AIDS-FORUM D.A.H.

BAND XII

Aspects of AIDS and AIDS-HILFE in Germany

Deutsche AIDS-Hilfe e.V.

AIDS-FORUM D.A.H.

Band XII

Aspects of AIDS and AIDS-HILFE in Germany

Dieffenbachstraße 33
D-10967 Berlin

Mai 1993

Redaktion: Klaus-Dieter Beißwenger, Christine Höpfner
Gestaltung: Detlev Pusch
Satz: CaJa Carmen Janiesch
Druck: Oktoberdruck
alle Berlin

ISSN 0937-1931

Spendenkonto: Deutsche Apotheker- und Ärztebank, Berlin,
Konto 000 3500 000 (BLZ 100 906 03).

Die D.A.H. ist als gemeinnützig und mildtätig und damit als besonders förderungswürdig anerkannt. Spenden sind daher steuerabzugsfähig.

CONTENTS

PREFACE

The Deutsche AIDS-Hilfe (D.A.H.) is the only organization worldwide which combines self-help and service functions under one roof: self-help of people with HIV/AIDS, of people from the main groups affected, the gay men and drug users, of partners, friends and relations; service functions such as counselling and care, setting up self-help structures, education work and media productions.

The theoretical basis is the health strategy of the WHO. Health and illness are no longer seen as being problems only of the body – their mental and social components are also seen. They are dependent on contentment, social relationships, food, accommodation, work, attention from other people, and the general social climate.

Prevention in the groups primarily affected means for the AIDS-Hilfe groups: providing people with knowledge, enabling them to determine their actions themselves. That can mean e.g. handling risk situations, doing something for their well-being. Whether infected or not, whether healthy or sick, effective prevention strengthens crumbling self-confidence, breaks the isolation of the individual, and gives added meaning to the solidarity many people talk of, within the various scenes, but also between them.

Prevention means for AIDS-Hilfe intervening wherever people are being used and manipulated, or discriminated and made outsiders, turning those affected into "cases" for doctors, researchers, lawyers and politicians. It also means public activity for a more level-headed approach to the problems of AIDS, with more consideration being shown for the interests of people with HIV/AIDS and the main groups affected.

In Germany the AIDS prevention campaign is run by the Federal Centre for Health Education and the D.A.H. In a division of labour the government body provides information for the general public, whereas the private association concentrates on producing specific media for the groups particularly affected by AIDS.

Such a partnership – when it works – can offer advantages. The D.A.H. is right in the thick of AIDS matters. It therefore has credibility when it comes to acting quickly to prevent problems building up – a good example of efficient subsidiarity. The government organization, for its part, provides much of the funding which the private association would not be able to mobilize.

The D.A.H., located in Berlin, is the umbrella organization for some 130 local AIDS-Hilfe groups in Germany. Under the division of labour with these groups the tasks of the D.A.H. include:

- Planning and carrying out national information and education work;
- Initiating and supporting the self-organization of people with HIV/AIDS;
- Developing strategies for medical services and psycho-social care;
- Developing, producing and distributing information material;
- Providing training and further training for voluntary and full-time staff of local groups;
- Public relations work;
- Acting as organ and mouthpiece for the local groups;
- Representing political interests at national level.

The tasks of the local AIDS-Hilfe groups include:

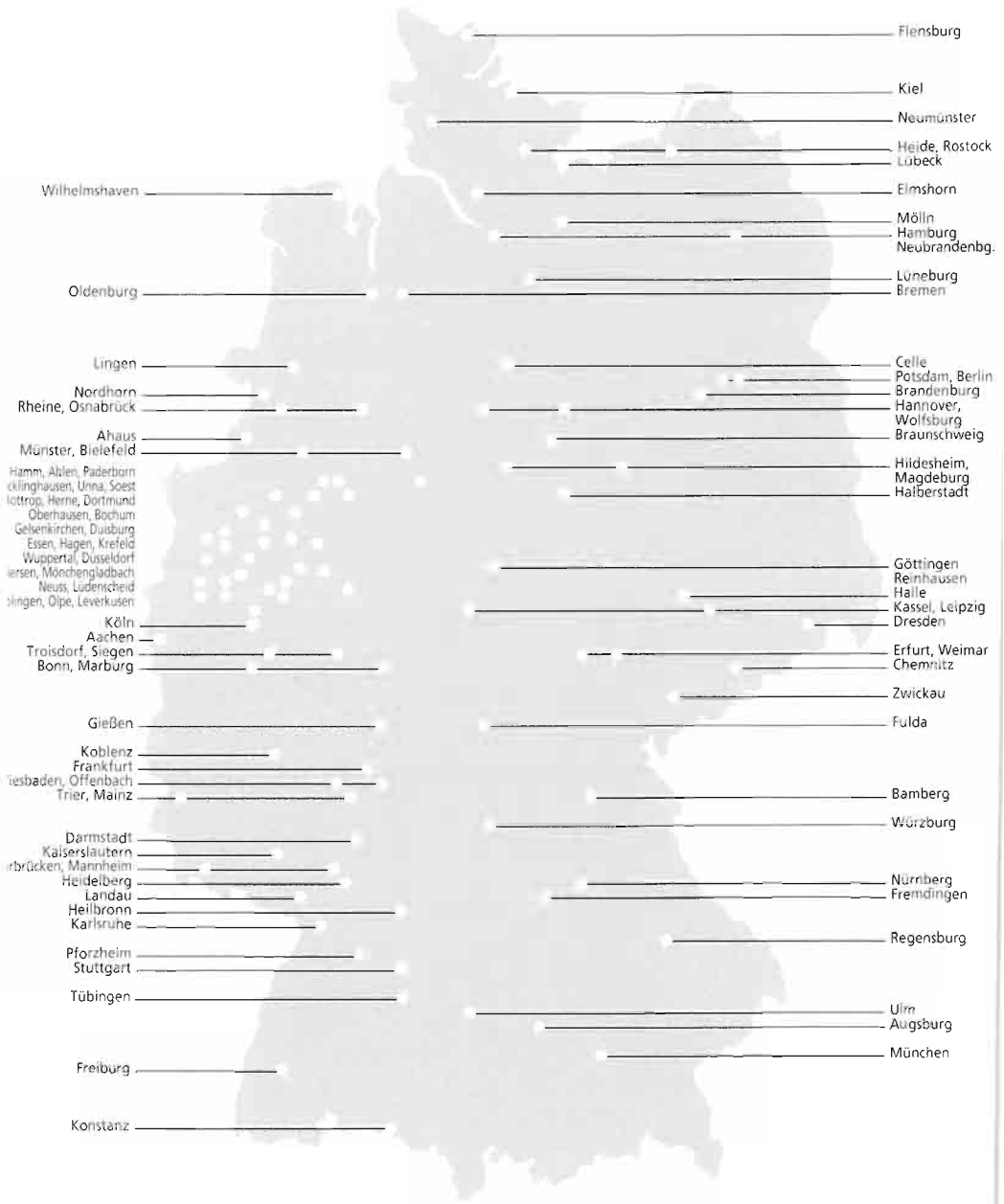
- Setting up self-help and discussion groups for people with HIV and people with AIDS, for their friends and relations; setting up Safer Sex discussion groups;
- Distributing information material;
- Providing information and counselling in the gay scene (bars, saunas), in the drug scene, in red-light districts;
- Looking after people with HIV/AIDS either at home (including non-stationary medical care), in hospital, in prison or in drug therapy institutions;
- Personal and telephone counselling for people from other groups of the population;
- Education and information meetings for various population and occupational groups;
- Local public relations work.

This publication gives the international readership an overview of its activities and its ten-year history. The publication coincides with the IX. International Conference on AIDS, being held from 7th to the 11th June 1993 in Berlin.

Klaus-Dieter Beißwenger, Christine Höpfner
Print media office

Berlin, May 1993

AIDS-HILFE ORGANIZATIONS IN GERMANY



ON THE HISTORY OF THE AIDS-HILFE

Kajo Pieper, Dr. phil., former board member of the Deutsche AIDS-Hilfe e.V. (1988-1990)

On 6 June 1983, the German public became acquainted with a new disease. On that day, the West German weekly newsmagazine Der Spiegel published its first cover story on this new illness: "AIDS: the Fatal Affliction/A Mysterious Disease." At that point in time, however, AIDS was not a new disease for certain circles which had become more aware. Der Spiegel reported that "100 suspected cases and six deaths" had until that time become known in West Germany. The German Federal Ministry of Health had warned physicians to take special precautionary measures in treatment of AIDS victims. Even the German Minister for Youth, Family, and Health – at that time Heiner Geissler – had taken cognizance of AIDS and had, in the month before the article appeared, "called out for a struggle against 'this dangerous disease'." (All citations and references here are from: Der Spiegel, No. 23, 6 June 1983, p. 144 ff.)

It was only a few months later, beginning in October of 1983, that the first AIDS-Hilfe organizations were founded in Germany: in Munich and Berlin. A number of additional organizations were soon founded in the following year of 1984. The first founding boom of German AIDS-Hilfen occurred in 1985, with organizing activities continuing at a relatively low level in the following years. During 1988 and 1989, such organizational activities reached a new peak. By now, in 1993, there are appropriately 120 AIDS organizations in Germany, most of which are organized as members in the umbrella organization Deutsche AIDS-Hilfe e.V. (D.A.H.)

Writing on the history of German AIDS-Hilfe organizations at this point in time – even in the form of an interim report – has proved to be a difficult venture: one necessarily associated with numerous shortcomings. The reasons behind this situation are many and various: the great variety and divergence of the subjective recollections of the "founding fathers"; the lack of sufficient detachment of those who were very involved in the AIDS-Hilfe movement, or of those who are still active there; as well as the countless hurts, the perplexity and the bewilderment, and the fears and anxieties – to which those active in AIDS work were and are still being subjected – and which are all still too fresh and too little reflected upon.

As a result, this attempt represents a further attempt to become more closely acquainted with the history of German AIDS-Hilfen. In any case, it will attempt to present one aspect of this history – and will be presented here with a goodly number of reservations of relativizing nature. I can predict already at

this point that many other women and men involved in AIDS-Hilfe will recall the history of their work in AIDS-Hilfen, and the work of other AIDS-Hilfen, in a different fashion. I also know very well that "erroneous" emphasis may appear in my account – and that even accusations of polluting our own well could easily turn up.

But I am prepared to accept the risks, and I willingly admit from the beginning that my account here is subjectively shaded. This attempt for me means the opportunity to reflect upon and to assimilate a period of six years of collaboration in AIDS-Hilfe including two years in which I undertook responsibility for AIDS-Hilfe with others on the German federal level.

First of all, in looking back, we cannot help but consider the marvelous achievements which took place over the six to seven years from the end of 1983 to the end of 1989, the period in which approximately 100 German AIDS associations were founded and officially recognized as nonprofit, charitable organizations. This has also meant that between 4000 and 6000 men and women have, on a voluntary and honorary basis, offered their services to the work of the AIDS-Hilfe: frequently under tremendous physical and psychic pressure, and often under extremely constricting structural conditions. These developments alone deserve recognition as a unique phenomenon in German history. An extraordinary diversity of innumerable motivations and objectives, however, seethes beneath the "smooth skin" of the German AIDS-Hilfe movement which I have sketched here. The following sketch of the history of the founding of AIDS-Hilfe organizations will hopefully make this a bit clearer.

With reference still to the period from 1983 to the end of 1989, we may distinguish among the following three phases of founding activities, although chronologically they are not neatly separated from each other:

1. The period from 1983 up to around the middle and end of 1985: The first AIDS groups were organized by gay-motivated activists, HIV-positive organizers, and circles of their friends and acquaintances. The first groups primarily came to life in German metropolitan and megalopolis centers which featured distinctively developed gay subcultures, or, at least, they were founded in the immediate environment of these areas.
2. The period until around 1987 and 1988 was distinguished by work which made up for lost time in relatively large and middle-sized German cities. The group work was still strongly influenced by gay contributors, but a growing tendency became evident in the direction of participation by professional specialists in social work and social pedagogy.
3. Around 1987 to 1989 further regionalization of the AIDS-Hilfe became apparent, with increasing "non-gay" orientation. There was significant founding influence from drug counseling centers, as well as further professionalization by social workers.

I admit that this classification into phases is rather vague and imprecise with respect to time spans, founding motivation, and nature of participation in the organizational work. I nevertheless consider this breakdown useful to enable a first approximation toward gaining insights into influences, motivations, and phenomena involving the German AIDS-Hilfe organizations.

It is undisputed that initial founding action for AIDS-Hilfe organizations – and this applies not only to Munich and Berlin – took place in those metropolitan areas in which the first and most numerous AIDS cases and deaths were registered. Precisely because AIDS struck gays – more strikingly in the beginning of AIDS-Hilfe work than now – gays represented, in the traditional sense, the group predominantly involved. These people with AIDS underwent diagnosis and therapy in those medical centers – usually university medical complexes – which were, for various reasons, more willing and able than were other facilities to confront the challenge presented by new syndromes, and to carry out the associated research work. The availability of superior medical therapy and research infrastructure in urban centers such as Berlin, Munich, Hamburg, and Frankfurt coincided merely by chance with the existence of substantial, distinctive, and differentiated gay subcultures in precisely these German cities. Even at the risk of sounding cynical, it may be pointed out that the gay subculture of large West German cities provided the locally available medical infrastructure with the cases required for research of the new symptoms complex AIDS.

The powerlessness of modern medicine and the fear among the gay subculture – manifested often enough, even today, as inflexible forms of psychological repression – were doubtless not insignificant factors in prompting the search for new, different, and mutual approaches toward coping with the challenges presented by AIDS. An additional element was the fact that there were still remnants of a gay movement, particularly in the gay centers: in other words, gays who had gained experience in political movements not associated with or constrained by government factors, and who were willing and able to employ this experience for the attainment of new objectives.

Notwithstanding the aspects already stated here, it is definitely not possible to comprehend Phase 1 of this process without at the same time being able to realistically imagine the general political situation in West Germany during those years. A so-called constructive vote of no confidence in October of 1982 brought down the national ruling coalition which had included the Social Democratic Party and the Free Democratic Party. The subsequent new elections for the lower house (Bundestag) in 1983 formally established the new coalition of Christian Democrats (CDU), Free Democrats (FDP), and Christian Social Democrats (CSU). Helmut Kohl, who was elected Chancellor of West Germany, declared the beginning of a moral and spiritual transformation. Many so-called fringe groups understood this declaration as the beginning of a new phase of repression against them. Harsh changes in the climate of social legislation and political discussions – for example, on the topics of foreigners in Germany, asylum seekers, and abusers of welfare privileges – confirmed these fears. The fact that many in West Germany had evaluated AIDS as God's revenge for a depraved way of life, created additional fears: not only fear of AIDS, but also fear that still existing refuges of tolerance for gays would be rigorously closed.

Political action in dealing with AIDS and AIDS Hilfe organizations was strongly influenced by two essential factors. First was the lack of sufficient knowledge of AIDS, as well as the resultant therapeutic powerlessness of medical possibilities. Second was the fact the primary group of those afflicted

by AIDS was – and still is – the gay population. This latter aspect was elaborated on as follows by Professor Dr. Steinbach, of the German Federal Ministry for Youth, Family, Women's Affairs, and Health, then responsible for this question complex:

"If AIDS were a bakers' disease, then we would have to 'suppress' the bakers – we'd have to harass them and penalize them. But it's the homosexuals, and they suffer from a heavy historical burden of socio-political dimensions. This fact makes the situation incredibly more complicated but it does not excuse us, in the context of the entire epidemiologic and hygienic problem complex, from taking account of this fact and nevertheless implementing the necessary measures." (from Der Spiegel, No. 52, 1984, p. 31)

In this situation, it was possible for a German federal minister, in the person of Rita Süssmuth, to truly beneficially influence the political processes underway. She, for example, was able to confine the public repressions and mandatory measures which threatened to develop around this time: most notably, in the federal State of Bavaria under the influence of the politician Gauweiler, where such measures received especially pronounced support.

Manifestations of the incipient politicization of AIDS included the action of the AIDS Investigating Committee of the German Bundestag, as well as the establishment of a national AIDS Commission in the German Federal Ministry for Youth, Family, Women's Affairs, and Health. At the same time, efforts increased for providing psycho-social services and care for AIDS victims. These efforts were exemplified in the foundation of the German AIDS foundation called "positiv leben", and somewhat later in the National AIDS Foundation. An additional indication for such politicization was readiness to "invest" considerable sums of money in HIV research, as well as in model projects with various objectives.

These processes initially tended – often without conscious intent – to attenuate the odium of depravity originally connected with AIDS. AIDS had in fact become a political matter, furnished with a relatively large amount of money. And this meant that prestige beckoned to researchers able to achieve new insights into HIV. And a new field of activity opened for the professions of social work and social pedagogy – the only aspect of expansion on a sector of the market which otherwise promised no chance of additional jobs.

This was one reason why more and more social workers rushed into AIDS-Hilfe organizations and that these women and men otherwise began to play an increasingly active role in the founding of new AIDS-Hilfen. Individual men and women from AIDS-Hilfen also accepted lectureship responsibilities at colleges and universities involved with the problem. Special curricula for highlighting and ongoing-study courses were even set up.

The consequence for the AIDS-Hilfen was that they became professionalized at a breathtaking rate. Money and jobs took over the roles of recognition which had been earlier granted for work on an voluntary basis. Some of those involved have interpreted this development as indirect public recognition – and legitimation – of their own being gay, with the not infrequently observed effect that they have not expressed or lived out their being gay as clearly as had been the case in earlier years. Talk about "degayification" made the rounds. Such talk was no more right than it was wrong.

Whoever calls to mind AIDS-Hilfe members' conventions of 1987 or 1988 associates these memories with large-scale gay meetings. As the years passed, however, it became impossible to overlook the increasing number of women working in AIDS-Hilfen, as well as the involved men who made it clear in private circles – or even from the lectern – that they were not gay. It would also be just as wrong to deny the presence of those who stood up for their work in the AIDS-Hilfe, but who also absolutely avoided definitely coming on as gay. Work in AIDS-Hilfe organizations therefore attained a certain distinction; at the same time, however, the regard for being gay that some wished for, or were content to merely accept, did not go hand in hand with this development.

The sentence about degayification of the AIDS-Hilfen actually meant to say that the originally almost purely gay organizations had become a more multifaceted endeavor. One of the significant factors contributing to this development was the fact that more and more varied groups – gay and not gay – had become organized in AIDS-Hilfen.

This period also saw the beginning of efforts made by the AIDS-Hilfe organizations and by the D.A.H. to avoid being labeled strictly as the organizations responsible for gays. Rather, they attempted to gain recognition as the organizations generally competent and accountable for AIDS information work. The claim for exclusive representation in the area of AIDS information work was, in addition to others, one motivating ground for softer-pedaling to the public the still recent and predominantly gay history of AIDS work, as well as the fact that many AIDS-Hilfe workers were gay.

In the most recent founding work of AIDS-Hilfen in Germany, this tendency has definitely attained a new emphasis: beginning about 1987 and 1988, AIDS-Hilfe organizations have been founded to a great extent in association with drug counseling centers, or even with support from these centers. It was no longer the case that the gay impetus was the driving force behind many of the new AIDS-Hilfen. Instead, the situation of the people with AIDS, increasingly composed of men and women drug users, prompted professional drug counselors to extend their previously limited area of activity to the AIDS-Hilfen.

This development was to some extent a reaction to the fact that more and more male and female drug users had been diagnosed as HIV positive, and/or became ill of AIDS. Also to some extent, this development anticipated the expected development in the drug area of AIDS: for example, the organization of a Drug Section in the D.A.H. in 1987. This process was also accompanied by a more pronounced tendency toward professionalism.

The greater emphasis placed on drug work placed us gays in the AIDS-Hilfen in a dilemma. On the one hand, gays were neither willing nor able to deny the necessity of such a development – especially since the new field of activity involving drug work offered the possibility of eliminating the exclusive identification in the public eye of AIDS with being gay. This situation was – and still is – countered, on the other hand, by the fact that the social living conditions and behavioral patterns of men and women drug users appeared and still appear – perhaps unavoidably – for the most part foreign, incomprehensible, and alarming for gays.

In a number of AIDS-Hilfe organizations, it was possible after difficult initial phases to very successfully overcome and to constructively work with such incompatible factors and such tendencies toward irreconcilability. There have been other groups, however, in which it has not proved possible to develop a mutual image. In such cases, the general result after tedious initial work has been suppression of the drug aspect of the image. Less frequently has it been the case that the gays are the ones to retreat sulkily.

The founding phases of AIDS-Hilfe organizations roughly sketched here correspond conspicuously to the development of AIDS cases according to regions and groups afflicted. They furthermore correspond to numerous other developments which can by no means be completely listed and much less described here. A number of comments, however, will perhaps suffice to encourage further analysis.

It has been observed – beginning roughly with the onset of the stated professionalization tendencies, and parallel with increasing publicity of AIDS – that the impression became established in wide sectors of public opinion that being gay and AIDS were more or less one and the same. Such mistaken preconceptions have demanded a double degree of self-assurance from the AIDS-Hilfe staff, once they detect that they have been identified as gay merely by virtue of their activity in AIDS-Hilfe. Double because of the self-assurance required for being gay, and for being active in AIDS issues – since those involved in the latter are labeled often enough as HIV positive, or as "AIDS people," merely because of such an association. In such a situation, it is logically understandable for the following:

- that those so involved gladly turned over to professionals the whole business of representing AIDS-Hilfe toward the outside
- that the share of gay staff and their life style was fully accepted on the internal level at AIDS-Hilfe, but that it should be soft-pushed with respect to the public
- that the claim was vigorously pressed to represent all sectors of the population as the competent and responsible organization with respect to AIDS.

