failed in the question of indiscriminate screening of symptomless patients with the HIV-antibody test. How the medical profession would have reacted to the offer, albeit legitimized by the government, of a test with comparable consequences for health, but therapeutically irrelevant, the target group of which would not have been gays, addicts and hookers, is not easy to say. In the question of the HIV-antibody test the double pull of prejudice and medicine's drive for expansion was evidently stronger than the medical ethics.

According to the unanimous opinion of experts there can be no talk of guaranteeing everywhere the "right of self-determination to obtain information" when dealing with blood samples. It does not appear unrealistic, however, to hope for self-examination within the profession regarding this practice and medical ethics.

e) In the main government education and medical policies positive steps as well as policy errors can be found. The relative calmness of government education in the face of something wild hysteria in some forms of mass media has proven to show a basic ability to conduct health policy in accordance with its own logic, despite resistance and temptations. On the other hand there have been, and there still are, irrevocable delays in relevant education and specific research promotion.

Any consideration, even only as an exercise, with the laws regarding epidemics, including any obligation to register with the authorities, would be wrong because it would be damaging to health: Corresponding attempts in the AIDS field in Sweden

and in the American state of Colorado in terms of health policy led to clear counter-productive results. The German Society of Combating Venereal Disease, in the words of one of their members of the board, arrived at the conclusion on the basis of 84 years of experience that "the most varied types of registration by name ... actually have to achieved anything." Since there are no examples of any positive effects from an obligatory registration, one cannot assume any medical logic behind attempts to introduce such a practice.

There must be different reasons for the delay of an absolutly open, public campaign for the necessity of using condoms for those having sexual intercourse with differing partners. Objectively, this delay can by no means be justified. There are at least two reasons amongst these which cannot be interpreted as the continuing discrimination of the initially visible groups:

1. Government health policy, which is not strongly oriented towards prevention anyway, generally has difficulty in taking extraordinary measures without disturbing numbers of visibly ill people.
2. The realization of such a campaign would cause an identity crisis for those sections and representatives of government agencies, who consider themselves to be the upholders of "public morality" based exclusively on monogamy, which are capable of being mastered.

The fast, and in part unbureaucratic, involvement of those persons affected and their organizations certainly represents an innovative and undoubtedly correct step in government health policy. Whether or not the government agencies' attempts to censor and to make decisions for the AIDS-help groups represent the usual infighting between seemingly "unpolitical adminstrative behaviour" and "autonomous projects with government dough" remains to be seen. This also applies for the questions of whether or not we are dealing with the effects of a generally inhibited sexual policy and whether or not discrimination specifically directed at gays, prostitutes,

and addicts is emerging. In each of the three cases above, however, the subjugation of AIDS-help activities to the internal logic of a subordinate agency (in this instance the german federal office for health education - Bundeszentrale für gesundheitliche Aufklärung) would cause the health policy to suffer as well as the level of health itself.
In summary, one can also say, that those "weaknesses" in health policy where the existing possibilities for combating and preventing AIDS have not been used or are not used now, do not point directly and incontrovertibly to a discrimination of the first visibly affected groups. This tendency seems to show through, however, at numerous points. It is therefore necessary and legitimate, when the persons affected and their organizations guard for such developments with a particularly keen awareness and in each of occurance sound the public alarm.

There can be no doubt that a compromise cannot be reached between the two major alternatives widely dealing with AIDS: One either backs prevention, education, personal responsibility, and self-help made possible by the government _or one carries out campaigns of fear, repression, and the exclusion of minorities. Put in an overstated way: The greater the repression the less the prevention. The thoughts presented here are based on the assumption that it will remain possible to work on the health problems of AIDS in a social atmosphere of rationality and education.

4. Problems and Perspectives of AIDS Self-Help

Above all the affected homosexuals, but to some extent the prostitutes also, have organized themselves surprisingly quickly and effectively. The degree of coverage of the approximately 40 gay AIDS-help organizations is impressive for a health network that has come out spontaneously. Political differences are treated pragmatically in these organizations

after having overcome initial difficulties. In addition to the expansion and continuity of this network, there are some other unsolved problems in this area:
Their attitude towards the question of the HIV-antibody test is unclear. They do not always recognize its dangerousness and its inherent combination possibilities. The question could be posed as to what extent those persons affected have been duped by the mechanisms of the expansion logic of the medical system.

The spectrum of possible alliances could be expanded if AIDS were also viewed by the organizations of people concerned with AIDS, above all as a health problem and not primarily as a problem in dealing with minorities. It is certainly difficult maintaining this balance. The weaknesses and problems indicated show that dealing with AIDS does actually fluctuate between the poles and no one can ever completely eliminate the possibility of the pendulum swinging in the direction of repression.
Nevertheless, the struggle against AIDS is that much safer from tilting towards repression the more one succeeds in transferring it into the arena of, health policy and keeping it there.

As we have seen, the thinking of health policy is, by far, not up to solving the problem under the existing structural conditions, but .this thinking does certainly relatively strong elements in its basic principles which "actually" exclude repression. The threshold of instrumentalization of AIDS for purposes lying outside the problem rises in relation to the extent that AIDS is viewed and treated as a genuine health problem.

Besides that, there are those social groups of allies in health policy discussions who, for other diverse reasons, also commit themselves against the low priority of prevention, against the imperial attitude of the medical system, against a combination of business and health, and for the strenghtening of non-medical authorities and organizations in health care.

Conversely, the consequences for all those groups interested in health policy is that they cannot be indifferent to dealing with AIDS. On the one hand, important future developments are being fought out in the entire field of health care, with AIDS as the example, and on the other because AIDS is not a fag, junky, nor a hooker epidemic.

There is still time to turn public reaction to the acquired immune deficiency problem into a successful test case for problem-oriented health policy because microbes neither make history nor do they engage in politics, but dealing with microbes is politics.

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