An initial countermovement materialized less on the basis of experience and insights gained in AIDS-Hilfe than as a result of impulses from the outside. Noteworthy here is above all the founding and the generally developing activities of the German Federal Association for Homosexuality (Bundesverband Homosexualität, BVH). Now, as initially, one of its prime motivations – despite and because of AIDS – is without doubt the formulation, the focussing, and the political and social representation of interests characteristically involving gays.

It would not have really been possible for relationships between the AIDS-Hilfe organizations – especially the D.A.H. – and the German Federal Association for Homosexuality (BVH) to remain peaceful and harmonious. One reason was that many gays, with emphasis on being gay, now as before became engaged in AIDS-Hilfen, and that they as a natural matter of course emphasized the AIDS-Hilfe aspects above those of gay political issues. Indeed, very few of these members were able to contribute actively in both organi-

zations. An additional factor was the fact that government subsidies, or even financing, for AIDS-Hilfen tremendously outweighed the financial resources of the BVH. A number of BVH activities which were nearly doomed for financial reasons were rescued and implemented by support from AIDS-Hilfe. From the standpoint of a number of BVH representatives, such support action should properly have taken place more frequently and in more generous manner. A number of AIDS-Hilfe staff, on the other hand, have considered such support as misuse of funds, and would have preferred to see such activities curtailed.

Behind the most apparent conflict over funding lurked a more concealed struggle involving professional jealousy: one which concerned competition over the possibilities of exerting an influence on society – possibilities which had in all likelihood been considerably exaggerated in the expectation of the parties. Even deeper behind these issues lay a further issue: irritation which arose from the expectations and objectives shared by each of the organizations. Indeed: gay politics could not then, and cannot now, ignore AIDS – and AIDS-Hilfe could not, and cannot, ignore gay politics. In addition to the intersection between sets composed of BVH and D.A.H./AIDS-Hilfen, there are now as before independent fields of activity. Without doubt, it has for easily understood reasons proved more difficult for BVH than for D.A.H. to define these stand-alone areas.

This tense relationship, which occasionally demonstrates a degree of absurdity, can be illustrated using the following example. In 1989 members of BVH initiated a campaign advocating deletion of Section 175 from the German Criminal Code. BVH championed this campaign as its own issue and worked to rally support for it, while basing its efforts on an urgent recommendation formulated by the Official Investigating Committee of the German Bundestag on AIDS. This recommendation read:

"Examination is required of the possibility of revision of the Criminal Code with the objective of deleting the Special Stipulation of Section 175 of the Criminal Code, and of implementation of a uniform protective regulation for male and female youth." (source: "AIDS: Fakten und Konsequenzen," taken from the series "Zur Sache", no. 3, 1988, p. 23)

It was precisely this approach of argumentation which D.A.H. refused to accept at that time: i.e., that AIDS be used as "justification" for an already legitimate and necessary socio-political demand. D.A.H. reasoned that deletion of Section 175 from the German Criminal Code was long overdue, regardless of AIDS, and further, that it represented a weakening of gay-political argumentation to exploit AIDS as justification in this context. As a result, so the argument went, this approach amounted to superfluous and potentially damaging resort to an erroneous argument.

The world apparently topsy-turvy: here was D.A.H., defending "pure gay-political principles" against BVH, the rightful guardian of such theory. Despite this confrontation, D.A.H. and BVH in fact later conducted a mutual convention in Bonn organized for the purpose of deleting Section 175. At this convention it became definitely clear – to the extent that it had not already been so before – that it was hardly possible to logically follow the position D.A.H. had assumed on pure principles.

At this convention it furthermore became clear that agreement on substance did not exist in all points between the D.A.H. as national federation, and the ground-roots groups consisting of individual AIDS-Hilfe organizations. Additional such examples are indicated in the following sketches:

- One AIDS-Hilfe organization allegedly refused to distribute D.A.H. information material, in the form of brochures and posters, because it was "too gay."
- Another AIDS-Hilfe attempted to sue D.A.H. after D.A.H. had provided addresses of AIDS-Hilfe member groups to a gay publishing house, for the purpose of indicating on a new addition of a gay calendar the AIDS-Hilfen as organizations essential for gays.

It is not pure coincidence which prompted me to mention precisely these episodes: indeed, they describe the gay-political dilemma from other perspectives such as this – a dilemma in which D.A.H. and the individual AIDS-Hilfen found themselves, and can easily still find themselves, again and again. From the very beginning, impulses and reactions from the D.A.H. member groups have prompted D.A.H. to concentrate its efforts on gay men as target group. For this purpose D.A.H. has developed a great number and variety of materials: posters, brochures, folders, comics, and video clips. Today as before, the characteristic feature of all of these materials is a language oriented to this target group, as well as provision of more than just information: i.e., the promotion of acceptance of gay life styles – not only among gays, but also among the hetero population.

The main effort of D.A.H. and the AIDS-Hilfe organizations which support it is to achieve the goal which they themselves have established: work toward the prevention of AIDS. The three associated primary services performed by AIDS-Hilfen are informative work, counseling, and care. Counseling and care are relatively uncontroversial: telephone counseling as well as confidential consultation on an individual, man-to-man basis, are part of the core offerings of any AIDS-Hilfe organization. Just as essential is the offering to assist persons with HIV/AIDS to receive care as it is individually required – insofar as men and women providing AIDS care are in fact available.

On the other hand, the goal of informative work – as the only sensible and effective type of prophylaxis – has indeed been a controversial point. Relatively widely accepted here, however, are the following efforts: provision of information to interested parties on HIV/AIDS, on the dangers of infection, on the possibilities of prophylaxis, on the possibilities of treatment, and on ways to avoid or to delay outbreak of the disease – in such a manner that those interested can assimilate this information, learn to live with it and handle it, and be capable of allowing it to become relevant for their actions and behavior. A history of German AIDS-Hilfe could indeed be written using as leitmotif the struggles which have taken place on the conflicting viewpoints and strategies involving informative AIDS work.

The basic message of all AIDS-Hilfe informative work reads: HIV/AIDS represents an actual danger. Prophylaxis in the form of protection from possible HIV

infection is, however, possible if "safer sex" is practiced. From the beginning, however, even this message was never uncontroversial: "safer sex" is, after all, not really entirely safe. Even those who practice only "safer sex" could indeed become infected with HIV. In the final analysis, there is no real, total protection from possible HIV infection – except by completely giving up sex with other men or women.

REACTIONS OF THE GAY COMMUNITY TO AIDS IN EAST AND WEST BERLIN

Michael Bochow, Dr. rer. pol., social scientist, Gesellschaft für interdisziplinäre Sozialforschung in Anwendung mbH (Intersofia), Berlin

I dedicate this article to the memory of Andreas Salmen, who was one of the most important AIDS-activists in the 1980's in West Berlin

Acknowledgements

From the very beginning in 1983, a great many gay men were involved in campaigns to prevent a further dramatic increase in HIV and AIDS in West Berlin. Thus when I began to write this chapter it was obvious to me that I should talk to those involved and take full account of their point of view. All of those I consulted took great time and trouble in supplying exact answers to my many questions and I would like to give them my very heartfelt thanks. In particular I wish to thank Sabine Lange, without whom the Deutsche AIDS-Hilfe would never have been so purposefully founded in 1983, Stefan Reiss from the first Deutsche AIDS-Hilfe board, and Gerd Paul, the chairperson of the second board from 1985 to 1987.

Further thanks and gratitude are due to Egmont Fassbinder, Karl Lemmen, Joachim Müller, Klaus Nolden, Rolf Rosenbrock and Marc Wiltzius who supplied me with many useful insights into the development of AIDS campaigns in West Berlin, and to Günter Grau, Rainer Metz and Hubert Thinius who were very illuminating about developments in the east part of the city. Ulrich Marcus of the AIDS Center of the Federal Health Office in West Berlin was extremely helpful in providing me with epidemiological material on the West German federal states and West Berlin, and Wolfgang Kiehl, who up to the end of February 1991 worked at the Central Institute for Hygiene, Microbiology and Epidemioloy in East Berlin and was a mine of information about the territory of the former German Democratic Republic. Last but not least the Prinz Eisenherz bookshop collective has to be mentioned who kept me so efficiently supplied with specialist literature and who have built up the most comprehensive department of sociological and psychological literature on AIDS and gay men in Berlin.

Sophinette Becker, Martin Dannecker and Albert Eckert all read and generously commented on the draft of this manuscript. Margret Meyer showed inexhaustable patience and good humor in typing the various drafts of the manuscript and its many insertions, and Paul Morland considerable resourcefulness in translating the whole into its readable English equivalent.

The Berlin Gay Scene before AIDS

During the last decade of the nineteenth century Berlin was already a flourishing gay capital; during the Weimar Republic in the 1920's, however, its reputation spread far beyond the confines of the German-speaking world. In the period after the Second World War, even though it was no longer the capital and had dramatically lost all of its former economic importance, West Berlin developed into a center for homosexual men in Germany, a process unimpeded by the building of the Berlin Wall by the GDR government in 1961. Indeed, it is probable that the resulting confined "insular" situation strengthened West Berlin's importance as a gay metropole. To counter the city's political and economic decline successive federal governments, regardless of their political colouring, pumped massive subsidies into West Berlin cultural, scientific and touristic spheres. Such permanent windfalls helped to create a variety of little ecological havens which served to attract many young people with nonconformist political ideas and life styles to the city. One unique and valuable feature of life in Berlin for any young West German gay was that the Wall – "an anti-fascist rampart" in the jargon of the East German Communist Party – assumed for them the advantageous function of an "anti-family rampart". Berlin's remote and fortress-like geo-political situation was highly attractive to young West-German gays precisely because it deflated interference from their parents and families and so screened many of them from the social control of the petit bourgeois and provincial milieus from which they originated. To a certain extent of course every large town or city has this function for gays – in West Germany main cities such as Francfort and Munich, Hamburg and Cologne. But although at a greater geographical remove from West and South Germany, the predominant role it enjoyed cannot be explained in terms of distance alone. West Berlin held a further attraction for nonconformist young men which no other West German city could rival: in the whole of post-war period up to the accession of the GDR to the Federal Republic residence in West Berlin meant automatic exemption from military service and from the prolonged civil service intended for conscientious objectors. Thus the decision to move to Berlin functioned as a sort of political filter which lead to the political spectrum among West Berlin students being more strongly coloured by the left – particularly after the debates on the Vietnam war in West Germany – than was the case for most West German university cities (with the possible exception of Francfort, Heidelberg, Marburg and "reform" universities such as Bremen, founded in the 1970's). In the 1980's West Berlin had a population of approximately 1,9 million inhabitants. An estimated ratio of 8 to 10 per cent homosexual or bisexual men in the adult (over 18) male population, taking into account the particular situation of the city, would give an approximate population of 60 to 80 thousand gay and bisexual men.[1] Indeed a variety of reasons make it probable that the actual figure lies somewhat under these estimates. For instance, for reasons of convenience, all foreign males were included in the estimate. But it is improbable that the percentage of homo- and bisexual men within the two main Berlin ethnic minorities, the Turks and the Kurds, is as overproportionally high as it is within the German male grouping.

This reservation brings us to the role of socio-cultural differentials in the construction of gender roles and psycho-sexual identity, a question that has been much discussed in recent years. It must not be assumed, for instance, that Turkish men in West Berlin have same sex encounters any less frequently than their German counterparts; however, it is most probable that the quota of self-identified gay men among Turkish males is considerably lower than among the West Berlin German male grouping.

From 1967 to 1970 Berlin and Francfort were the two main centres for the West German student movement. The ensuing gay movement in the Federal Republic of the 70's for the most part had a student or at least academic background, so it was not surprising that once more Berlin should become its epicentre. The Homosexuelle Aktion Westberlin (HAW) was founded in 1971, and during the 1970's provided the forum for many heated debates in which "revolutionaries", "anarchists", "revisionists", and "reformists" attacked one another with as much vigour and passion as their counterparts in the student movement which by now had collapsed into a plethora of sectarian factions. From 1974 onwards the HAW increasingly fell apart; in 1977 it finally disintegrated and transformed itself into the "Gay Centre" ("Schwulenzentrum" = SchwuZ) which is now well-known in Western Europe. Together with the student movement the gay movement helped shape the "Zeitgeist" and has had a long-term effect on styles of life, persons and institutions. The first gay bookshop in Germany, the "Prinz Eisenherz", opened in 1978, and one of the most widely read intellectual gay periodicals in the Federal Republic, the "Siegessäule" ("Victory Column": this title alludes to one of the most frequented cruising grounds in Berlin's central park, the "Tiergarten"), was founded in Berlin in 1984. As early as 1984 the project-group "Friends of a Gay Museum" were able to mount a large exhibition on a hundred years of lesbian and gay city life in the Berlin Historical Museum, which enjoyed considerable critical success in the German speaking world (the lesbian section was put together by a women's group of course, as was the lesbian part of the 1984 exhibition catalogue; see Eldorado 1984).

By the end of the 70's West Berlin's flourishing commercial gay scene was unrivaled by any other in the German speaking world. Two gay publishing houses were established in the beginning of the 1980's. The first fully comprehensive gay city guide to appear since the war was published at the beginning of the decade. Devoted exclusively to West Berlin, it listed a total of 50 pubs, bars and cafés. Despite its marginal geographical position, off the beaten track for most of West Germany and West Europe (600km east of Cologne, 800km east of Brussels) many gays still found it well worth the journey.

All this is to say that in 1983, when the first 3 cases of AIDS were diagnosed among West Berlin gay men, the gay community disposed of a wide and rich variety of informal and formal networks of groups, projects and initiatives. During 1983 and well into 1984 AIDS in Germany was considered by gay men primarily as an American problem – so far as they considered it at all. Thus it is all the more remarkable that in the summer of 1983 a group of gay men was meeting regularly with Nurse Sabine Lange of the Institute for Tropical Medicine to discuss the extremely disturbing reports coming from America.[2] In September 1983 this group founded the Deutsche AIDS-Hilfe as a non-profit making organization. It is also remarkable that with a few exceptions the members of this group did not belong to politically active groups within the gay movement and in most cases were not connected with other gay initiatives and projects. Although influenced in no small measure during their professional training or university studies by ideological spin-offs from the student and gay movement, they were nevertheless more representative of a certain hedonistic middle class; their closest equivalent in the States would be "young urban professionals". "Yuppie" is widely held to be a synonym for egotistical consumerism and lack of or contempt for social responsibility. But whereas the AIDS activists of the first hour might also have been avid consumers, they were by no means devotees of the cult of narcissistic individualism but showed every sign of a strong social conscience. For many of them the yearly trip to New York or California was a matter of course. In common with other gay men their life style was the result of a long and often laborious process of self-emancipation and AIDS, in their eyes, posed a global threat to everything achieved up to 1982. Thus although the reaction to AIDS was not primarily politically motivated it was quite the reverse of "unpolitical".

Indeed, the two crucial points around which early AIDS activists in Berlin organized should not go unmentionned. First of all, the blatantly discriminatory treatment of the first AIDS patient by the staff of a Berlin University Clinic. And, secondly, the unwarrented use of the first AIDS patients as guinea pigs for medical trials. Much of the treatment they underwent had more to do with the cold curiosity of the doctors assigned to them than with effective therapeutics. Thus, shortly before his death, an AIDS patient was "prepared" to undergo a completely pointless brain operation, which was only prevented by a resolute demonstration of AIDS activists before the operating theatre doors – an ACT-UP intervention "avant la lettre".

It's one of the ironies of history that the first AIDS activists were viewed with mistrust and suspicion by fellow gay political activists. In Germany and France they viewed AIDS as a dangerous instrument in the hands of conservative governments and the anti-gay media, whielded to annule the first tentative advances made by the gay liberation movement. Even the Gay Doctors Group – a working party of former medical students who published the widely esteemed little book "Sumpffieber – Medizin für schwule Männer" in 1978 – were highly reluctant at first to associate with the AIDS-Hilfe. Nevertheless,

many of the men (and women) of the first hour were competent in the fields of medicine and social therapy.

The early activists knew that in order to meaningfully counter the threat posed by AIDS the essential prerequisite was to activate the enourmous potential for self-help among gays. Gay self-help was of vital importance, and the more so since, as they saw it, the bodies and institutions of professional medicine which produced the dominant discourse on sickness and health over the years had heavily colluded in defining and containing homosexuality within the twin paradigms of psychiatry and pathology. Moreover, the vicious Paragraph175, a legacy of Prussian Germany and the Nazi era, was a valid part of the legal code up to 1969 when it was finally revised. Up to then every homosexual contact between men in Germany was illegal and punishable by law. Homosexual contact between men over the age of 21 was first allowed in 1969. Four years later, in 1973, the "age of consent" was lowered to 18.

In England and the States as well as in Germany the two principal academic professions, jurisprudence and medicine, were seen as providing the legal justification and scientific rhetoric for state persecution and psychiatric harassment. And underlaying this, specific to Germany, was the memory of the appalling brutality of the treatment of homosexuals under fascism. Consequently politised German gays showed much greater distrust of the state and all its activities than their counterparts in the USA or France. This marked scepticism pre-empted a close and confidential collaboration with the German General Practitioners and the established medico-scientific community, such as was developed in San Francisco from 1981-85 and in Paris from 1984-88. But a further explanation for the critical distance German gays maintained to medical bodies lies in the fact that the German medical authorities are substantially more conservative in outlook than their North American counterparts (at least in the two states of most importance to gays, California and New York).

The Expansion of the Self-Help Groups

However, during the course of 1984, it became increasingly apparent to the first Deutsche AIDS-Hilfe activists that effective information and counselling work to the Berlin gay community required the mobilization of ressources on such a large scale that without financial state backing it was completely unfeasible. In 1984 the Deutsche AIDS-Hilfe applied for a grant to the West Berlin Parliament and the West Berlin Senat and was allocated 50,000 DM for 1985. This money was used to set up the Berlin AIDS-Hilfe, which was conceived in 1985 as a special project of the Deutsche AIDS-Hilfe and for which two people were now employed to ensure a minimum of continuity in the work. The Berlin project was immediately successful and served as a favourable precedent facilitating the passage of a larger grant of 300,000 DM for the Deutsche AIDS-Hilfe's nation-wide work in 1985. In 1986 its annual expenditure, financed by government grants, had risen to over 2 million DM mainly for information campaigns and by the end of the year it was employing ten

people on a full-time basis. In 1987 the number of permanent employees rose to 20 and the budget was increased to 5 million DM. During this period the Berlin AIDS-Hilfe was also able to rapidly expand its budget and the number of its activities. In 1986 it disposed of a budget of 280,000 DM and five permanent posts. In 1987 the budget and personnel doubled in size, and by 1988 the annual budget had risen to 1,2 million DM. One of the main reasons for the spectacular success in building up the two AIDS-Hilfen certainly lies in the adept political manoeuvering of activists and lobbyists from the Deutsche AIDS-Hilfe who were later joined by their colleagues from the Berlin AIDS-Hilfe. The highly proficient work of the second board of the Deutsche AIDS-Hilfe (1985-87) under the presidency of Gerd Paul was so effective precisely because it was an amalgam of self-confident assertive lobbying, and pragmatism, clearly defined goals and strategies, imagination and sensitivity. But fund raising from state institutions in Berlin and West Germany – so very efficacious in comparison to other European countries – was also facilitated by the happy chance that the Portfolio for Health in the conservative government was held by a woman whose unusually liberal and innovative views were not always shared by the rest of her party but fortunately by the West Berlin Health Senator. Indeed, the founding years of the German and Berlin AIDS-Hilfen are unthinkable without the (sometimes contentious) co-operation of Senator Ulf Fink in Berlin and Minister Rita Süssmuth in Bonn. They both displayed great political acumen in dealing with the material and personnal requirements of the two AIDS-Hilfen in a circumspect calculation that this would further serve their political career.

Conflictual Cooperation: The Deutsche AIDS-Hilfe and Public Institutions

Even though during the Süssmuth era the co-operative elements in the relationship between the AIDS-Hilfen and the Health Ministry by far outweighted the conflictual ones, the AIDS-Hilfen never veered from their initial principle of "the readiness to troubleshoot and resilience (of self-help organizations) when standing up for members' interests against public and private institutions" (Rosenbrock 1986, p.73). Shortly after the Deutsche AIDS-Hilfe was founded a conflict arose with the leading authorities in viral research in Berlin. From its very inception the German medical profession viewed the HIV-antibody test as an important prophylactic measure, whereas the AIDS-Hilfen spoke out forcefully against blanket antibody testing and insisted that the antibody test should be used solely as a means of differential diagnosis, of checking blood products, or as an instrument in certain epidemiological surveys (comp. Rosenbrock 1986, p.93). The antibody test was also declared medically invalid for symptomless individuals on the grounds that it could not entail any specific form of treatment (comp. Rosenbrock 1986, p.115). It was expressly stated that this position would be revised as soon as new forms of treatment became available which could either postpone or even block the outbreak of AIDS, thus prolonging the patient's life (Rosenbrock 1986, p.127).

Early in 1991, after the introduction of AZT, DDI and Pentamidin the Deutsche AIDS-Hilfe duely changed its position on the HIV-antibody test. Nevertheless, as long as no meaningful therapeutic consequences could be drawn from an antibody test it was seen as completely irresponsible to produce masses of healthy, symptomless "patients" by inordinate and indiscriminate testing. And so when members of the Deutsche AIDS-Hilfe distributed a leaflet in 1984 warning about the undifferentiated use of the test, a group of renowned Berlin Professors of Medicine publically resigned from the board of trustees, a body that had been created in the first place to increase the organization's prestige and standing. This was an acid test for the organization's readiness and ability to stand up for the interests of those it claimed to represent, and it avoided running into "a collaboration-trap", a course which would have vitiated its own specific innovative positions. And this in spite of the fact that these positions – at first – held no broad consensual basis, not even among the majority of Berlin gays who were more than eager to be HIV-antibody tested. But when the initial phase of "test euphoria" had faded away, it became increasingly apparent to many gays that the AIDS-Hilfen were right in advocating a wary, critical approach to the antibody test. After a period of initial irritation this "advocatory" role the Deutsche AIDS-Hilfe had assumed actually served to strengthen its general credibility – not least among those gays who for the most disparate reasons had either taken the test or were continuing to do so.

Safer Sex: Problems in Shaping the Message

The specific development of the Safer Sex message through the channels of the German and Berlin AIDS-Hilfen from 1986 to 1987 served to consolidate the prestige and standing of the various AIDS-Hilfe groups. Ignorance and uncertainty about possible transmission means of the HI-Virus – doubts which its identification could by no means totally dispel – promoted a great crop of catalogues with abstruse safer sex rules throughout the USA and in San Francisco in particular. Such catalogues were not only indigestable but tended to increase rather than dispel anxiety. However, during 1985-86 it became increasingly obvious that the main sexual means of transmission of the HI-Virus was during anal and vaginal intercourse (see van Griensven etal. 1987). Acting on the recommendations of Nathan Fein, a leading member of the Gay Mens' Health Crisis (GMHC) in New York, the Deutsche AIDS-Hilfen embarked on a radical simplification of their prophylactic message.

Two basic rules were introduced:

- During anal intercourse use a condom.
- During oral intercourse don't get sperm in your partner's mouth.

It was hoped that these technically – though not psychologically – simple messages would integrate more easily into the life styles and sexual mores of the

targeted groups, "without being less effective than other practicable concepts" (Rosenbrock 1986, p.46). This never meant to imply that following these two golden rules would assure hundred per cent protection: to underscore this the comparative form "Safer Sex" was deliberately adopted whilst the old absolute term "Safe Sex" was scraped.

Thus the German prevention message was clearly differentiated from that of the Netherlands, for instance, which urged a general stop to anal intercourse and reserved the use of the condom for the rare "emergency" when the need for anal intercourse could not be resisted. West German sexologists such as Martin Dannecker, Volkmar Sigusch and Gunter Schmidt subscribed to the AIDS-Hilfen view that the psychic function of anal intercourse was too important for the vast majority of gay men to make calls for a total ban on the practise a viable proposition. The perspective then developed by the AIDS-Hilfen postulated that wide-spread acceptance of Safer Sex among gay men plus long-term stability in the trend to Safer Sex could only be achieved when the indispensable recommendations for changes in sexual behaviour were kept as few in number and as sexually affirmative as possible. Rolf Rosenbrock's pointed question summed up the whole debate in a nutshell: "How to bring about the maximum reduction of transmission-means (of the HI-Virus M.B.) through the minimum of change in sexual behaviour?" (Rosenbrock 1986, p.49)

The divergence between the Safer Sex guidelines of West Berlin and West Germany and the Netherlands stems for the most part from differing methods of risk assessment. The Dutch guidelines are based on the probability of condom rupture during anal intercourse, and give high priority to the irreductible "danger margin" of regular condom use. This assessment strategy is empirically based. But whilst giving due weight to unavoidable practical considerations, German risk assessment was more psychologically oriented, and held the view that campaigns based on undiscountable "danger margins" in the use of condoms and advocating the total elimination of anal intercourse would only provoke situations whose participants would simply jetison all safety precautions. Without concerted efforts to habitualize condom use anal intercourse would occur without it.

The 1985 Berlin pamphlet "Join In! The Safer Sex Action!" still followed the San Francisco model of a checklist grading a range of 12 sex techniques into categories of unsafe and possibly unsafe, safe and possibly safe. The first brochure to be published by the German AIDS Hilfe in compliance with the simplified Safer Sex guidelines – "Prevention: Safer Sex" – came out as late as July 1986. However the debate that raged around the moral admissibility of attempts to influence sexual behaviour were much more protracted and controversial than in the USA or France.

The urgent need to dispense educational material about the transmission means of the HI-Virus was acknowledged by all parties. But left wing "alternative" circles, including those of the gay movement, hotly contested the ethical admissibility of public campaigns whose aim was to influence and change the sexual behaviour of the private individual.

Two distinct lines of argument emerged. The first, more politically grounded, held Safer Sex campaigns to be albeit unwilling tools of the state or other private institutions for the "standardization" of sexual behaviour. Any attempt by the state to establish norms in the sexual domaine had to be unconditionally rejected on political grounds, since it implied nothing less than a "nationalization" of sexuality. The politically motivated critique further rejected the counter-argument that quite apart from the impossibility of compelling behavioural changes in sex, such campains could only offer guidelines in a confused and precarious situation on which the individual could base his or her decision.

A particularly vehement diatribe was penned by Günter Amendt – a well known West German author – in 1986: "The AIDS campaign can only function because its 'Safe Sex' message presents a sanitary counter-image, that transforms victims of disease into guilty parties if and when they don't grovel to the rules of 'Safe Sex'. 'Safe Sex' is a social hygiene campaign propagating a new repressive sexual order. 'Safe Sex' is an expression of North American moral imperialism, transplanting the dominant sexual ideology of the white middle class into everything it touches. 'Safe Sex' is a prescriptive catalogue in the full tradition of American technocratic sexology. With its restrictive and puritan exhortations it does not merely signal the end of the epoque of 'sexual liberalization', it expresses its very essence. But not only that: 'Safe Sex' is also a very welcome excuse for the propagandists of the AIDS-Hilfe groups, the left-overs of the gay movement and its apologists; it spares them the trouble of confronting lifestyles and forms of relationships in which solidarity, mutual respect and a will to end exploitation played a central role. ... SDI is the collecting bowl for a collective obsession with security, 'Safe Sex' the response to a collective sexual neurosis; SDI as condom, 'Safe Sex' as a rocket shield, – the same phantasies – who can spot the difference. Following the seizure of power by the American industrial military complex, the sexual ideology of the white middle class is now beginning to make headway against libertarian and emancipatory trends. Safety and cleanliness are promised, and these are the twins of law and order." (Amendt 1986, p.26)

Such phrases are self-explanatory and need no further comment.

The second line of argument stemmed more from psychological considerations, and contained three main critical objections.

1. Safer Sex rules comprise of a series of "Do's" and "Don'ts" and so tend to infantilise their target groups who may no longer assume responsibility for their sexual lives but, in Freudian terms, must abandon it to the authoritarian dictates of a collective Superego.

2. Although Safer Sex means in fact a drastic limitation to sexuality publicity campaigns present it as though it were the hottest of all possible forms of sex: "Disavowal of the restrictive and to a certain extent castrating nature of Safer Sex gives these campaigns their unequivocal nature. Renunciation and loss are forced into and maintained in the unconscious" (Clement 1986, p.232).
3. North American Safer Sex campaigns accentuate exhibitionistic and voyeuristic sexual tendencies to the detriment of vital intersubjective elements. Thus sexuality is robbed of its erotic content and degraded into a set of technical rules for the release of accumulated tension.

This psychologically-oriented criticism, brought forward by a large number of sexologists, was far more perceptive and sophisticated than the politically-oriented kind which mainly stemmed from left-wing sections of the gay movement. The sexologists mainly sought to warn AIDS-Hilfen activists of the dangers of naive suppositions and a too simplistic presentation of their information and education material, whereas, all too often, the political criticism aimed at the practical closure of all Safer Sex campaigns. This discussion still continues; within the Berlin AIDS-Hilfe it lead to the first Safer Sex brochure being distributed only after several months' delay.[3]

Difficulties in Coping with AIDS

The number of diagnosed cases of AIDS among gay men in Berlin tripled in the first three years (1982: 3 cases, 1983: 8 cases, 1984: 25 cases). From 1985 to 1986 the number of new cases doubled (1985: 41 cases, 1986: 101 cases). (Comp. Table 2). Thus it became a matter of increasing urgency not only for the Berlin AIDS-Hilfe but also for many non-related projects in the West Berlin gay community, to drastically raise awareness among West Berlin gays about the global threat posed by AIDS and the consequent crisis it would provoke in the gay community. In June 1985 a benefit concert for the Deutsche AIDS-Hilfe was organised in the "Tempodrom", a favorite circus tent venue for many young Berliners, also due to the efforts of Rosa von Praunheim. Famous TV personalities, actors and actresses, and stars from pop and cabaret all took part in a televised program which was widely acclaimed by the Berlin and West German media, but especially by the West Berlin gays. In the autumn of 1986 appeared the first of a series of Safer Sex posters to be printed by the Deutsche AIDS-Hilfe which were subsequently to be greatly admired not only in West Germany but in many other European countries. These posters were characterized by a high degree of esthetic styling and through their use of good-looking charismatic young men they provided role models for many gays. The first poster, depicting two naked male torsi, was hung not only in most gay bars but displayed on hoardings in the Berlin underground. In Berlin, as in many other cities, the public presentation of gay life styles – financed, moreover, with public funds – first became possible through the advent of AIDS. It was indeed feared that AIDS would threaten the social emancipation of gay

men, and reinforce once more their marginalization and stigmatization. However, one of the many paradoxical effects of the epidemic is that it is actually accelerating the process of social integration of gay men.

A third action in the winter of 1986/1987 was also well-received by gays in West-Berlin: the gay magazine "Siegessäule" brought out a special issue on AIDS, a comprehensive and widely-distributed publication made possible by a 20,000 DM grant from the Senator for Health.

During the middle 80's gay pubs, bars and cafés were a focus for the campaigning work of the Berlin AIDS-Hilfe. After some initial resentment AIDS-Hilfe activists were soon accepted as welcome guests. For the gay clientele of the Berlin AIDS-Hilfe it was particularly reassuring to know that a telephone helpline had been set up in 1984; from 1985 onwards it was staffed around the clock. In the first three years of this service half of all callers were homosexual; by the end of the decade the situation had altered somewhat, and by now two thirds of those calling for advice are heterosexual. Cooperation with the gay bathhouses proved much harder to establish. The bathhouse owners were afraid that open talk about AIDS would mean a further drop in the number of their customers. The "AIDS-Shock" of 1984-85 had already caused a dramatic falling off of business and was responsible for the closure of one of the three West Berlin bathhouses. Unlike San Francisco or Stockholm, however, in West Berlin there were no calls from either heterosexual or homosexual circles for the closure of the bathhouses. The Health Senator of the time was swayed more by the arguments of the German and West Berlin AIDS-Hilfen – and by the pragmatic approach of his adroit advisors – which held gay bathhouses to be the most appropriate venue, among all others of the gay subculture, in which an efficient practical dissemination of Safer Sex techniques could be conducted. In this context the elaborate, ritualised behaviour-patterns of the gay scene would provide an expedient base from which the AIDS-Hilfen could promote forms of sexual interaction that were fully adapted to the threat posed by AIDS. Closure of such venues would simply mean that sexual contact would be displaced into other areas less accessible or indeed impervious to reasonable influence. Consequently, there was no official move to shut down the two remaining Berlin bathhouses. The party thrown to celebrate the 10th anniversary of one of the bathhouses in 1987 was the spring-board for a series of regular events run by the Berlin AIDS-Hilfe in conjunction with the Gay Switchboard "Mann-O-Meter". Since 1988 they take place monthly and are hosted alternatively by the two bathhouses.

None of the debates within the West Berlin gay community about AIDS-related issues was as controversial as that around the closure of the backrooms in the leather bars. Anticipating legal prohibition, the bar owners had provisionally shut them; in 1989, however, three of them were reopened. Writing in the major German news weekly "Der Spiegel" ("The Mirror") in 1990 Rosa von Praunheim used their reopening as a starting point to launch a much publicised and lengthy attack on the AIDS-Hilfen and what he saw as their collusion in the dramatic increase in high-risk sexual practices among gays. He accused the AIDS-Hilfen of imploding under the sheer weight of their state-financed "successes", and of stultifying bureaucratic paralysis. Moreover, he continued their permissive and slip-shod Safer Sex strategies actually promo-

ted favourable conditions for the further spread of the HI-Virus. The AIDS-Hilfen response was sharp and personnel, labelling von Praunheim as hysterical and vindictive. During the ensuing debate it became clear that the protagonists were using one another in fact as screens on which to project their mutual unsolved dilemmas. Rosa von Praunheim admitted in press interviews that his personal difficulties in coming to terms with Safer Sex and his deep-rooted fear of infection formed the motives for his diatribe against the AIDS-Hilfen. For their part the AIDS-Hilfen felt so fundamentally insecure about their adopted positions that they over-reacted by breaking off contact and calling for a boycott of the most famous German gay film director since Fassbinder.

So at least a well-intentioned summary of the debate might run, untinted by partisan malice. In Berlin at the time, however, various cynics claimed that the only intention von Praunheim had in writing the "Spiegel" article was to stage yet another meretricious personality show, giving a further hype to his media-image. Whatever the case might be, for a short time the West Berlin gay community was radically divided. The majority of gays found von Praunheim's polemic to be lacking in solidarity and largely discreditable, whilst his conduct was dismissed as egotistical and narcissistic in the extreme. Only a minority found that he had shown great courage in opening a debate that was long overdue.

This temporary but complete communication break-down, occuring precisely in a situation where communication was of the utmost importance to the gay community, is clearly indicative of the traumatic impact of AIDS on gay men. At the Berlin conference on "AIDS prevention and the Social Sciences" early in 1989, Martin Dannecker had already warned that the massive threat posed by AIDS both to the sexuality and the physical and psychological integrity of homosexual men had plunged them into a crisis of self-esteem of unprecedented proportions (Dannecker 1990a, pp.216-217). The bitter polemic between the AIDS-Hilfen and Rosa von Praunheim demonstrates that such traumata have consequences that reach out far beyond the sphere of the purely sexual to have a marked influence on the whole domaine of interactional patterns between gay men. That AIDS had effected a radical transformation of sexual behaviour became glaringly apparent as early as 1987, from the findings of the survey of gay men in West Berlin and the Federal Republic, commissioned by the Deutsche AIDS-Hilfe.

The results of the survey were backed up by a second one which was carried out in 1988.[4] The results of both surveys show that the Deutsche AIDS-Hilfe and the Berliner AIDS-Hilfe had succeeded in creating a considerable degree of sensitivity and risk awareness among the gays in West Berlin and West Germany (comp. Bochow 1988, 1989, 1993). This risk awareness lead to a significant decline in the number of HIV relevant situations of transmission among gays since the mid-80's. However, this result cannot be attributed solely to the prevention efforts of both AIDS-Hilfen. Their prevention concept could be successful, because both organizations were supported by various institutions and projects which had come into being in the course of the 80's. Some of them, which had already existed before, had shifted parts of their manpower to the field of primary and secondary AIDS prevention.

First of all it should be noted that during the 70's in West Berlin a number of gay medical practices had sprung up, informally catering for a gay clientele and mainly specialized in the treatment of sexually transmitted diseases (STDs) and Hepatitis-B. Thus, even before the advent of AIDS, a domaine of the West Berlin Public Health Service was adapted to the specific needs of gay men and, to a certain extent, had established a tradition for their health care. Even in pre-AIDS times the risk of infection from syphilis or Hepatitis-B meant that "promiscuous" gay men had every cause to keep a careful check on their state of health. These ready-made structures for gay health care furnished the basis for a prompter response to AIDS – an aspect that has been largely neglected in previous discussions of the subject, although it is by no means particular to West Berlin and may be equally noted in other gay metropoles with an open liberal climate such as Amsterdam, Paris or San Francisco. In 1987 the medical practices specializing in AIDS officially regrouped as "The Working Party on AIDS", two thirds of whose members were gay doctors. But before AIDS became a public issue in Berlin, a further bond of co-operation had been forged between the Public Health Service and the gay community that was to prove invaluable in dealing with the epidemic. In 1982 the Institute for Tropical Medicine launched a campaign for immunization against Hepatitis-B in conjunction with gay doctors and gay groups and the Green Cross, a branch of the World Health Organization. This campaign had a very positive feed-back from the gay community and was viewed by many gay men as exemplary in that a Public Health Authority had taken active steps to support the health of the gay section of the population withoug patronizing, moralizing or seeking in any way to control them. When the AIDS epidemic reached Berlin, the Institute for Tropical Medicine immediately became a central clearinghouse for information and counselling. And when the HIV-antibody test was introduced, the gay men who came forward to take it showed confidence in the Institute's assurances of anonymity and impartiality.[5] That such bonds of trust could be forged in the first place is due in large part to the unstinted efforts of one co-worker at the Institute, Nurse Sabine Lange, who was particularly successful in building up a sound working relationship with the leather scene, which in Berlin, as elsewhere, was particularly hard-hit by the epidemic. In 1986 she received one of the two posts assigned to Berlin from the federal government's pilot project "Streetwork". With guaranteed state backing for the next five years, it provided another major strand in the Berlin network of AIDS prevention work.

In order to adequately document the sheer diversity of initiatives that sprung from the gay community and the extent of social support such initiatives received, two further projects should be mentioned, both of which have played an important role in AIDS prevention work, although neither was founded as a result of the syndrome.

The Gay Switchboard "Mann-O-Meter" founded in 1985, has received substantial backing from state funds since 1987 (in 1988 it was allocated 200,000 DM). Originally planned as a communication, information and coun-

selling center for gay men, over the past few years it has widely extended its scope to take on an increasing role in AIDS prevention work. Its contribution is twofold and consists of disseminating information on counselling and welfare options for AIDS specific problems in West Berlin, plus the organization of safer sex workshops. In the heady days following the collapse of the Berlin Wall on the 9th November 1989, its rooms were packed with gays from East Berlin; wanting general information on West Berlin, but also showing a keen interest in information material on AIDS.

The work of the "Schwulenberatungsstelle" (Gay Counselling Agency) is less well-known than that of the Gay Switchboard, but over the past years it too has expanded its counselling and therapy options to encompass psychosocial problems arising from AIDS. From the agency staff of 13 persons, 3,5 full-time employees are involved in continuous psychotherapeutic support for HIV-Positive or people with AIDS.

The above account, dealing as it does mainly with areas of primary prevention for gay men, is by no means exhaustive; however it does attempt to indicate the main actions and projects in West Berlin between 1983 and 1989. The author hopes that he has managed to convey at least some impression of the sheer diversity of responses to AIDS in West Berlin. However, any account of the situation in West Berlin would be incomplete without more than a passing reference to the situation in East Berlin. Not only because the Berlin Wall fell in November 1989, and ever since 1990 the two halves of the "divided city" have strived to re-unite. Even before 1989 the Berlin Wall was by no means insurmountable, but rather constituted, in the catch-phrase of Meinrad Koch, Head of the German AIDS-Center, "a semi-permeable membrane" – pervious, that is, from one side only.

AIDS in East Berlin

In the latter part of the 80's West Berliners paid about two million visits a year to the east part of the city. Most of these visitors crossed over to visit relatives in the East, but it may be safely assumed that gay men made up an over-proportionally large part of those visiting the east for other than family reasons. This hypothesis is based on the recognized greater mobility of gay men, especially those adapted to life in big cities. Moreover, in 1987 the decrees regulating overnight stays for West Berliners were relaxed somewhat: previously West Berliners with a day visa had to leave the East by midnight at the latest; now, under certain conditions they could stay overnight. Viewed from this context it is surprising how widely disparate the epidemiological situations are in the two cities. Tables 1-2 summarise the different incidence of HIV and AIDS in West and East Berlin.

Given the permeability of the Wall the vast divide between East and West is by no means self-explanatory. It needs to be asked why the HIV incidence in East Berlin is not much higher than it actually is. A possible answer might be that gay tourism in East Berlin was more of the sightseeing kind, conducive to

social rather than sexual contact (which by no means implies that sexual contact is anti-social). Although East Berlin could offer flourishing cruising areas and restrooms, it was an ill-advised Western visitor who sought his "quick sex" there. Quite simply, until the AIDS-Shock made itself felt in 1983 – 1984 and lead to a distinct drop in the number of sexual contacts, it was much easier to find a partner for casual sex in one of the West Berlin darkrooms, bathhouses or parks. Two further factors should also be noted:

1. For every trip to East Berlin it was obligatory at the border to make a disadvantageous change of 25 DM for 25 East Marks. West Germans and foreign visitors had to pay an additional charge of 5 DM for an entry visa. Thus the "entrance fee" for East Berlin was considerably higher than that for a West Berlin bathhouse.
2. Account must also be taken of the influence of sexual networks as Michael Pollak has described them in his analysis of the situation in France (Pollak 1988, pp.58-68). Such sexual networks were of course also existant in East Berlin and the GDR. Since a commercial gay scene existed only in East Berlin – and there only in the most rudimentary form – the circle of gay friends and acquaintances became of incomparably more importance than in West Berlin or West Germany. But West Berlin gays day-tripping to the East had no easy or direct success to such private circles. On the contrary: West Berliners and West Germans – and not just the gays among them – were often accused of being patronizing and arrogant. Aggressive behaviour, flashy clothes and other forms of conspicuous consumption were viewed with great distaste by many GDR citizens. The cultural clash between West and East and the low-key but permanent cultural imperialism shown by many Westerners confirmed many East Germans in their guarded aloofness and thus forestalled a more thorough "mixing" of Western gays with those in East Berlin. The low prevalence of HIV and AIDS in East Berlin cannot be solely explained in terms of the isolationist politics of the East German government – though doubtless such policies has considerable repercussions – but must be viewed in connection with certain sociocultural factors, themselves the product of the state's drive to self-isolation. Moreover, the economic situation of the GDR and the lack of a free monetary system prevented the development of a drug trafficking scene such as is typical for West Berlin, West Germany and other West European countries.

The GDR's state planned economy with all its concomittant restrictions on the Public Amenities and Private Services Sector ensured that a commercial gay scene in the western sense could hardly take root. Up to 1989 there were two cafés in East Berlin and two bars mainly frequented by gay men; however, the city had no bathhouse nor was there a bar with a darkroom. Due to the very lack of suitable facilities for a high turn-over in sexual partners, the quota of "promiscuous" gay men in the East was considerably lower than in West Berlin. Thus the low prevalence of HIV and AIDS in the GDR is much less the result of particularly successful campaigns for primary prevention, as the GDR government claimed (comp. Grau and Herrn 1989), and more a direct consequence of the specific economic structuring of GDR society.

Such remarks should not, however, create the misleading impression that in the period 1984-89 the number of sexual contacts between West Berliners, West Germans and East Berliners was virtually negligeable. On the contrary: there must have been a greater number of them – though evidently not enough to reach the "critical level" that would have made for higher HIV incidence level in East Berlin up to 1989. Since there is no information available on the frequency of sexual contacts between West and East further speculation on the matter is otiose. However, it may be assumed that from 1984-85 onwards a substantial number of gay sexual contacts between West and East were no longer at risk (in relation to the transmission of the HI-Virus). At this point in time there had as yet been no official pronouncement from the GDR Health Ministry. But the theme AIDS had already received extensive coverage on West German television and West Berlin radio, both of which had long been considered by East Germans as reliable sources for "withheld information", both of which enjoyed far greater credibility than their East German equivalents. And even if Western TV and radio coverage of AIDS between 1984-85 was by no means optimal, at least it was more differentiated and less luridly sensationalist than the coverage by the West German tabloid press. Once again, it may be safely assumed that the Western TV and radio coverage of AIDS was followed attentively by many East Berlin and GDR gays and that such coverage brought about corresponding changes in their sexual behaviour.

The AIDS-Hilfe GDR and its predecessor

The AIDS policy measures of the GDR government were based on the rigid traditionalist approach for the control of infectious and contagious disease and comprised of interventions for the "exposure of the infectious source" together with mandatory registration of the infected and sick and a relentlessly persued program of contact tracing. The HIV-antibody test was considered an integral part of the prevention agenda, and homosexuals in general were called on to take it. Despite the fact that the majority of HIV infections and AIDS cases were to be found among gay men, the information campaigns of the GDR Health Ministry were kept determinedly non-specific, taking no account of addressing homogeneous target groups. In conception GDR policy measures may best be compared to those of Bavaria or Sweden; they are worlds apart from the liberal strategies adapted by the West Berlin Parliament, not to mention the open-minded approaches of Switzerland or the Netherlands in the 1980's. Such restrictive measures soon aroused strong criticism from East Berlin gays; nevertheless under the old autocratic régime it could be articulated only with the utmost prudence. Early in the 80's "autonomous" gay groups had formed under the auspices of the Protestant Church – which did not necessarily make them "ecclesiastical". Under the draconian surveillance of the ancien régime those gays wishing to formulate a gay response to the threats posed by AIDS also had little alternative but to

organize under the Churche's patronage. In December 1987 the "Zentrale AIDS-Arbeitsgruppe der Kirchlichen Arbeitskreise in der DDR" was formed ("Central Working Party on AIDS of the Church General Working Committee in the GDR"). The chief concerns of this gay group were to formulate a critique of the rigid and narrow agenda of the GDR Health Ministry and to establish a non-discriminatory information and counselling service for gays, that took full account of their sexual diversity. During 1988-89 numerous weekend seminars were organized for information, discussion and training in an attempt to launch an alternative counselling service for gays. Early in 1989 an anonymous and confidential telephone counselling service was offered once a week in East Berlin's main protestant church the Berliner Dom; however, this found little resonance. Unlike the West Berlin AIDS-Hilfe the East Berlin group recommended condom usage during both anal – genital and oro – genital sex. Photostate material and handbills were distributed from 1988 onwards in an attempt to directly address specific groups. But the first "official" pamphlet of the "Central Working Party on AIDS" was brought out in the weeks following the collapse of the Berlin Wall: a "memorandum" containing a critical assessment of the outgoing AIDS agenda of the GDR government, published in December 1989. A month later, in January 1990, the "AIDS-Hilfe GDR" was founded; in July 1990 the newly – elected GDR government granted them premises in East Berlin; in September of the same year government allocation paid for a staff of five employees.

Concurrent with the first free elections for the "Volkskammer" (the GDR Parliament) in March 1990 the anonymous HIV-antibody test was officially sanctioned and the decrees for mandatory registration after a positive HIV-antibody test were abolished, together wich compulsory testing in GDR prisons. However, there remained insufficient time both for the new GDR government and the numerous self-help groups even to lay the foundations of a new AIDS program for the GDR. In September 1990 the "Länder" of the GDR reconstituted themselves anew, reverting to the status quo they held from 1947 – 1952 in the Soviet occupied zone until they were abolished by the East German communist government. Having thus granted itself a federal status, on the 3rd October 1990, the GDR formally acceded to the German Federal Republic. In January 1991 the AIDS-Hilfe GDR merged with the Deutsche AIDS-Hilfe, which thus also became the umbrella organization for 16 local AIDS-Hilfe groups that by then had formed in East Germany. Since the AIDS-Hilfe GDR has assumed the role of a local group for East Berlin its premises shall be kept until June 1991 as the "Eastern secretariat" of the Deutsche AIDS-Hilfe.

Current Problems in East Berlin and East Germany

The Federal Government's serious miscalculation of the cost of German reunification has reduced public finances to a state of disaster. This has direct and drastic consequences for Berlin, now a "unity" of two very unequal halves. At the beginning of 1991 West Berlin, which has always been extremely

dependant on large subsidies – now being reduced – reunited with an East Berlin which has lost its function as capital city and whose unemployment figures rose to more than 200,000 in 1992 – a staggering 40 – 50 per cent of the total work-force. Berlin's financial situation is, mildly put, catastrophic, and the Federal government shows little intention as yet of prioritizing aid. The Berlin Parliament is trying to survive the crisis by means of a rigorous austerity program and extensive borrowing which will involve drastic middle-term retrenchment for the whole domaine of AIDS self-help groups. Cut-backs in finance mean that many planned measures for the welfare and psychosocial counselling for people with AIDS, for the supervision of volonteer workers and the provision of adequate housing for those with HIV or AIDS would no longer be viable. But in the light of the low HIV and AIDS incidence in East Berlin and the high HIV and AIDS incidence in the other part of the city, long-term programs for primary prevention in East Berlin that are not merely pressed from Western models, are of crucial importance. The sociocultural divide that segregates the two halves of the city is too markedly pronounced to be bridged easily in the coming years.

If, over the past few years, government funding for AIDS self-help groups in West Germany and West Berlin was remarkably high in comparison to that of Paris or London, it now appears that the financial repercussions of German unity shall downgrade the positive West German situation to the impaired level of France or England. At the very time when great exertions are required of self-help groups in secondary and tertiary prevention work in West Berlin – and primary prevention in both West and East Berlin – government backing is rashly withdrawn. The grim situation in the former GDR will be further exacerbated by the implosion of major areas of the Public Health Service, casualities of the East's brutal assimilation to western systems and structures. The East German system of out-patient care – the Polikliniks – has mostly been destroyed. Moreover, it is highly probable that in East Berlin the greater part of welfare facilities catering for alcoholics are to be shut down, although in view of the current social crisis in East Germany there should be massive reinforcement of alcohol-abuse programs and deintoxification units. At present the population of the former GDR is experiencing the collapse of its institutions and the breakdown of all normative orientation to a degree unparalleled since the end of World War II. Aggravating this highly charged situation of unforetold psychic stress is a deep and general ecological catastrophy from which only the northern part of the territory is largely spared. The demotion of East Berlin from its status as capital and the consequent loss of many privileged positions for East Berliners is a further turn of the screw. In short, the pre-conditions for the physical and psychic well-being of the majority of GDR citizens are incontrovertably bad. The massive loss of self-confidence and self-esteem the crisis entails for many East Berliners and other citizens of the former GDR threatens to conglomerate into a "collective trauma".

Using the spurious argument that at present the prevalence of HIV infections and AIDS cases in the old federative states of the FGR has not yet reached the level predicted in 1986/87, and under the stamp of the fiscal pressure of German reunification, federal funding for AIDS related prevention

work and social research into AIDS is to be drastically cut back. Euphemistically put, this holds out no rosy future for the five new East German states and East Berlin.

Table 1 demonstrates that the number of newly diagnosed cases of HIV infection in East Berlin doubled from 1989 to 1990. In comparison to West Berlin and West German metropolitan areas, the absolute figure for new cases is still extremely low. However, from 1991 to 1995 there is likely to be a much more dramatic expansion of HIV on the territory of the former GDR than in the previous five years. The level of HIV incidence and prevalence in the five new federal states and East Berlin, in terms of a general West European comparison, is one of the very lowest; but whether it may be maintained at the present low level remains highly uncertain. Research findings from studies on changes in gay sexual behaviour under the impact of AIDS (in West Germany, France and North America) all concur in pointing out that there is only a putative – or at the very most negligible – correlation between behavioural change and the level of perceived informations. Significant changes in sexual behaviour are brought about more by personal experience of AIDS in friendship or acquaintanceship networks, by a positive self-accepting attitude to one's own homosexuality, by supportative recognition of homosexuality by the immediate social environment, and by firm integration in gay networks. Whilst integration in gay networks is privileged in East Berlin in comparison to other cities in the former GDR (with the exception of Leipzig and possibly Potsdam), due to the epidemiological situation in East Berlin personal awareness of AIDS is still very limited. A concept for the primary prevention in the new Länder which takes their specific situation into account has not been presented by the Deutsche AIDS-Hilfe or the local AIDS-Hilfen in East Germany until now. It remains an urgent desideratum and should be developed and discussed by the Deutsche AIDS-Hilfe.

From July 1989 onwards the legal basis for the social acceptance of homosexuality in the GDR was more favourable than in the Federal Republic. Discriminatory treatment of gays before the law was abolished by the abrogation of the relevant paragraphs from the Penal Code, and the "age of consent" was fixed at 16 for homosexual and heterosexual persons alike. Nevertheless, if in an open society such as the Netherlands the laws governing the "age of consent" are a reflection of the whole society's liberal views, this cannot be the case for an autocratic bureaucratically structured society such as the GDR. The abolition of Paragraph 151 from the Penal Code should be seen more as a gift graciously bestowed on gays by the ruling communist party (the SED), as a concession to civil rights activists and progressive SED party members. Indeed, it may well have been primarily conceived as part of a "strategy of subjection" that can proceed more efficiently with social repression behind a camouflage of liberal window dressing. Within the scope of the merger program for the legal systems of the two German states, it is now finally intended to abolish Paragraph 175 from the West German Penal Code, and to lower the "age of consent" to 16, independent of the sexual orientation of the parties involved. That such an initiative is now being legally contemplated may hardly be ascribed to the conservative government's better judgement – otherwise they would have immediately advocated lowering the "age of con-

Diagnosed cases of HIV-1-Infection in West and East Berlin, classified according to the year in which the blood sample reached the laboratory and classified by sex*

	West Berlin				East Berlin			
Year / Sex	Unknown	Male	Female	Total	Unknown	Male	Female	Total
before 1985	78	366	38	482	0	0	0	0
1985	285	1093	198	1576	0	0	0	0
1986	152	1132	174	1458	0	3	0	3
1987	105	1036	191	1332	0	19	0	19
1988	88	797	182	1067	0	12	0	12
1989	74	533	110	717	0	11	1	12
1990	92	710	143	945	2	28	0	30
1991	102	586	153	841	0	37	3	40
1992**	65	417	88	570	2	28	6	36
Total	1041	6670	1277	8988	4	138	10	152

*In the Federal Republic the sexual orientation of more than half of the people with HIV-1 Infection is unknown. Thus data can only be classified according to sex.
** Data not complete yet.

Table 2

Registered cases of AIDS in West and East Berlin. Classified according to sex

	West Berlin				East Berlin			
Year / Sex	Gay	Male	Female	Total	Gay	Male	Female	Total
before 1984	12	13	0	13	0	0	0	0
1984	27	31	0	31	0	0	0	0
1985	40	45	2	47	0	0	0	0
1986	108	115	5	120	0	0	0	0
1987	192	222	10	232	2	3	0	3
1988	252	294	17	311	2	2	0	2
1989	276	330	14	344	5	6	0	6
1990	248	304	21	325	6	7	0	7
1991	198	252	24	276	4	5	0	5
1992*	177	212	30	242	7	9	1	10
Total	1530	1818	123	1941	26	32	1	33

* Data not complete yet.

sent" to 14. It is largely due to the force majeure generated by the conflation of two incommensurable judical systems. The reintroduction of the prejudicial paragraph would only serve to aggravate the already considerable social unrest in the former GDR.[6]

The Present Concept of the Deutsche AIDS-Hilfe

Thus there still remains a great deal to be done before gay lifestyles can be fully accepted in both parts of Germany, and both halves of Berlin. This sobering appraisal underpins the concept of "structural prevention" adopted by the Deutsche AIDS-Hilfe in 1990. Health care policy planning is seen as an integral part of comprehensive social interventions as defined by the Ottawa Charta of the WHO: "Our special contribution ... as infected gay people ... is to seek to influence our communities and lifestyles with a view to health promotion. This involves not only comfort and integration in a supportative social environment, free and ready access to essential information sources, and the empowerment of practical abilities, but also endorses individual decision making ... in relation to individual health concerns. People may only develop their full health potential when allowed to participate in policy making decisions affecting their health." (Vorstand der Deutschen AIDS-Hilfe 1991, p.6).

The health-care principles of the WHO Charta can only be effectively applied when social structures that stand in opposition to them are reformed or abolished. Widespread poverty, social and cultural deprivation, social stigmatization and discrimination, a deficient Public Health Service and a government economic program dominated by an ethic of possessive individualism, are all forces that militate against the implementation of the WHO Health Charta. The "structural prevention" concept of the German AIDS Hilfe takes into account the preconditions for primary, secondary and tertiary social prevention programs in an attempt to realize them within society. Underpinned by consciousness raising and self-empowerment strategies, "identity development" activities with marginalized individuals also form an integral part of the program, together with collective "identity options" (the plural is important). Such programs are of particular relevance to young gays, who still go through their coming out and going public in a "normative vacuum" (Dannecker and Reiche 1974, p.146), since all the educational processes in all socialisation agencies in our society are monolithically and rigidly orientated towards (compulsory) heterosexuality.[7]

Based on strategies that seek to de-stigmatize population constituencies particularly hard hit by HIV and AIDS, the Deutsche AIDS-Hilfe's program is broadly comparable to that of many self-help groups in West Europe and North America. However, the difference lies in the special "anti-integrationist" variant the Deutsche AIDS-Hilfe has produced, one that vigourously proclaims gays' and drug injecting users' right to difference.

The outstanding feature of the campaign must lie in its emphasis on "dealing with the prophylactic dilemma at the level of primary prevention

activities" (Vorstand der Deutschen AIDS-Hilfe 1991, p.6). This somewhat cryptic formula seeks to encapsulate the sense of erotic loss and deprivation induced by the sustained application of safer sex (comp. Bochow 1990b, p.39). The concept "prophylactic dilemma" seeks to elucidate the contradictory Janus-like nature contraception assumes when safer sex is practised during anal intercourse. On the one hand – when properly used – the condom prevents a potential transmission of the HIV virus. But for many gays, for whom unprotected anal intercourse is of prime psychic importance, the condom also effectively blocks the indispensable feeling of dissolution and blending with the partner, thus placing severe restrictions on the interactive "dyadic" dimension of sexuality. Even when "in fact" the condom is "only" a transparent shield of 0,005mm thickness, projected on the symbolic level it can assume the overwhelming proportions of a meter-thick prison wall. Nevertheless important as such reservations are, it should be stressed that they are the inevitable side-effects accompanyng sustained condom usage, and involve neither a rejection of the condom nor of anal intercourse as such. Martin Dannecker has analysed the main motive that leads to the rejection of the condom and of anal intercourse as follows: "Resistance to condom usage, including condom usage during anal intercourse does not only spring from a limitation of sexual desire or from the inability of most gay men to find a piece of rubber erotically attractive. The condom (also) poses restrictions on sexual gratification because it is inextricably associated with AIDS. For gay men the condom has but one meaning: it blocks HIV infection. They will hardly use it for any other reason than to stop falling sick of AIDS some day. And so use of the condom inevitably and immediately calls to mind the very scenario fraught with sickness and death that its use is designed to avoid. It is most likely that a great number of gay men have extricated themselves from this dilemma by limiting their sexual practices to those which – while still taking account of safer sex – eliminate the condom and thus eradicate the central symbol of the presence of AIDS." (Dannecker 1990, p.107)

Given these strong background reservations, perhaps the scepticism expressed by those in and around the Deutsche AIDS-Hilfe about the current "relapse" debate in the USA is more readily understandable. In the current debate, the term "relapse", derived from Public Health Literature, and used in a perfectly analogous way, is taken to mean the "retrogression" from adopted safer sex to unsafe sexual practices. Thus the resumption of sexual practices that could lead to a potential HIV virus transmission is equated with infringement of the abstinence precept for clean alcoholics or drug injecting users, with weight-watchers disregard for their calorie count or cholesterin diet, or with the acceptance of frequent stress situations by those with cardiac disorders.

However, it is a highly questionnable procedure to set safer sex recommendations for gay men on a par with abuse therapy for alcoholics, dietary plans for the over-weight or stress reduction measures for the weak of heart, and to discuss them within the same health care context. Both from their social context and from the resultant psychic dynamics the violation of the abstinence precept by an alcoholic and the disregard for safer sex guidelines by a gay man are widely incommensurable acts. For a clean alcoholic, infringement of the

abstinence precept involves the reactivation of psychic problems that he or she thought they had overcome. For a gay men unprotected sex may represent surmounting the barrier of condom-linked anal intercourse. Whilst this is most healthy from a psychological point of view, to treat the occurrence as a "relapse" is to pathologize the spontaneous freedom of a sexual act within the structures of a psychic problem.

Initiators of and activists in prevention campaigns for gay men should be fully aware that although the guidelines "Fuck with a rubber" is an easily formulated, even catchy slogan and the central tenet of the safer sex campaign, it can in no way obviate the immense difficulties involved in its practical application. The impossibility of making the condom erotically desirable – a goal that is frequently tried for in the campaigns of gay self-help groups – is strikingly illustrated by the findings of studies by Martin Dannecker and Peter Davies etal. (comp. Dannecker 1990, p.105; Davies etal. 1990, p.151). Such studies unanimously find that condom use encounters a core of psychic resistance that can be overcome neither by the conditioning programs of cognitive psychology nor by behaviourist therapy. Even the most ingenious safer sex campaigns will never achieve a hundred per cent compliance with the guideline "Use a condom during anal intercourse". Changes in sexual behaviour – fortunately! – cannot be achieved with the advertising strategies for soap powder. What are needed are counselling options and scene-oriented activities that seek to find individual solutions to the individual problems gay men encounter when tackling the "prophylactic dilemma"[8]. Individually designed risk strategies, not the dictates of "consenting compulsion" sculpt the perspectives of an AIDS agenda that is firmly grounded in the principle of individual responsibility. The Deutsche AIDS-Hilfe's concept of structural prevention is an attempt to mediate these strategies. An explanation of sexual behaviour is to be found in the dynamics of sexual interaction and of sexual fantasies but not in the social or scientific construction of maladjusted problem individuals (comp. Dowsett et al., 1992, p. 7, and Davies et al., 1992, p. 140).

Notes

1 West Berlin's Statistical Year-Book for 1990 (p.58 onwards) specifies an adult male population of 783,905 for 1987. 8 per cent of this total gives 67,712 homo- and bisexual men; 10 per cent brings the number to 78,391. Since these quotes are based on estimates they can only indicate approximate dimensions and are not to be read as "exact" figures.

2 In 1983 the Institute was still the department of tropical medicine of the "Landesimpfanstalt".

3 For a recent summary of debates in the AIDS-Hilfen see the account by Hans Hengelein and Christine Höpfner (1990).

4 An English summary of the results of both surveys may be found in Bochow 1990.

5 The Institute for Tropical Medicine also participates in the "Multi-centered prospective cohort studies on AIDS" in the Federal Republic, in cooperation with centers in Francfort, Hamburg, Hanover, Cologne and Munich. Comp. Koch and Schwartländer 1990.

6 The expression "merger of the two judicial systems" is of course an euphemism – as the judicial system of the former GDR is practically abrogated to make way for West German law. However, in spite of great coertion, a few points of highly symbolic order resist this rapid forced transformation. Neither Paragraph 175 nor Paragraph 218 of the Federal Penal Code, which allows abortion in the first three months only under certain restrictive circumstances, could be forced on the population of the former GDR.

7 Even the majority of liberal teachers and parents still consider – and only tolerate – a young person's homosexual orientation as "the unfortunate exception", never viewing it as one possible variation of human sexuality to be accepted – or even anticipated – by the education system.

8 To the best of my knowledge the Norwegian research by Annick Prieur is alone in the fields of Anglo-American and Scandinavian publications in presenting an in-depth study of this complex range of problems; the German translation has been published late in 1991 by the German AIDS-Hilfe as "Mann-männliche Liebe in den Zeiten von AIDS" (Man-to-Man Love under the Impact of AIDS), AIDS-FORUM D.A.H. Vol. VII.

References

Amendt, G. 1986. "Jetzt ist alles Gras aufgefressen." In: Sigusch, V. and Gremliza, H.L. (Eds.). Operation AIDS. Das Geschäft mit der Angst: Sexualforscher geben Auskunft. pp.22-26. Hamburg: Sexualität Konkret.

Berlin Museum (Ed.) 1984. Eldorado. Homosexuelle Frauen und Männer in Berlin 1850 – 1950. Geschichte, Alltag und Kultur. Berlin: Frölich und Kaufmann.

Bochow, M. 1988. AIDS: Wie leben schwule Männer heute? Berlin: AIDS-FORUM D.A.H. Vol. II. Deutsche AIDS-Hilfe.

Bochow, M. 1989. AIDS und Schwule: Individuelle Strategien und kollektive Bewältigung. Berlin: AIDS-FORUM D.A.H. Vol. IV. Deutsche AIDS-Hilfe.

Bochow, M. 1990a. "AIDS and Gay Men: Individual Strategies and Collective Coping." European Sociological Review 6: 181-188.

Bochow, M. 1990b. "Safer Sex und kein Ende". Deutsche AIDS-Hilfe Aktuell Herbst 1990: 37-41.

Bochow, M. 1991. Le Safer Sex – une discussion sans fin. In: Pollak, M., Menses-Leite, R., van dem Borghe, J. Homosexualités et SIDA. Actes du Colloque International 1991: pp. 117-131. Lille.

Bochow, M. 1993. Die Reaktionen homosexueller Männer auf AIDS in Ost- und Westdeutschland. Ergebnisbericht zu einer Befragung im Auftrag der Bundeszentrale für gesundheitliche Aufklärung/Köln. Berlin: AIDS-FORUM D.A.H. Vol. X. Deutsche AIDS-Hilfe.

Clement, U. 1986. "Zur Sozialpsychologie des 'Safer Sex'." In: Frings, M. (Ed.). Dimensionen einer Krankheit – AIDS. pp.227-238. Reinbek bei Hamburg: Rowohlt Taschenbuch Verlag.

Coates, T., Stall, R.D., Kegeles, S.M., Lo, B., Martin, S.F., and McKusick, L. 1988. "AIDS Antibody Testing. Will It Stop the AIDS Epidemic? Will It Help People Infected With HIV?" American Psychologist 43: 859-864.

Dannecker, M. 1990a. "Sexualität und Verhaltenssteuerung am Beispiel der Reaktion homosexueller und bisexueller Männer auf AIDS." In: Rosenbrock, R. and Salmen, A. (Eds.): AIDS-Prävention. pp.207- 217. Berlin: edition sigma rainer bohn verlag.

Dannecker, M. 1990b. Homosexuelle Männer und AIDS. Eine sexualwissenschaftliche Studie zu Sexualverhalten und Lebensstil. Stuttgart, Berlin, Köln: Verlag W. Kohlhammer.

Dannecker, M. 1991. Der homosexuelle Mann im Zeichen von AIDS. Hamburg: Klein Verlag.

Dannecker, M. and Reiche, R. 1974. Der gewöhnliche Homosexuelle. Eine soziologische Untersuchung über männliche Homosexuelle in der Bundesrepublik. Frankfurt a.M.: S. Fischer Verlag.

Davies, P.M., Hunt, A.J., Macourt, M. and Weatherburn, P. 1990. Longitudinal Study of the Sexual Behaviour of Homosexual Males under the Impact of AIDS: A Final Report to the Department of Health. London: Project SIGMA.

Davies, P.M. and Project SIGMA. 1992. On Relapse: Recidivism or Rational Response? In: Aggleton, P., Davies, P.M. and Hart, G. (Eds.). AIDS: Rights, Risk, and Reason. pp. 133-141. London and Washington

Dowsett, G., Mark, D. and Connell, B. 1992. Gay Men, HIV/AIDS and Social Research: An Antipodean Perspective. In: Aggleton, P., Davies, P.M. and Hart, G. (Eds.). AIDS: Rights, Risk, and Reason. pp. 1-12. London and Washington.

Grau, G. and Herrn, R. 1989. Memorandum der AIDS-Hilfe DDR. Berlin: AIDS-Hilfe DDR.

van Griensven, G.J.P., Tielman, R.A.P., Goudsmit, J., van der Noorda, J., de Wolf, F., de Vroome, E.M.M., and Coutinho, R.A. 1987. "Risk Factors and Prevalence of HIV Antibodies in Homosexual Men in the Netherlands." American Journal of Epidemiology 125: 1048-1057.

Hengelein, H. and Höpfner, C. 1990. "Die AIDS-Hilfe." In: Jäger, H. (Ed.): AIDS und HIV-Infektion. Diagnostik, Klinik und Behandlung. Handbuch und Atlas für Klinik und Praxis. XI-8. Landsberg: Ecomed.

Kiehl, W. 1990. "Zum Ablauf der HIV-Epidemie und zur AIDS-Prävention in der ehemaligen DDR." AIDS-Nachrichten 5/90: 14-18.

Koch, M.A. and Schwartländer, B. (Eds.) 1990. Multizentrische prospektive Kohortenstudie zum erworbenen Immundefektsyndrom. Zwischenbericht 10/89. Berlin: AIDS-Zentrum im Bundesgesundheitsamt.

Marcus, U. 1990. "AIDS im vereinten Deutschland – droht mit der Angleichung der Lebensverhältnisse auch eine Angleichung der AIDS-Verhältnisse?" AIDS-Nachrichten 5/90: 1-10.

Michel, S. 1988. HIV-Antikörpertest und Verhaltensänderungen. Literaturstudie. Berlin: Veröffentlichungsreihe des Wissenschaftszentrums Berlin für Sozialforschung.

Pollak, M. 1988. Les homosexuels et le SIDA. Sociologie d'une épidémie. Paris: Editions A.M. Métailié.

Pollak, M. 1990. Homosexuelle Lebenswelten im Zeichen von AIDS. Soziologie der Epidemie in Frankreich. Berlin.

Pollak, M. 1991. AIDS prevention for men having sex with men. Final Report. Assessing AIDS Prevention. EC Concerned Actionon Assessment of AIDS/HIV Preventive Strategies. Lausanne.

Pollak, M. and Schiltz, M.A. 1988. "Does Volontary Testing Matter? How it Influences Homosexual Safer Sex." Abstract 6023. In: IV International Conference on AIDS. Stockholm. Vol.1: 359.

Pollak, M., Paicheler, G. and Pierret, J. 1992. "AIDS – A Problem for Sociological Research" In: Current Sociology. Vol 40, No.3: 1-117.

Prieur, A. 1991. Mann-männliche Liebe in den Zeiten von AIDS. Eine Untersuchung zum Sexualverhalten norwegischer homosexueller Männer. Berlin: AIDS-FORUM D.A.H. Vol. VII. Deutsche AIDS-Hilfe.

Rosenbrock, R. 1986. AIDS kann schneller besiegt werden. Gesundheitspolitik am Beispiel einer Infektionskrankheit. Hamburg: VSA-Verlag.

Rosenbrock, R. und Salmen, A. (Hg.) 1990. AIDS-Prävention. Berlin.

Vorstand der Deutschen AIDS-Hilfe 1991. "Vorschlag des Vorstandes für einen Beschlußtext zum Selbstverständnis." Deutsche AIDS-Hilfe Aktuell Februar 1991: 6.

GAY MEN AND HEALTH PROMOTION

Rainer Schilling, head of dept. "Homosexual and Bisexual Men", Deutsche AIDS-Hilfe

The concept for prevention of the Deutsche AIDS-Hilfe is based on the WHO Ottawa Charter for the Promotion of Health from 1986. The general aim of health promotion is to enable people to have a greater degree of self-determination with respect to their health and thus puts them in a position to improve their health. Health promoting measures affect the individual as well as the society and the environment.

In terms of the prevention of AIDS among gay men, this aim sets up some questions: First, what can we do in order to give gay men a broader range of behaviour patterns and more self-determination? Furthermore, how can we enable them to deal with the risks of HIV-infection, of sero-positiveness, and of the illness in such a way that they can achieve the best possible health? In brief, what can we do to increase the individual's ability to behave in a competent way?

The concept which helps to achieve this aim is named "structural prevention" by the Deutsche AIDS-Hilfe. This term refers, on the one hand, to the complex interrelation between personal contributions to health and the social environment, and, on the other hand, it includes primary, secondary and tertiary prevention.

What do we mean by "behaving in a competent way"? Literature differentiates between various types of social behaviour and various levels of behavioural orientation, which come together in individual behaviour and can compete with each other. The first printed media for homosexual men relied on providing knowledge or just giving the message of safer sex. They were thus designed to reach the level of rational behaviour. The idea behind was that knowledge and standardized messages given with a certain frequency would automatically lead to a change in behaviour. We know, however, and not only since the relapse discussion, that the stimulus-response model does not do justice to sexual reality.

Our aim is to reinforce the behavioural patterns and values which facilitate more self-determination for the individual. Here we must always bear in mind that behaviour in a given situation is the result of competing needs, techniques and risks. The prevention dilemma, for example, "consists of weighing up health against sexual impulse, the conscious control of sexual intercourse against the way a person sees himself in terms of his sexuality, the risk of infection against that of loneliness." (Michael Pollack, Homosexuelle im Zeichen von AIDS, Berlin 1990, p.106, translated from German)

What values should be reinforced in prevention, and what is the greatest obstacle when it comes to self-determination in the behaviour of homosexual men? Is it inadequate self-acceptance, or an impaired identity, feelings of guilt or shame, or homophobia?

Regardless of how we want to describe it, it leads in the final analysis to the well-known motto: emancipation is prevention. The D.A.H. concept for prevention among homosexuals was from the very start emancipationary, and aimed at providing a positive feeling about the homosexual world and individual lifestyles. Identity and self-esteem are essential prerequisites for the acquisition of the ability to behave competently. Homosexual sexuality must be promoted both on the rational and the emotional level and the tendency to withdraw from sexual activity must be counteracted, particularly because self-esteem is so closely linked to sexuality in the case of homosexual men. This is by no means just applicable to men who have been tested as negative or not tested at all.

The prevention campaign of the Deutsche AIDS-Hilfe for gay men does not exclusively aim at preventing each and every new infection. The goal is to increase health promotion for both men with HIV/AIDS and men at risk. While prevention in its traditional sense relates only to potential disorders and deficits, health promotion relates to a new quality of life on the individual and the community level.

The promotion of a social atmosphere which is positively inclined towards homosexuality is an essential part of structural prevention. The fight against section 175, and getting rid of the classification of homosexuality as an illness are equally important. Acts of aggression against homosexuals and the subtle everyday discrimination must also be combatted.

Our concept for prevention is implemented in two different ways. On the one hand, we use various media, e.g. pamphlets, posters, post cards, educational material, give-aways like beer mats, matchbooks, T-shirts and video-tapes, among them safer sex video clips and a porn strip. Since the media portray homosexual lifestyles and gay sexuality without taboo, they can easily cause offence to the general public. However, we cannot do without being open. Printed media of this kind do not only help to convey the message of safer sex to the subgroups of homosexual men but also build up the self-esteem of the individual belonging to one ore more specific gay scenes.

We are, however, aware of the fact that printed media are not enough to achieve our aims in prevention. Even a poster with the strongest message, or a brochure which has been designed in the best didactical and methodical way possible can only be effective for a short period of time, if they are not supported by other means of communication. That's why we also employ personal communication, e.g. in streetwork at gay locations, in the local AIDS self-help organizations, in discussion evenings, and safer sex workshops.

Our concept for prevention differentiates between the following target groups: coming-out homosexuals, leather men, bisexuals, sado-masochist homosexuals, promiscuous homosexuals, closet homosexuals, disco-goers, large town homosexuals and country-side homosexuals. In our posters, we also differentiate according to the places of sexual and social encounters: pubs, discos, pick-up spots, parks, saunas. Some posters are restricted to different forms of

sexual play or partial aspects of sex: kissing, oral sex, fist fucking, sado-masochism, rimming (in preparation), golden shower (in preparation).

Other posters promote the idea of solidarity, or are aimed at counteracting the exclusion of people with HIV and AIDS.

In the ideal case, our posters have three important aspects:

- a message about safer sex,
- the presentation of a sexual situation,
- the presentation of a specific target group, and/or a specific place.

The importance given to each of these aspects varies from poster to poster. It should be clear why we produce very few or indeed hardly any posters at all for homosexuals in general as target group. Such posters would not achieve what we are aiming at, i.e. promoting the individual's ability to behave in a competent way by improving his self-esteem.

Our printed media are distributed in homosexual meeting places. This way, we can reach many homosexuals: those tested as negative, the untested, and those with HIV and AIDS. All these gay men are appealed to in most of our brochures and leaflets which convey specific messages and information.

Since our posters and brochures also carry messages about primary prevention, the objection could be made that they are thus hardly suitable for reinforcing the self-esteem of homosexuals who are HIV-positive. This must not be the case. Given that we have interpreted the feedback correctly, we can assume that our posters at least lessen their feelings of guilt and shame resulting from the stigma of being homosexual.

It is evident that a successful homosexual coming-out and a self-assured homosexual identity are the prerequisites for coming-out as an HIV positive. On the basis of recent research we also know that there is a correlation between identity and survival time and between identity and making use of the available health care facilities. For us, this is unmistakable proof of the importance and necessity of work aimed at reinforcing identity, since this work does not just solely have an effect in primary prevention.

Another aspect is pointed out by Martin Dannecker in his new book: "... even the mildest threat of punishment expressed to people infected with HIV and ill with AIDS by their environment may trigger off a severe psychic crisis. Such a crisis cannot be coped with other than by assigning a value to homosexuality, i.e. a 'revaluation' of that which is experienced as being reprehensible." (Martin Dannecker, Der homosexuelle Mann im Zeichen von AIDS, Hamburg 1991, p.92)

Through our accepting approach, we can give help towards coping with a crisis. All our material and communication offers are aimed at upgrading homosexuality. It should be mentioned that any censorship can increase the feeling of inferiority and must therefore inevitably have an effect on primary, secondary and tertiary prevention.

It was explained that identity and self-esteem are essential prerequisites of the ability to behave competently. This means

- being self-determined in sexual contexts,

- being able to deal with the risk of infection,
- being able to deal with being seropositive,
- being able to deal with the illness.

Obviously, this is more than just preventing HIV-infections. No doubt, identity and self-esteem are necessary to prevent other diseases as well, particularly STDs. It is evident, that reinforcing identity is the prerequisite for gay men's health promotion in general, not only focussed on AIDS. Considering the WHO-definition of health, it could be said, that there is no gay health without gay identity.

As Ursula Lehr, Health Minister at that time, expressed it at the 3rd German AIDS Congress (on 25.11.1990): "It is a matter of making people feel that their life is worth living and helping them to see that there are positive ways of organizing their lives in the future. Only those people who really have a positive attitude towards their lives are motivated to protect their health."

This must be the gay community's perspective. We have to discuss the ways of how to establish structures and organizations for gay health promotion.

"HARM REDUCTION" AND THE POLITICAL CONCEPT OF THE "WAR ON DRUGS" IN GERMANY

Ingo Ilja Michels, Dr. phil., co-director, head of dept. "Drug Users and Prison Inmates", Deutsche AIDS-Hilfe

Although highly dependent on the respective governments and their health and drugs policies, drug service organizations have started to examine their own role within the system in a critical way, particularly in the light of the pressure resulting from the worsening AIDS crisis among drug consumers and the developing self-help organizations and competence of those affected.

The idea of abstinence and the method of long-term therapy remained decisive pre-requisites in treating opiate consumption until the late 80s, whereby use and addiction were seen as being synonymous. The amendments to the Federal Narcotics Law in 1972 and 1981 led, as Bossong put it, to a sort of "neo-corporative system of addiction control, the structural core of which lay in a close intertwining of political intentions, institutional and professional interests and administrative decisions; ... opponents and alternative methods of treatment, discourse accepting addiction and against prohibition were systematically excluded" (Bossong 1991).

It was the AIDS crisis which first led to a revision of the prevailing drug policy, and then only very gradually and in the face of massive resistance.

Total acceptance of the old concepts started to falter with regard to two aspects, not least also due to the work of the AIDS service organizations:

- the question of using Methadone as a substitute for heroin – a form of treatment which was still strongly opposed and prohibited in Germany till 1987;
- the question of distributing sterile syringes to intravenous drug users.

There is still much resistance in both cases, although it has weakened and is now presented in a different way. The main arguments inevitably amount to the reproach that thus addiction is prolonged and given a pharmacological basis.

Up to now, the Federal Government and the responsible Federal Departments have without reservation taken on this point of view. The so-called "National plan for combatting drugs", which was passed by the government in June 1990, is in line with this tradition. This plan was introduced with pathos in a declaration by the Federal Chancellor Helmut Kohl: "... the fight against the misuse of drugs is an enormous challenge for all democratic systems within society." (Kohl 1990)

Preventive measures are hardly understood as a social or socio-cultural matter. Although it has long since been proven by the social sciences that

preventive strategies which are based on the idea of fear are ineffective, millions of DM are spent year by year on such "educational programmes" with the main idea of "... creating a climate, which energetically counteracts the glorification of drugs and the playing down of illegal drugs, while at the same time also decisively opposing the stigmatization and exclusion of addicts." (National plan for combatting drugs "NRB", p.19).

This amalgamation of punishment and help in one model is apparent throughout the plan of the Federal Government, and is permeated with war metaphors on the one hand, and charitable attention on the other. Furthermore, the government declared its intention to initiate the following:

- ratification of the new UN Addictive Drugs Agreement of December 1988;
- confiscation of property or fines for serious cases of drug trafficking;
- making money laundering a criminal offence;
- extension of investigatory methods to the police by using under-cover investigators, under-cover observation, technical means and computer based networks of information (all within the competence of the police and also used to combat terrorism).

Moreover, the Federal Government does not only plan to extend the access to "organized crime", knowing very well that the possibilities of really getting to the "dirty money" of the large dealer organizations or of confiscating their assets are extremely small. They are estimated by experts advising the Federal Government to amount to perhaps five percent of the assumed total profits in illegal drug trafficking (Albrecht 1990). The government also plans to combat street dealing, particularly small deals involving heroin, and to destroy the open scene, even though, particularly for an effective AIDS prevention, access to the open scene is extremely important. Furthermore, prison authorities are to be provided with more personnel and equipment, specialized public prosecution is to be institutionalized, the Federal Bureau of Criminal Investigation (BKA) is to get 400 more civil servants, and the customs, too.

In the Federal Republic of Germany, drug users are subjected to a legal system which is based on a mixture of punishment and assistance. The principle of "therapy instead of punishment" is firmly established in the Federal Narcotics Law. Drug addicts who are sentenced to prison can, under certain conditions, be treated in a therapeutic community instead of going to prison.

What in brief has been the experience with this principle? The number of consumers is estimated to be between 60,000 and 90,000. The number of people who start taking drugs, particularly heroin, has increased in the last few years and amounts probably to 3,000 or 4,000 persons per year. It is difficult to estimate how many people stop taking drugs. There are approximately 3,000 places available for treating people in therapeutic communities or psychiatric clinics. Per year, about 9,000 drug consumers make use of drug therapy, up to 70% are forced to do so by law. About 70% drop out of treatment. Of the remaining 30%, about 1/3 remains off drugs completely. About 10,000 drug consumers are in prison every year, that is to say between 15 and 50% of the total prison population.

The concept behind the 1981 amendment of the Federal Narcotics Law, which was aimed to deter dealers and encourage drug users to undergo therapy, has failed. Even the Federal Government admitted this in a report on the administration of justice according to the Federal Narcotics Law in the years 1985 to 1987: in these years, the number of criminal offences against the Federal Narcotics Law which were investigated by the police rose drastically from 60,000 to 75,000. Recent statistics say that nowadays about 90,000 investigations are carried out. The number of criminal proceedings has also increased from 25,000 to 30,000 per annum. Of these, two thirds are in connection with the so-called basic offences, in particular acquisition, possession and dealing for individual consumption. Wholesale trading only plays a role in 9% of the proceedings, and "dealing by gangs" in just 1/2%!

About 3/4 of the proceedings are in connection with offences where cannabis is involved, 80% of which are then finally dropped. However, people who have been addicted for many years are always more severely punished for quite minor offences. In the meantime, there are about 20,000 long-term addicts who are socially despised and destitute, and more than 30% are HIV positive or ill with AIDS (the prevalence of HIV is considerably lower in therapeutical institutions and on average, it totals 10-20%).

The debate about the direction drug policy should take has been rekindled against this background and cuts across all political parties, although with some clear differences. The Conservatives adhere to a very strict rejection of anti-prohibitive demands. They are against a decriminalization and view the concept of "harm reduction" with scepticism. So, for example, the Deutsche AIDS-Hilfe was recently put under pressure to withdraw its new series of posters for intravenous drug users with the messages "safer use" and "safer sex" which were financed by the Federal Government. The reproach was that they would present illegal drugs as being "harmless" and clearly show a basic attitude of acceptance which could not be promoted with public funds.

The Social Democrats have also so far not taken a consistent position, and have only spoken in favour of a cautious opening up of attitudes towards a liberal drug policy. However, particularly due to the PR activities of the Young Socialists (the young people's organization of the SPD), there has been a clear trend towards a change. The working group on drug policy of the SPD members of the Bundestag has proposed an amendment to the Federal Narcotics Law which takes up to a large degree the longstanding demands made by the critics of a repressive drug policy. In the amendment, the SPD demands:

1. the extension and clarification of the permissibility of treatment with substitute drugs (in-patient and out-patient treatment);
2. investigation into the administration of original drugs;
3. clarification concerning the legality of providing single use syringes, and the setting up of so-called "shooting rooms" where drugs can be injected under hygienic conditions and with medical assistance in order to avoid the risk of HIV infection or an overdose;
4. improved possibilities for dropping legal proceedings (which is, for example, typical in the Netherlands: according to the "opportunity principle", the police or public prosecutors can drop proceedings; thus offers of assistance can be used of one's own free will;

5. refraining from criminal proceedings in accordance with the principle of "helping instead of punishing", and dispensing with the so-called state evidence ruling, which grants mitigation of sentences in cases where others are incriminated, but has not to any extent led to gaining access to the large dealer organizations – indeed, it has solely led to an atmosphere of less solidarity among consumers.

At a hearing of the Bundestag Health Committee on 4th December 1991 on suggested reforms to the Federal Narcotics Law, the majority of the invited experts, including myself, pointed out that it is absolutely essential to decriminalize drug consumers. My statement was as follows:

"Unfortunately, we have begun to intensively discuss decriminalization and the improvement of the living conditions only in the light of the spread of HIV and AIDS among drug consumers ... Of all people with HIV and AIDS drug consumers get the worst medical treatment and care. To them maintenance treatment can be a very important element of assistance and support. This we have concluded from studies and also experienced in our practical work. We have many contacts to the local AIDS-Hilfe organizations as well as the self-help groups of those in maintenance treatment, and to drugconsumers. The living conditions of these people have been improved considerably thanks to Methadone maintenance. This is an indisputable fact. Maintenance treatment also stabilizes the immune system, as was shown by studies from the Essen Clinic which were presented at the VII. International Conference on AIDS in Florence. Whether this results from the opiate or the improved living conditions is not yet clear and needs further discussion. But in either case maintenance treatment is concrete help for survival." (Uncorrected proceedings of the 20th Session of the Health Committee, 4th Dec 1991; Public Hearing on the Draft of a Law to Amend the Federal Narcotics Law; Drucksache 12/934)

For the first time in the history of the Parliament also a drug consumer answered questions in this hearing – namely my colleague Werner Hermann, co-ordinator of the self-help initiative JES. He commented:

"To give you an idea of the importance of Methadone programmes, let me say something about my personal history. I think it is representative, because during my work in the self-help group JES as well as in the German AIDS-Hilfe I have daily contact with people who are still in the drug scene. To my person: Four years ago, there was a police warrant out for my arrest. I had several abscesses on my legs, and no flat. I went to the AIDS-Hilfe and then into hospital. Finally, the AIDS-Hilfe found a place for me in a Methadone programme. Since then, my life has changed completely. I had been a no-good for twenty years. I had not been on the edge of the drug scene, as you might perhaps think, but in the midst of it. I had stolen, I was a dealer, a fixer. The fact that I am here with you now and that I do this work really means, of this you can be sure, that my life has changed. I don't steal anymore, I am a normal tax-payer, I go to work at the AIDS-Hilfe, and in the last one and a half years, I have not been ill for one day. Before I die of AIDS, and I have been infected for 10 years, I have found something, namely this self-help for people suffering the same fate, which gives meaning to my life. This is a tremendous gain for me towards the end of my life.

Like most people I don't want to be a no-good, and I am very happy that I got the chance to manage my life in a different way. I owe it to Methadone ... I think, there is no chance anymore to find a solution for the problem of a minority numbering some millions in Europe – namely the minority of drug consumers, particularly the intravenous drug consumers. If you include Russia, if you include the former Eastern Bloc, if you include southern Europe – they are millions. In this Europe of political change, a role must be found for these people different from the traditional one. That is what we demand. Human rights are rights for us, too. The key problem is that we are deprived of these rights by law when we are jailed or incapacitated in psychiatric institutions. Therefore, everything leads to the question: Is the European and international community of states prepared to redefine this problem, to really abolish the laws and the prohibition, and to control the drug problem from the producer countries through to the demand? This would mean the elimination of the organized international crime. This would certainly not end drug use, but it would be an opportunity to involve those affected in the solution of their problems. I am sure you believe me when I say that it is not possible at all to find a solution to these problems without those who are affected." (Uncorrected proceedings/ibid.)

Just recently there has been a resurgence of the debate on drug policies. On the one hand, politicians, lawyers and drug workers have demanded a revision of repressive drug policies, on the other hand, the courts in Lübeck in Northern Germany have caused considerable controversy by arguing that it was unconstitutional to punish the consumption of the largely innocuous drug hashish (cannabis) while the consumption of dangerous drugs like alcohol and nicotine remains unpunished. The citizen has a "right to euphoria".

This decision caused a fierce public debate (see "DIE ZEIT" of 28.2.1992). In the well-known German weekly magazine "DER SPIEGEL" of 2.3.1992, the Bavarian minister of the interior Stoiber was quoted: "Those approving the free use of cannabis are irresponsibly accepting the deaths of thousands of young people." But it was also noted that "Many social democratic politicians in the German Länder no longer support the war on drugs with excessive police armament, legislation and powers for law enforcement agencies."

For several years, workers in AIDS and drug counselling as well as the self-help groups of junkies have been trying to organize and improve the living conditions of drug consumers and to offer appropriate AIDS-specific prevention work by establishing contact centres and syringe exchange projects, supporting Methadone treatment, and demanding "shooting rooms" where intravenous drugs can be consumed under hygienic conditions. There are still structural barriers, such as special police operations to smash drug scenes, as was the case in Bremen, Hamburg or Cologne, where the police even made arrests in the contact centre.

Now I would like to go into the epidemiology of the AIDS crisis among intravenous drug consumers which is the result of the obstruction to structural prevention before documenting some models of acceptance-oriented AIDS and drug help. In this outline of the current situation of HIV prevalence among intravenous drug consumers in Germany I refer mainly to data collected by Ursula Koch between July 1990 and March 1991 as part of a research project for the German AIDS Hilfe which was published recently:

- The random sample had 64.2% males and 35.8% females.
- The women were on average younger than the men.
- The level of education was below the national average, for the females relatively less so than for the males.
- More than one third had acquired a vocational qualification.
- The majority were single.
- The females lived more frequently together with a partner or friend, males more frequently in institutions (especially the 26 to 30 years' olds). The 15 to 20 years' olds were particularly often without fixed abode and lived more frequently in hotels/hostels.
- Main sources of income were, for males: state support and "illegal" income; for females: state support, parents/relatives/friends and prostitution.
- More males had custodial experience and for a longer total period.
- More than two thirds lived in conurbations.
- 43% were classified as belonging to the public scene, 37% to the private scene, 20% were in neither, or lived in institutions.
- Overall HIV prevalence was 19.6% (21.8% for females, 18.4% for males)
- The higher HIV prevalence for females was closely related to prostitution.

Features, HIV-Prevalence and Sex

Feature	Males	Females	Total
Sample	21.8	18.4	19.6
Scene			
Public scene	18.8	15.7	16.8
Private scene	22.2	19.7	20.7
Neither/institution	27.8	21.6	23.4
Experience as prostitute			
At present	36.2	35.3	35.9
Not at present	38.3	25.0	33.8
None	8.4	17.1	14.9
Prison experience			
Yes	35.6	19.8	23.7
No	11.5	13.8	12.5

If we assume that of the estimated 100,000 intravenous drug consumers some 20% are HIV-positive (i.e. 20,000; c.f. the conservative estimate of the Federal Health Office which puts the figure near 10,000), then the data available show that the HIV prevalence in drug-free therapy institutions is presently between 5 and 15%. The rate is two to three times higher in the open scene and in prisons. Given some 9,000 drug addicts in in-patient therapy annually, then at present perhaps between 400 and 1,400 of them will be HIV-positive. Between 1,500 and 3,000 HIV-positive drug consumers are to be found in German

prisons according to the available estimates of HIV-prevalence and figures from the authorities. However, the majority – between 60 and 90% – is to be found in the private or public scene, and they are either reached through the contact centres or by self-help groups, or else live without any support. Finally, several hundreds are in treatment in clinics for serious AIDS-related illnesses.

The challenge facing the public health services is very clearly demonstrated by these figures. And the maintenance treatment with Codeine (Remedacen) and /or Methadone (L-Polamidon) is an essential prop of assistance in this field. At present, some 3,000 intravenous drug consumers in maintenance treatment use L-Polamidon and some 5,000 Codeine.

This data correlates with the results of a study by Kleiber/Pant of the Social-Pedagogic Institute in Berlin (SPI) who, although concluding that there was no statistically relevant change in the sero-prevalence of HIV among drug consumers between samples in 1988/89 (17%) and 1990/91 (16.3%), observed a marked divergence between the therapy groups and non-therapy groups: "Even in the first survey in 1988/89 a higher HIV prevalence could be observed in the non-therapy area (public and private scene: 20.3%) than in the therapy area (out-patient and in-patient: 15.4%). This difference has increased considerably according to the data for 1990; for the non-therapy area a prevalence of 27.4% was determined, against 7.6% for the therapy area."

Kleiber and Pant conclude: "The increasing divergence of the HIV prevalence between junkies in therapy and junkies in the public scene requires the establishment of low-threshold secondary prevention measures (street workers, medical and psycho-social counselling, supervised accommodation projects) since obviously many HIV-positive drug consumers prefer a life in the public scene to the problematical prospects of an HIV-positive ex-drug consumer with no job, no flat and no social network." (Kleiber, D & Pant, A.: HIV-Prävalenz, Risikoverhalten und Verhaltensänderungen bei i.v. Drogenkonsumenten. Ergebnisse einer sozial-epidemiologischen Studie; Berlin 1991)

What are the HIV-relevant risk situations, what do we know about them, what changes can we observe, and what is the importance of in-patient treatment? If we look at the main routes of HIV transmission among intravenous drug consumers, namely needle sharing, drug sharing and unsafe sex, we find the following aspects: In Kleiber's as well as in Koch's study we find that needle sharing is declining as a relevant HIV transmission risk, but is still practised by some drug consumers. But we must be careful to avoid generalizations. We can certainly assume that this mode of transmission is known to virtually all drug consumers in Germany. Nevertheless, in the Koch study 56% report that they still share syringes (26% rarely (7x), 15% sometimes (27x), 9% frequently (144x), and 6% very frequently (260x)).

According to this study, habitual needle sharing is frequent in institutional frameworks. This finding indicates that drugs are still consumed under conditions where they are forbidden or tabooed (e.g. in prison or therapeutic communities). Habitual needle sharing was also linked to the availability of syringes, especially at night, on the weekends and in institutions. Moreover, it is frequent in stable partnerships or among good friends. This shows that the network of syringe supplies is still inadequate and that the criminalization of

drug consumers stronly impedes in the implementation of HIV prevention measures.

As far as drug sharing is concerned, the Koch study concludes that this "hidden" risk has been overlooked largely. In the sample 36% reported that they apply front/back-loading together with needle sharing (2% always and 7% often). Only 15% in both studies cleaned syringes adequately, although most of them said they use cleaning rituals (in particular washing out with cold or hot water) which they think to be sufficient.

Despite awareness of the HIV transmission risk through sexual contacts, regular use of condoms was found to be relatively low in both studies. The data show that there is still no adequate sexual counselling in the drug service system and that a fixation of the message merely on rational considerations is inadequate, because there are addiction dynamics and driving forces both in relationship to drug use and sexual behaviour, as well as emotional relationship patterns (e.g. a monogamy ideal) which counselling should take into account.

There is also a need for radical rethinking in health policies: In the "National Anti-Drugs Plan" of the German government a core group of 15,000 – 20,000 "long-term junkies" is mentioned. It is defined in negative terms as a group which "seduces" others to consume drugs. "The possessors of drugs are of interest to the police since they frequently deal on a small scale and can thus be multipliers of drug use ..." (Nat. Anti-Drugs Plan; ibid; p.33). But here it would be important to involve these persons in, for example, syringe distribution projects, using this potential for prevention. In a snow-ball system they could supply sterile syringes together with the drugs to private customers who do not frequent syringe exchange places of the public health system. This seems to be very important, since it is clear that the injection of drugs is basically a "private" act. In the Koch study, nearly 60% reported they use drugs "only or mainly in private", whereas only 12% do this "mainly" or "solely in public". In our study we mainly reached drug consumers in contact with the AIDS and drug service system. A study among the frequenters of the "Platzspitzszene" in Zurich has shown that even in this public drug scene some 40-60% of the irregular consumers had not yet come into contact with the AIDS and drug service system. 50 – 60% had not even come into contact with law enforcement agencies (Künzler, H: Analyse der offenen Drogenszene "Platzspitz" in Zürich. Sozio-ökonomische und medizinische Aspekte. Dissertation; Zürich 1990). Indications of a lack of attention paid to the "private scene" in the research is to be found in de Loor's study of Dutch Ecstasy consumers (de Loor, A: The drug XTC does not exist. A survey; Amsterdam 1991). This sector of consumers has as yet hardly been reached at all by the specialized services, although consumers of Ecstasy and cocaine need not be a target group, in the narrow sense, for AIDS-prevention messages (c.f. Cohen, P.: Cocaine use in Amsterdam in non-deviant subcultures; Amsterdam 1989, and also Waldorf, O/Reimann, D/Murphy, S.: Cocaine changes. The experience of using and quitting; Philadelphia 1991). Rather they should be informed about "hidden risks", for example by the media. It must be accepted that there is a side effect: the rational explanation of consumption patterns (cf. Dutch flysheet on Ecstasy) will also be received by non-consumers who may be

encouraged to try drugs. But firstly, this is almost always a one-off experiment, as with cannabis, and secondly, risky forms of consumption are minimized by clandestine use.

Practising doctors are very important in the system of HIV counselling and HIV testing for intravenous drug consumers. They are also important for prescribing and issuing "legal" opiates or opiate substitutes. Some 33% of the study samples received such drugs (of which 61% Codeine, 31% L-Polamidon), 80% from practising doctors and 7% through state programmes. Therefore, they are multipliers for information about methods to prevent HIV. This applies for less risky injection practices, which the doctors and medical personnel can be expected to know anyway, as well as the avoidance of HIV relevant sexual practices. It must be noted, however, that medical training does not provide adequate knowledge about drug use and addiction, about the pharmacology of opiates, opiate derivatives and substitutes, or about the psycho-dynamics of addictive behaviour. Neither does it train special abilities for non-directive counselling methods, particularly not for counselling on sexual problems, nor does it convey adequate knowledge about HIV and AIDS and their specific medical and psycho-social treatment.

Although persons seeking help react positively in particular to acceptance and to non-moralizing attitudes, practising doctors should nevertheless be used for counselling on behaviour relevant to HIV risks, in the context of an inter-disciplinary discourse between doctors, drug and AIDS service organizations and self-help groups. (In the study of Kleiber & Pant: HIV Prävalenz, Risikoverhalten und Verhaltensänderungen bei i.v. Drogenkonsumenten; Berlin 1991; for 62.6% of those questioned the doctor's surgery was a place of AIDS prevention; 92.3% made use of it; 84.9% found doctors credible, about the same as the values for streetworkers, 85.1% and higher than for drug counsellors, 79.3% and AIDS helpers, 77.3%).

Our study clearly shows that prisons are still the places with the highest risk of HIV-infection. A large number of persons in the sample had prison experience (71% of the males, 41% of the females). Particularly the males had spent long periods in prison – 1/3 between 2 and more than 5 years. Almost half of them continued using drugs in prison – 1/3 using heroin between several times daily and several times weekly. Therefore, it does not surprise that the HIV prevalence among former prisoners is twice as high as among persons without prison records, for women even more than three times as high.

This highlights an urgent need for HIV prophylaxis and for "safer use" programmes which, if no sterile syringes are provided, convey methods of disinfection. A model for this could be the procedure adopted by the Regensdorf Prison near Zurich. Here, all prisoners are provided with a "First Aid" kit containing disinfection material for syringes.

Without doubt, self-organization of drug consumers is the best measure to gain identity and to mobilize the potential for self-help and healing. In this field, there have been positive developments. For example, in the Koch & Ehrenberg study 47% of the sample reported they know self-help groups (49% of males, 43% of females).

Group known by (%) of:

Group	Males	Females	Total
Narcotics anon.	16	15	16
Junkie Bund	35	39	36
J.E.S	36	42	38
Local Groups	24	23	24
SHG AIDS Help	2	4	3
Name unknown	12	4	9
3 or more named	5	5	5

The best known were the J.E.S with 38% and the Junkie Bund with 36%. Both groups are better known among the females. Of those who said they know of one or more self-help groups, 24% said they themselves are active in such a group. We also asked about personal ideas to improve the living conditions and about urgent structural and social changes. Here, we found a high degree of agreement with the demands concerning AIDS prevention from the German AIDS-Hilfe (Ahrens, H.; Michels, I.: Drogen-Strategiepapier: Befunde und Strategien zur AIDS-Prävention im Bereich AIDS und Drogen. AIDS-Forum D.A.H., Vol. 1, Berlin 1988, p. 13).

Comments on some findings

1. The assessment of recommendations show gender-specific differences:

- Of the females not shooting at present, 69% said that "more out-patient therapy" is important (males 81%) and 39% "more in-patient therapy" (males 66%).
- A "more differentiated therapy" is important for more females not shooting presently (53%) than males (46%); similarly for female junkies (59%) as against male junkies (41%).
- The legalization of heroin is important for 68% female junkies (males 71%). This aspect is important for more females not shooting at present (44%) than males (41%).
- For female junkies the availability of injectable Methadone is less important (42%) than for males (50%)
- Among those not injecting drugs at present, counselling for "safer use" (57%) and "safer sex"(63%) is regarded important by less females than males (68% and 69% respectively). Females not shooting presently assess this aspect slightly higher than males.

2. Between drug consumers and persons who presently do not inject drugs the following differences can be identified:

- Out-patient supplies, more rapid availability of detoxication, more out-patient therapy, more in-patient therapy and therapy wards in prison are more important to persons not shooting at present.
- 87% of the persons not shooting presently think it important to support self-help as against 84% of the junkies.

- The instructions for "safer use" and "safer sex" are thought to be more important by persons who do not inject drugs presently (safer use: 65%, safer sex: 67%) than by those who do (safer use: 58%, safer sex: 53%).

The results of the study emphasize the demands raised in the "Memorandum on the present debate on drug policies in Germany" from June 1990:
"Structural prevention means to strengthen the ties which are still intact in the communities of people addicted to drugs and the drug scene..." Considering the current AIDS crisis among intravenous drug consumers (HIV prevalence 20%), "harm reduction" strategies must receive unprejudiced support and funding.

Syringe exchange/distribution programmes at drug and AIDS counselling centres.

Since the mid-eighties more and more drug and AIDS counselling centres have integrated the exchange or distribution of syringes in their work. The initial uncertainty about possibly encouraging the use of drugs with such measures has given way to an understanding that providing or exchanging syringes is a necessary element of protecting health and a survival aid in drug work. The experience of the last five years has shown that this measure does not contradict other offers such as out-patient care or therapy counselling. On the contrary, it offers the opportunity to extend the range of work, to establish contact with drug consumers who would otherwise stay away from counselling centres.

In some places the numbers of syringes handed out or exchanged has increased enormously (Hamburg, Bremen, Frankfurt/M). In other places there is still no effective service (Munich, Stuttgart), and in some cases these programmes have as yet only a symbolic function.

At most drug or AIDS counselling centres, sterile syringes are only handed over in exchange for a used syringe. If there is a high risk of being searched for used syringes by the police, as for example in Bavaria (e.g. Nuremberg) these are not required. The MUDRA drug counselling centre in Nuremberg distributed over 40,000 disposable syringes in 1990, either through streetworkers, their centres, or the only dispensing machine in Bavaria. In the first half of 1991, 18,500 syringes were distributed to the scene. 8,000 syringes and 4,000 needles were sold from the dispenser. A pack contains 2 disposable syringes, 3 needles and a MUDRA hygiene set.

The importance of a location near the scene for an exchange programme in cities has been demonstrated by GROS & BEST (1990). An exchange programme, based in a caravan at a central meeting point for addicts near the Main Station, was running well, but after being ordered to move by the local authorities the number of drug addicts making use of the programme declined significantly.

The KOMMUNALE DROGENPOLITIK/ Society for Accepting DRUG COUNSELLING in Bremen conducts a number of low-threshold projects with current intravenous drug consumers. In 1986 the public distribution/exchange of syringes was still observed by the police and sterile syringes were confiscated. In an action designed to draw attention to the supply bottleneck at the weekends (Schuller & Stöver 1989), syringes were distributed on Sundays. In 1987 a contact centre was opened, and the exchange of syringes was offered together with other services such as crisis counselling, first aid, accompaniment to doctors or hospital, social work, and legal counselling.

Attention is drawn to the importance of responsible disposal of syringes. Since 1988 visitors receive sterile syringes only in exchange for used ones. Every month some 10,000 syringes and 20,000 needles are exchanged. Recently, "Hygiene Sets" are also included in the exchange.

The problem of used syringes is central to the public discussion of syringe distribution. Since syringes are still often confiscated by the police, or used as an indicator for the consumption of illegal drugs, many drug consumers just throw the used syringes away, sometimes without putting the protective cap over the needle. Convenient corners for an injection near the point of purchase are also often places where children play, such as playgrounds, parks or entrances. Many children have hurt themselves on needles which has lead to a public outcry. There is a risk of infection, though probably less with HIV than with hepatitis-B. A number of receptacles for used syringes are placed around the quarters most frequented by the drug dealers and consumers. Handouts remind the drug consumers about a responsible way to deal with used syringes.

Until recently, the highest number of syringes was exchanged in Hamburg's contact centre "Drob Inn" – about 10,000 a day! Up to 800 visitors came into the centre. The "Drob Inn" then closed in March because police activities (checks in front of the entrance, raids on the scene near the Main Station, where the centre was located) severely hampered the work.

Syringe dispensers

Currently, some 60 syringe dispensers are integrated effectively in syringe exchange programmes in 35 towns and cities. A start was made in Bremen. The KOMMUNALE DROGENPOLITIK/ Society for Accepting DRUG COUNSELLING installed a dispenser for syringes and needles outside its centre in June 1987.

The dispensers are refilled almost every day and regularly maintained. Some 5,000 syringes and 10,000 needles are extracted every month. The income serves to finance specific running costs (packing costs for the syringes, labour costs, maintenance and repairs). None of the income is kept as reserves, and any profit is used directly for the drug addicts. Once a week there is a free breakfast spread at the contact centre, and visitors can also take free dressing materials if they have injuries.

In Berlin in May 1988 a first dispenser was installed at an urban railway station with the support of the district health authority and with the per-

mission of the transport authorities. Since then the self-help group "Fixpunkt" has taken on the operation of 7 dispensers, which are used up to 10,000 times a month. The group is working to establish the acceptance of the police and the neighbourhood for these measures.

In the largest German Land, North-Rhine Westphalia, the Ministry of Work, Health and Social Matters pledged support in 1988 for the installation of syringe dispensers. The original intention was to set up 25 dispensers in 12 towns, but since the Health Authorities and the AIDS Help were also willing to support the programme, in addition to the drug counselling centres, the number was doubled. The AIDS-Hilfe North-Rhine Westphalia received DM 120,000 from public funds for the installation of 50 dispensers.

At present some 40 dispensers are already in place, and a further 10 are planned. Some 3,500 disposable syringes and some 1,350 condoms are dispensed every month. A scientific evaluation of the effect of syringe distribution models in reducing the rate of HIV/HBV infection has not been carried out.

Bleach has not been included in the HIV prevention strategies in Germany, neither on a national level nor at the level of initiatives and self-help groups. Officially, bleach is not felt to be a 100% safe method (including for surface disinfection in hospitals etc.). For the counselling institutions it was always the inferior alternative and it has therefore never been intensively propagated, for example by being distributed together with precise instructions about how to use disinfectant without risk.

In the long-term all prevention strategies rely on the structural improvement of the living conditions of those affected, and this in turn requires above all the decriminalization of the consumers.

Recommendation at the IVth European Discussion on Education in Prevention of AIDS in the field of AIDS and drugs; 10 – 12 October 1990 in Bad Honnef, Germany:

"We recognize that the main aim of drug prevention strategies in all of Europe is to achieve drug abstinence, and that abstinence will reduce the transmission paths for HIV. We continue to support this strategy as a general goal. We also accept that drug addicts go through a number of different stages before they decide to take no more drugs. HIV education work and the appropriate prevention strategies must reach potential drug consumers and drug addicts in all stages of their "drug career". These strategies must therefore not obstruct abstinence and not stigmatize or alienate the drug addicts, which in the final analysis would make the message of this strategy ineffective."

Specific recommendations:
"Workers in drug and AIDS counselling should act on the assumption that drug consumers, as any other grouping, are not a homogeneous group. Therefore, programmes must be developed which not only take account of the need of women, young people and members of various ethnic groups, but which also reflect their cultural, social and linguistic background..."

Health campaigns should be developed, in co-operation with drug consumers, to encourage safe drug consumption and safe sex practices.

HIV and drug education programmes and health campaigns should not stigmatize the drug consumers, or alienate them from their social environment, but should respect their rights as citizens. HIV and drug education programmes should reflect the needs of drug consumers and their HIV status.

These programmes should encourage and inform about

- living without drugs
- handling drugs as safely as possible
- safer sex
- ways of living, such as nutrition etc.

The existing legislation and sentencing should not conflict with the aims of the strategy to improve health and health education and thus make it ineffective."

JES – HISTORY, DEMANDS AND FUTURE

Werner Hermann, JES coordinator

The continuing inadequacy of drug policies and a short history of JES

When drug users in the Federal Republic of Germany discuss their situation, they are in full accord on the following points:

We need a lobby, i.e. an association which will combat marginalization and official policies of prosecution and which will fight for our civil and human rights as well as promoting and representing our interests and seeing that they are put into practice.

Self-organization of addicts is only possible if criminalization and prosecution of drug users ceases, if a minimum level of existential security is available and also if group consciousness of the common lot of those concerned does not lose its binding force. These preconditions have developed in the last few years mainly as a result of drug substitution treatment using Methadone for heroin addicts. This has taken place due to the threat of HIV, AIDS and deaths resulting from the state's drug policy named "war on drugs". (In this connection mention should be made of already existing initiatives towards drug self-help projects.)

Solidarity of thought and action starts to arise as soon as we are able to free ourselves of being labelled criminals, as soon as the pressure inherent in the necessity to find some means of acquiring an adequate supply of drugs is relaxed, as soon as drug users are permitted to get substitute drugs (such as Methadone or dihydrocodeine) and as soon as we – as people in prison and as addicts in a crisis – are able to break out of our individual isolation. By this means links can be forged to movements directed towards realistic, more humane and acceptance-orientated approaches to drug work. Such approaches include those adopted by the Deutsche AIDS-Hilfe e.V., local AIDS-Hilfen, associations of progressive doctors and social scientists and professionals like the Deutsche Gesellschaft für Drogen- und Suchtmedizin (DGDS) and AKZEPT e.V. and some government authorities.

JES means Junkies, Ex-Junkies and Substitutees

The organization JES emerged as a campaigning group in the summer of 1989 from a seminar on the drugs and AIDS situation convened by the Deutsche AIDS-Hilfe (D.A.H.). This seminar acted as a meeting place for people in many different situations including members of self-help groups, persons who had suffered harm due to addiction or as a result of official drug policies, people with drug experience, addicts and former addicts, HIV positive drug users and substitutees on either codeine preparations (e.g. Remedacen) or, more often, Methadone.

In view of the fact that the AIDS problem is becoming more and more serious and that drug policies are such that the main emphasis is placed not on health care but rather on police operations and legally repressive measures, the intention of the founding members of JES was to respond with an authentic and competent lobby. The purpose of this interest group was to provide a means of articulation and representation for the demands of member groups and also for needs and rights which are common to everyone. An important factor for the legitimacy of this coalition of interests is that JES should become not only a mouthpiece for ex-junkies or substitutees but should transcend sectional interests thus giving greater weight to the demands shared by all the persons concerned in the struggle against drug-related impoverishment.

To this end, the approval and support of the D.A.H. as well as the regional and local AIDS-Hilfe associations are very important because of their endeavours to establish solidarity amongst victims and in particular solidarity which extends beyond sectional interests. This is needed primarily to ensure that the voice of the addicts concerned is heard. The competence of those directly concerned has hitherto failed to be recognized. Without the D.A.H. and the solidarity of other organizations and persons concerned, we are afraid that the launch and existence of our self-organization would be either ignored or suffocated.

In spite of imprisonment, in spite of therapy, in spite of self-cure and in spite of many thousands of deaths in the course of the years, the number of intravenous (i.v.) drug users and those addicted to opiates is thought to have reached 100,000 to 150,000. In addition to this there are thousands of ex-junkies who in various ways bear the stamp of their past.

The drug experience which is our common feature, the fact that there are almost 20,000 HIV-positives, the threatening wave of sickness amongst persons dependent on drugs, the fact that bureaucrats seem to be ignorant of our impoverishment and our real social and health needs, their indifference towards our civil rights and the rights of minorities, and finally the National Rauschgiftbekämpfungsplan (National Plan for Fighting Narcotics) which employs the same old unsuitable methods has brought home to us the present deterioration of drug problems as reflected in increased repression, in drug-related trials, in penal sentences and in imprisonment and compulsory therapy.

At the beginning of the 90's we experience drug policies as methods of circumventing aid for self-help, as encouraging repressive conditions of con-

trol, as promoting socially marginalized existences and as providing reasons for refusing prescription of opiates on ideological grounds. In short we consider them to be superficial cosmetic policies to cover up the fears of drug act enforcement bureaucrats.

The sacred principles of medical ethics and of public health policies which demand that people should receive treatment irrespective of their social position apparently do not apply to us. Although the life-prolonging and preventive effects of Methadone substitution for opiate users with AIDS have been proved in various studies both in Germany and elsewhere, prescription is in many ways restricted and Methadone is only available to about 2,000 or 3,000 IVDUs in the Federal Republic of Germany.

Some of the effects of drug policies as we experience them are as follows: Berufsverbot (which implies exclusion from all civil service professions by government ruling), prevention from integration in the labour market due to confiscation of driving licences and discrimination in our attempts to obtain jobs and flats. The peak of injustice inherent in drug policies is achieved where they are associated with discrimination of persons suffering from AIDS including: homelessness, imprisonment of persons who are terminally ill, promotion of dehumanizing conditions of polytoxicomania leading to a life-and-death situation stemming from the necessity to acquire the required drugs, unwillingness to provide provisions to facilitate withdrawal and refusal to prescribe substitute drugs because the particular indications do not accord with the preconditions for such schemes or due to the fact that HIV tests have turned out to be negative.

This summary still provides an incomplete picture of national drug policies at the beginning of the 90's. For example, no mention is made of self-help neither in the National Rauschgiftsbekämpfungsplan nor is self-help assisted more than as an alibi in regional concepts of drug-and AIDS help efforts.

The National Rauschgiftbekämpfungsplan creates hundreds of jobs for drug counsellors and 314 jobs for the police and prosecution lawyers. In contrast to this, mention should be made of the difficulties encountered to create just ONE job for JES coordination work. So much for the balance between repression and emancipation in present-day drug policies.

JES and its role within the Deutsche AIDS-Hilfe e.V. (D.A.H.)

The basis of JES are, of course, self-help groups at grassroot level: junkie leagues, groups of "substis" (substitutees), addicts and prison groups in various AIDS-Hilfe organizations as well as ex-junkies associations, not to mention Fixpunkt and Palette, two groups of substis in Berlin and Hamburg respectively who run day-centres with extensive facilities. More than 40 local JES groups and junkie leagues are active at the national and regional level.

We see ourselves as a coalition and mouthpiece for grassroot groups with the purpose of social emancipation of the drug using minority and preventing AIDS and discrimination against people with HIV/AIDS. We are financially

supported by the D.A.H. and embedded within the framework of the D.A.H. We are actively supported by the Department for Drugs and Prison Work.

As a network, JES avoids the burden of organizational work associated with registered associations. Every year a speakers' council is voted in which the speakers as the leading body of JES decide on activities.

A scheme of educational and organizational workshops is seen as the backbone of JES and provides the organization with permanent and temporary features which cover the whole range of tasks in public relations and in improving working conditions in our local groups, and in know-how of prevention and organizational matters. The network uses the training possibilities of the workshops and of exchange of local or regional experience. Below the national level at present three regionally oriented networks have developed.

Gay men in the AIDS-Hilfe movement have an advantage in experience and organization. The AIDS prevention concept developed by the D.A.H. for drug users as a target group is the outcome of a precise analysis of the needs and of real commitment to our problem. But it is as yet unfinanced. This method is however undoubtedly correct since help towards self-organization is the standard method of approach for the D.A.H. Nevertheless, our experience (as the second largest group of persons concerned) in various AIDS-Hilfe associations and in the D.A.H. makes it necessary for us to touch on the subject of equality which would still appear to be lacking within the organization.

An extract from the minutes of a meeting of members of the committee (06.01.1990) will show how we conceive working together. This three-year-old statement holds still the truth, while our organization grew by success and defeat during the last three years.

"All the participants are disconcerted and dissatisfied about the inadequate representation in the D.A.H. of former drug users, HIV positive persons and persons who are actually suffering from AIDS. Attention must be given to the day-to-day work and to support of the self-help project as well as to provision of personnel and funds... Our concentration was focused on the members' conference which took place on 17. and 18. February in Wiesbaden and on the election of a committee... The speakers should attempt to analyze the relationship between drug users and gays in particular with respect to policies of cooperation within AIDS-Hilfe associations, with respect to self-help projects, with respect to decision-making processes in connection with AIDS-Hilfe and with respect to distribution of funds and resources. A clarification of this relation aiming at equality must take place – and this must go beyond lip-service... Support often fails to go beyond the verbal level... We feel we occupy the role of simply being tolerated. Practical support is seldom forthcoming. We are merely petitioners within the AIDS-Hilfe organizations. Admittedly we are impeded in our actions by long years of illegality and we are weakened in our motivation towards self-determination. It is difficult for us to bring ourselves into line with the norms of the society. Since gay men are also detached from the norms of heteros, we naturally ask ourselves whether every deviation from social norms is treated in the same way.

Are we people who no-one is interested in apart from the police and drug therapists?

From our ranks, 15-20,000 are infected and/or sick or will become sick if they cannot find suitable treatment. All drug injectors are in danger of becoming infected. Prison or compulsory therapy is of no use to us whatsoever.

We got support for our self-help movement from men and women with drug experience. We organized ourselves as a self-help project within the AIDS-Hilfe movement and became independent in many ways and in the course of our projects. Apart from this we are basically not different from other people. We would like to live in peace and whenever this is applicable we would like to die with decency and dignity.

It is necessary for us to talk about a policy of coalition with the AIDS-Hilfe organization and with human rights organizations, with the networks and associations of other minorities, especially those affected by AIDS. Even on a European scale we need to develop mutual support and drug policy reforms in favour of legalization of illicit drugs, and with the purpose of recognition of our minority needs regarding the AIDS crisis and structural prevention of HIV/AIDS. We need coalition partners to become more capable of counteracting repressive AIDS policies and repressive drug policies. We would thus like to discuss our basic needs as people who are directly concerned in the AIDS-Hilfe organization. For this reason, we would like to make the following demands:

Two members of JES on the committee of the D.A.H. Representation at all levels of decision-making. Permanent positions and jobs for former drug users in the Department for Drugs and Prison Work.

A fair distribution of funds in accordance with the principle of the degree to which people are directly concerned and not just on the basis of numbers but rather as a group which continues to live for the most part in illegality and which should be approached primarily by the AIDS-Hilfe organization as consisting of persons who are sick, who are HIV-positive or who are homeless or prisoners or unemployed and who are addicts. The question of a fair distribution of funds also applies to incoming donations.

We demand generous treatment with respect to travel costs for our active representatives and we demand more support for Methadone and other substitution programmes. The AIDS-Hilfe should organize campaigns for exchange of needles, for the release of prisoners who are HIV-positive and for prisoners who are sick. It should also develop and establish housing projects and job creation projects within the AIDS-Hilfe organization..."

What is JES?

We are organizing ourselves, we are working on our concepts of AIDS prevention and self-help and we are attempting to make ourselves known in order to establish a firm foundation for a coalition of solidarity. As addicts and former addicts, we are proving that we are very able to work responsibly and continuously when we are not subject to pressure with respect to our addiction.

Since the start of the campaign four years ago, JES has run a series of seminars within the context of the D.A.H. These have been directed at the following subjects:

- AIDS and impoverishment in the drug scene and in drug policy
- Safer use and safer sex for drug users
- Self-help in the drug area
- Substitution treatment
- AIDS in prison
- The situation of the drug using population in Europe
- Solidarity between people with HIV and AIDS
- Unemployment and homelessness: Where is help?
- Anger and grief about discrimination
- Reconstruction of sexuality
- Harm reduction and survival in drug scenes

In the time between these seminars, a regular exchange of experience takes place in the speakers' committee. They report on the regional activities of self-help groups, they coordinate them and transform them into nationwide campaigs.

What does JES demand?

On the basis of the shared experience of everyday criminalization, of social exclusion and stigmatization on account of their addiction-orientated behaviour and of the common experience of dependence, JES is striving for:

1. Establishment of solidarity on the basis of self-help
2. Legalization and equality with other dependent groups (alcoholics, pill users)
3. Greater social acceptance of the lifestyle of drug users and ex-junkies.
4. A cultural, legal, socio-medical and, in the last analysis, political alternative to society's way of dealing with the needs and the problems of drug consumers, substitutees and ex-junkies.
5. Realization and recognition of the competence of persons directly concerned on the drug scene by drug and health politicians.

The organizational method of JES follows the principle of voluntary participation. Anonymity and solidarity are maintained in the interest of pluralistic representation of interests. In decision-making processes, our aim is to strive for consensus of values and interests when controversial positions and demands are discussed.

In practice this means that in spite of differences in the way values are conceived and the way we see ourselves in regional self-help groups, it is essential that we join together autonomously and in solidarity to assert our political interests.

Demands which have been worked out by JES on this basis and which extend beyond just sectional interests follow under the heading "reduction of drug related harm":

1. Decriminalization of drugs which have hitherto been illegal
2. Abolition of the BtmG (Illegal Drugs Act) as a routine or special law against illegal drug users.
3. Social and cultural normalization in dealing with problems of survival and the needs of drug users and ex-junkies.
4. Revision of past methods of combatting drugs. These operate as politically designed social and health care programmes which in fact only lead to impoverishment. For individual drug consumers and ex-junkies they are more liable to result in sickness than health. Instead, a drug policy under the heading "harm reduction and pro survival acting" has to be established and consistently applied.
5. Political support for and recognition of self-help organizations at all levels of use, i.e. during the early phase of the user becoming addicted and during withdrawal.
6. Recognition that drug users and persons with drug experience have basic rights including recreation for prisoners, access to drug assistance organizations and psychiatric and medical care.
7. Material, political and conceptual support of self-help projects in the drug scene with public funds, so-called no or low threshold project i.e. protected places for hygienic injection and medical first aid.
8. Recognition of the necessity for and funding of health-oriented preventive drugs as well as AIDS education in and by self-help organizations. There should be guarantees for projects organized by drug users, ex-junkies and substitutees to ensure provision of health care during drug dependency and drug usage phases.
9. Political and social measures for provision of free and protected premises for people who for long years have suffered prosecution and criminalization in the drug scene.
10. Recognition of the dignity of drug users, ex-junkies and substitutees and respect for their problems as well as aid towards solidarity.

Our goals and demands are most urgent where the crisis is most acute: on the drug scene, in hospitals and prisons.

The risk of HIV infection is highest where the burden placed on addicts and the sick is heaviest.

We demand:

No obstacles to AIDS prevention programmes, provision of clean needles also in prisons, prescription of substitution drugs for those dependent on heroin. We demand substitution treatment without "ifs and buts". This applies to the many persons on the scene who are waiting for Polamidon (Methadone) treatment but who have the "wrong" indications, for persons whose health is

seriously endangered, for persons who are not infected, for those harassed through the pressure of the need to acquire an adequate supply of drugs and for persons facing impending imprisonment.

Our demand is not for long-term experiments on people receiving substitution treatment in special programmes but rather for implementation through the usual health care channels with their capacity for easy distribution of substitution drugs.

The ruthless enforcement of prison sentences against drug-dependent or HIV-infected people must be stopped. We demand early release!

We demand that special AIDS departments in hospitals and all wards which accept sick intravenous drug users should examine their special regulations and should, where necessary, abolish them. It is not possible to build up mutual confidence where there are additional withdrawal complications or particularly inappropriate conditions resulting from unsatisfactory provisions for addicts. We demand that mistrust of drug users be reduced in hospitals. The climate must be improved.

Drug addicts with AIDS who require continual attention should be provided with accommodation to live together in special care projects. We share with them the horror of premature removal to homes or closed institutions. Where alterations are arrived at or where structural shortcomings render positive developments invalid, credibility will be generated because our demands will appear plausible.

We intend to realize these immediate demands through working groups, projects, campaigns and demonstrating our solidarity. These very concrete and urgent demands as well as humane and well thought-out AIDS policies for sick and infected drug users overlap time and again with the demand for a more humane, low-threshold and acceptance-oriented approach to drug policies. At these points partial improvements can be achieved only through structural alterations.

At these intersections, solidarity will be possible because of the pressing need for it. Fields of overlap include AIDS prevention and substitution programmes, decriminalization, assistance with self-help projects and release from jail.

Prospects for the future

For the self-help movement, drug substitution treatment for persons dependent on heroin is the key to further progress, because there are simply not enough people to work with us. We must forge alliances inside and outside of the AIDS-Hilfe organizations. The precondition for this is that we first establish contacts among ourselves and organize ourselves.

A growing number of drug consumers who are acting responsibly will only join us if they are provided with the most elementary human rights e.g. the right of a secure living which can only be established by decriminalization of drug consumption.

JES will only be able to achieve this in combination with acceptance-oriented drug policies and by becoming the mouthpiece for junkies, ex-junkies and substitutees. We need the support of the D.A.H. and other democratic organizations to achieve stage by stage victories in the struggle to gain our social rights and to obtain structural improvements.

In the AIDS prevention work carried out by JES we will apply our concepts of public education. Funding, media and their distribution will be organized in the D.A.H. Through this we will be able to present ourselves to the informed public and to become a partner inside and outside the AIDS-Hilfe. In addition to initiating further self-help groups, JES intends to build up an image based on these concepts of publicity and public information.

To widen the European and international scope of our work we gather information about harm reduction programmes and practices outside of Germany and establish links with foreign self-help groups. This way we want to organize further international campaigns. Particular attention should be paid to the international aspects of the War on Drugs. The co-operation with European self-help and non-governmental AIDS groups should amplify the scope of the drug users self-help and combine its efforts with international expertise and supranational institutions like EUROCASO and WHO. The Berlin Declaration of E.I.G.D.U. (European Interest Group of Drug Users) – ratified at December 1, 1991 – shows the common intention and direction of the drug users self-help movement towards acceptance and equality of the drug using minority.

The success of JES will above all depend on the persuasive power of its commitment. In spite of the manifold reasons for grief and in spite of sickness and impoverishment, self-help is oriented towards life.

Junkies, Ex-Junkies, Substitutees (JES)

JES is an association of junkies, ex-junkies and substitutees who wish to bring the skills and experience of those directly concerned to the fore and who demand recognition of their association by the authorities responsible for official drug and health policies. JES believes that drug users, like everybody else, have a right to human dignity. They do not need to earn this by abstinence and conformism. In addition they have the right to health care and humane living conditions.

JES wants improvements in the legal, health and social situation of drug users and ex-junkies in the Federal Republic of Germany.

JES wants decriminalization of people who take drugs.

JES wants access for drug users to information on health risks associated with their drug consumption.

JES wants both drug users and former users to be permitted to choose their own lifestyle.

JES wants recognition of the right to self-determination of drug consumers and ex-junkies and their right to self-organization.

JES wants health care for drug users. JES wants the risks of drug use to be reduced. SAFER USE!

JES wants improvements in help for drug users who want to stop taking drugs.
JES wants Polamidon (Methadone) substitution treatment to be freely available for heroin addicts. This is at present only available to two or three thousand persons in the Federal Republic of Germany with an estimated total of 150,000 intravenous drug users.
JES declares its solidarity with all persons with HIV/AIDS and needs their solidarity in return.
JES has its own point of view. "I am not prepared to take part in the legalization debate. People assume we are biased and hardly believe anything we say. JES must first become active, if it is to be asked to take part in helping to establish legality by self-help."
JES demands solidarity for drug users who suffer from political repression and from impoverishment.
JES demands to stop tabooing drug addiction and drug use in society.
JES wants social integration and help from society without any preconditions.
JES demands relief from needs.
JES wants to be a negotiating partner for dependent and formerly dependent drug users. We are committed and confident but we do not overrate ourselves. JES is still in its infancy.
JES wants the assistance of the Deutsche AIDS-Hilfe to reach both the drug users and society. JES wants drug users and ex-junkies to play a more important role in the Deutsche AIDS-Hilfe. Many of us are infected and many of us are already sick. In the end, if nothing changes, all of our dead will fall into oblivion.
JES is a political initiative and a network of drug consumers aiming at solidarity and self-help. JES is an umbrella organization for various groups and activities and intends to act as their common mouthpiece.

Contact with JES is possible through Deutsche AIDS-Hilfe, Dieffenbachstr. 33, 1000 Berlin 61 (new postcode from July, 1: 10967 Berlin).

THERAPY STUDIES, ETHICS AND DESIGN – INVOLVING DIRECTLY AFFECTED PEOPLE IN CLINICAL TRIALS

Matthias Wienold, Dr. med., head of dept. "Medicine and Health Policy", Deutsche AIDS-Hilfe

Introduction

In view of the power of the therapists, based on their knowledge of the possibilities of therapy, one of the fundamental goals of the medical tradition has been to limit the freedom of therapy by oaths, membership of schools, and the establishment of professional standards so that it loses the negative aspects of its power. The implementation of the various types of therapy, e.g. drugs, surgery, or other methods such as psycho-therapy is subject only to the ethical principles governing the physician's actions, and is seen these days as requiring the approval of the patient.

As a consequence of the Thalidomide scandal, legislation was introduced in most countries governing the introduction of new drugs. Medicinal trials of new therapies must be carried out under state control, reflecting as a mechanism of bureaucratic structures the caution of the controlling institution. People with HIV and AIDS (and others suffering from chronic and life-threatening diseases) see these protective measures as constraints on their free choice of medical treatment. No account is taken of the urgency and size of the problem of AIDS, in particular in view of the rapid development of the HIV-infection in individual cases.

The stages of multiplication of HIV in a typical infected cell are almost completely understood, and can be followed in vitro (in a test tube). Sequential and structural analyses have been made of the functional regions of important enzymes (reverse transcriptase and protease) and genes (tat), which make it possible to develop ideas of the spatial configuration necessary for a blocking substance. The systematic research for substances which are effective against HIV, using screening procedures and structural design can lead to a number of substances whose activity against HIV can be demonstrated in vitro. Tests with animals (mice, macaques, chimpanzees) can give an idea of the systemic effects of the substances. In addition to these experiments, toxicity tests are also carried out with various dosage levels. The two criteria of efficacy and toxicity determine whether a drug is ready to be subjected to a therapy study.

Various preparations are necessary before an experimental drug can be given to humans: a study design; the selection of a site for the study; and the avail-

ability of a suitable amount of the drug in a form in which it can be applied. In Germany a clinical study does not require the approval of a control body or an ethical commission. As a rule, however, an ethical commission is consulted in accordance with the Helsinki Declaration. Clinical testing of drugs is divided into four stages, investigating the tolerance (desirable effects in relation to undesirable ones), dosage and the efficacy. The point in time in the four phases at which a drug can be cleared for use depends not least on the level of proof provided by the results of the trial. In the regular course of testing and approval of a drug there are therefore logistic, technical and factual hurdles which must be cleared.

Problems of therapy research

Logistical problems can arise when those running a clinical trial operate in an area of research which is not familiar to them. Inadequate information can lead to misjudgments concerning the study group, the wrong choice of location for the trial, failure to take into account competing developments in therapy, or miscalculations of the effort involved. Technical problems arise from the inadequate galenicity of a substance, the non-standardization of a substance, the choice of an unrepresentative study group, or even the inadequate reproducibility of a procedure. Profit orientation is also a questionable "normal" state when it leads to a restriction of the availability of the therapy procedure. The hurdles are particularly high when patients are excluded because of their sex, lifestyle and age.

The demands placed by people with HIV and AIDS on the clinical research for therapies for their condition are in part due to the fact that nothing is as yet available, so that individual hopes are directed towards progress. No less important, however, is the understandable anger when bureaucratic and seemingly pedantic processes hinder the release of drugs, or when the sorts of mistakes mentioned above lead to funds being wasted which could otherwise be used for promising research.

The cooperative design and implementation of clinical studies can simplify the research work. At the same time the integration of the interests of a study population leads to a greater practical relevance, which in turn helps to project the image of humane research.

Please be patient – community involvement in clinical studies

Seven years ago, when I began to work within the framework of AIDS-Hilfe, medical science had little to offer in the way of therapy for the treatment of AIDS. Some progress had been made in the diagnosis of individual opportunistic infections, so that therapy could begin earlier, but in 1986 there was no talk of prophylaxis or antiretroviral therapy.

Although the inadequacy of the therapy was demonstrated clearly enough, the doctors and scientists nevertheless succeeded in dominating the discussion

about AIDS. Their approach to the problem of AIDS was often marked by damage limitation and breaking chains of infection (isolation, behaviouristic methods of condomization, banning and avoiding) or by exaggeration (generating hysteria, prophesying doom). The only really realistic approaches to dealing with AIDS which addressed the actual situation of the people with HIV and AIDS were introduced to Germany from the USA.

Whereas in Germany HIV research concentrated on the virus (and some excellent work was done on the virus morphology), the clinical research merely plodded along. It is truly shameful to see the time which medical researchers and clinicians spent arguing about the prevention and epidemiology of HIV, while at the same time proving unable to share information to create even a remotely accurate picture of the numbers of patients they were treating. But it is precisely this open exchange of experience which can provide the basis for planning joint strategies. Thus the majority of centres and service institutions did not have the slightest chance of discussing on a sound basis the experience they gathered. A profound impression remains, for example, of the competition for the most graphic colour photographs with which to depict both the experience in handling AIDS and its terrible reality.

As a consequence, treatment was completely individualized without establishing standards; medical treatment was not subject to discussion either by patients or by colleagues. People with HIV and AIDS were reinforced in their role as victims, and the formation of "schools" of treatment was encouraged. Notorious examples are the argument about the so-called "Frankfurt Definition", and more recently the incredible variety of opinions about the primary prophylaxis of toxoplasmosis. The predominant belief was that if only a centre was large enough, it would be able to meet all expectations for the development of a drug. The number of patients in the clinical studies, however, were so small that any critical discussion of the results presented was out of the question.

In 1988, this situation was suddenly disrupted by the announcement of a drug which was supposed to offer a considerably improved prognosis for AIDS. Belief was strong, but there was little actual experience. The result was disagreement, left and right. Instead of seriously addressing the questions of the patients and self-help groups, the only answer was "You will just have to believe me!"

This attitude only began to change in 1989, when the publication of the results on prophylaxis for pneumocystes carinii pneumonia (PcP) demonstrated that the large university apparatuses at an American university did not necessarily produce the better results. A group of practising physicians had asked themselves if a common approach might help to solve common problems. The most pressing problem for treatment was the PcP, and so it was decided to develop a prophylactic strategy. The success of this train of thought demonstrates how much the pragmatism of the approach can affect the relevance of the results. Under American liability legislation the doctors carrying out this study were under much greater pressure to keep their patients fully informed than scientists would be. This pressure is probably the reason why, for the first time, they attempted to integrate the people with HIV and AIDS in their studies right from the beginning, in what they referred to as 'community-based research'.

What developments had there been meanwhile on the part of the people with HIV and AIDS?

The discrimination showed no signs of ending. After a wave of hysteria had spread through Germany, things had become a little calmer. Many of those involved assumed that sooner or later the sickness and death would give rise to compassion and sympathy. As if the threat of death were not enough, in 1987 the Bavarian Government took a step which was to cause lasting damage for people with HIV and AIDS, and also those who placed themselves at risk. State intervention, carrying the message that those infected with HIV were bad, dangerous and should be excluded, put an abrupt end to dealing openly with the HIV infection. It placed such barriers in the way of accepting one's infection that it is hardly surprising that people with HIV and AIDS sought comfort, rather than actively confronting their situation. The reaction of the less "Bavarian" population also tended to confirm the role as victim, rather than helping to dismantle it – however emancipated they may have felt. The activities of the Bavarian Herr Gauweiler therefore had much the same effects as those of Peter Duesberg (who argues that HIV is not the cause of AIDS), in that in the place of reality an illusion is projected which promises safety and offers leadership for those not directly affected.

It must have been because they felt so powerless that in 1989 the executive committee of the German AIDS-Hilfe (the majority of whom were themselves HIV-positive) decided to appoint a medical scientist, although the consensus was that the real confrontation with AIDS and HIV was a social and psychological one. This professionalization was to help to gain entry to the ivory towers of medical science. And in fact it did turn out that a gay doctor, with only the conviction of being at the right place at the time, gained influence and a hearing.

But this is not enough for me. If the involvement of those directly affected really leads not only to the reality becoming more visible but also helps to avoid wasting research funds, then this role as proxy cannot and should not be continued. In Germany the awareness of the size and urgency of the problem AIDS is lacking, with the exception of a few activists. "Please be patient" is the standard answer to the request for effective therapeutic approaches. "Please be patient" – a formulation which bears witness to the distance – professional or otherwise – between the clinical research and the needs of the people affected in the widest sense by HIV and AIDS.

Examples of this attitude, which prevents a significant cooperation of people with HIV and AIDS in the research which affects them, or at least their involvement, are:

1. The Deutsche AIDS Gesellschaft, whose chairman is Professor Dietrich of the Bernhard Nocht Institute, Hamburg, refused the Deutsche AIDS-Hilfe (D.A.H.) full membership on the grounds that it was not a scientific society.
2. The Federal Ministry of Research and Technology refused the D.A.H. the right to attend as speaking guest the meetings of the Research Council at which the distribution of funds for AIDS research was discussed.
3. The Drugs Commission of the Federal Office of Health has refused even to consider allowing a representative of those directly affected to be present at the discussion of applications for new AIDS-related drugs.

4. The AIDS Centre of the Federal Office of Health continues to operate without any form of advisory group made up of people with HIV and AIDS.
5. The German Association of Medical Practitioners Caring for the HIV-Infected is primarily concerned with their own further training. There is no initiative to increase the involvement of those directly affected, or any open dialogue with doctors in their own ranks with HIV or AIDS.
6. Pharmaceutical companies use the D.A.H. in their advertising to increase the acceptance of dubious therapy trials. The label "discussed with D.A.H." (or ACT UP etc.) really means little, since important information is often withheld in the discussions. It is the exception rather than the rule when those directly affected are seriously consulted.
7. The Clinical Association AIDS Germany restricts full membership to clinicians or doctors involved in treatment. Although the D.A.H. has the status of a clinical centre in the meetings of delegates, it must be represented by a doctor.

In view of this experience the question is no longer "Why should those directly affected become involved in clinical research", but rather "Why are researchers, scientific bureaucrats, drugs manufacturers and doctors so afraid of normal, active patients?"

Models of involvement

Since German clinical research has proceeded almost totally without the integration of people with HIV and AIDS, despite the positive international experience, some models of involvement are presented here:

1. Planning consultation

In the planning phase it is important to register the subjective perception of a study, and to estimate its relevance. At this stage of planning an adviser will be able to introduce the interests of those with HIV and AIDS, particularly in the following areas:

- What hopes are attached to the study?
- Who wants to take part in the study?
- What groups should be particularly involved?
- Can the language used be understood by the patients?
- Are there irrational exclusion criteria?
- Is the goal of the study acceptable?
- Will support be forthcoming from those directly affected?

Ideally the adviser would be an HIV-positive staff member of the institution planning the study. This seems realistic in the larger institutions (e.g. Federal

Ministry of Research and Technology, Federal Ministry of Health, AIDS Centre of the Federal Office of Health, the Centre for Health Education, Bundeswehr). A second level of consultation would compensate for the selective perception of the adviser.

2. Consultancy seminars

A relatively cost-effective approach for smaller institutions and organizations is to establish an advisory group consisting of people with HIV and AIDS. Experience has shown that using suitable training methods an interested lay-person can become an adviser during only a weekend. Such groups can consider the following points:

- Acceptancy
- Interest
- Accessibility
- Structural requirements to carry out the study
- Communication
- Quality of life

3. Inter-professional consulting group

In addition to the initiators of a study, who have reached agreement about the aims of their study as developed in the initial consultations, experts should also provide an additional assessment of how realistic a study hypothesis is. After completion of the planning stage, but before the study is set up, a consultancy group is therefore regularly called together. Wide-ranging and intensive discussions are necessary at this stage of the preparations. Important aspects of the implementation of the study can only be illuminated by the test persons themselves. The planners must take the step from the prospective study population in their heads to the reality. In contrast to the initial seminars, the preparations made here are directly related to the actual implementation of the study. The professional advisory group can prepare a catalogue of rights of the study participants. In addition to the participation structure, such a catalogue can outline the participants' right to quit the study, and the examinations which are necessary.

4. Involving community representatives

In the course of a study rumours can drastically reduce the level of participation. The only remedy for this is unreserved openness and the creation of information structures which operate outside the doctor-patient relationship.

Individual test persons with contact to others taking part shall be consulted systematically on a confidential basis. A circular produced by the community representative can be useful.

The community representatives should be integrated in on-going consultations in the course of the study. Alarming reports, or even the termination of the study should definitely be prepared for in consultations.

5. Focus groups

One way of registering the changing moods in the test population, or of testing the level of acceptancy, is to consult a selected group of test participants at regular intervals in a group meeting.

6. Study parliament

Just as in a normal parliament, a study parliament can provide a structure in which the scientific advisers, medical staff and sponsors of a study can discuss relevant topics with the test persons.

A study parliament can meet at regular intervals (every 3 months) from the start of the study. It could be comprised in equal parts of basic scientists, clinicians, and test persons. In addition to the open discussion this can help to form a community supporting the study. This form of integration of those involved is recommended in particular for innovative studies, or for those which are long-term or which investigate psycho-social factors.

An interesting glimpse of the effects of this involvement is provided by the regular evening meeting held for the past 1 1/2 years at the University Clinic Frankfurt/Main for the participants in their study of the new nucleoside analogon L-661. In the course of the study regular and open discussions of the results between the testers and the tested have not only helped individuals to learn about the contents of the study, but have also had as a consequence a fantastically high level of compliance on the part of the test persons.

7. Involving relevant media

When it comes to making public the results of a study, information deficits often arise in the network of AIDS advice centres. Just as stock markets are informed in advance when publications may effect the markets, as a bar to insider trading, so the results of studies should be recognized to be potentially relevant to counselling activities. Confidential prior information for advice centres and people with a multiplier function can help to avoid confusion. It is extremely counter-productive to rely on the lay press for the publication of preliminary results, and can damage the image of the study organizers. In addition to structures of consultation and information the involvement of those directly affected can be improved by the following measures:

1. Child care
2. (Drug) substitution during the study
3. Free provision of contraceptive pills during the study

4. Free provision of condoms
5. Repayment of travel expenses
6. Report of individual results before the official end of the study (after breaking the code in double-blind placebo trials)
7. Guarantee of further free treatment with the trial therapy after the end of the study until the treatment receives approval (unless there are serious negative effects)
8. Information prior to publication.

CARING FOR OUT-PATIENTS WITH AIDS

Beate Steven, care officer, Deutsche AIDS-Hilfe

The initial situation

1. The situation of the health system in Germany

The social insurance system in Germany, which includes health insurance, is seen as a model in Europe and internationally. Nevertheless, the results of this "all-round insurance" are not convincing. The financing of health care in the Federal Republic of Germany is facing bankruptcy, while at the same time providing a relatively poor quality of care and nursing. There is a growing discrepancy between the considerable funds needed for the highly specialized medical-technical services to restore and ensure health on the one hand, and their actual success on the other hand. The latter should be reflected, for example, at the levels of participation in regular preventative medicine programmes (such as screening for cancer), in the reduction in the number of working days lost because of sickness, and in shorter stays in hospital – but this is not the case.

Many analyses describe German health care as being disconnected from the interests of the population, having followed for some time the interests of the drugs industry and professional bodies. The cost-intensive and highly differentiated advanced medicine, apparently available to everyone, creates the impression of appropriate care but obstructs the vision when it comes to judging its quality and its limitations.

However, with the growing clientele which no longer requires intensive medical treatment, but rather intensive care and nursing, the focus of public interest is shifting. People with cancer, AIDS, multiple sclerosis, Alzheimer's disease or mental illness, the chronically and terminally ill, as well as old or disabled people and addicts all emphasize the deficits of the health care and nursing system.

There is a shortage of:

- acceptable, professional diagnostics, therapy and care on a local basis
- an adequate and integrative care network
- health counselling, education
- support and monitoring of lay care

- support for self-help resources outside the health services
- preparedness to take account of criteria such as "quality of life" and "dignity", in particular when dealing with and caring for the seriously and terminally ill, and when assessing existing service structures,
- the integration across professions of care approaches,
- involvement of those directly affected in policy and planning matters

2. The care situation in Germany

The deficits in the health system also affect the provision of care and nursing for the sick, as reflected in public discussions of excess bed capacity, apparatus medicine, care emergency etc. However, these rather superficial considerations of care leave the real problems untouched.

Care and nursing in Germany is in a deep crisis: One sign of this is the lack of young trainees, the high sickness levels, early retirements, and the poor quality of care in international comparison. On the other hand, the wide variety of interpretations placed on care and nursing ("Pflege" is a 'service of love', 'everyone can care' etc.) only serve to emphasize the lack of a clear self-image and professional profile.

The uncertain legal position surrounding actions of the caring personnel such as setting up and monitoring infusions, and a legal, contractual and insurance framework which varies from Land to Land, leave little scope for creative work oriented toward the patient. It seems that the formal structures (e.g. changing shifts, including weekends and nights, low pay, poor in-job training, little chance of promotion) are the main reason for the collapse of the status of the occupation and thus for the declining quality of care.

Such a hypothesis could be the subject of scientific research. But here, too, caring and nursing is slow to advance. It still does not have its own access to academic training. The contents, organization and basic criteria of caring and nursing are therefore largely untested, unsystematic and on an unsound footing.

In the hierarchy of the health profession the carers are near the bottom. They are increasingly caught in a conflict between their role as carer (humanity) and their identification with the goals and methods of the medical system (functionality). In order to increase their standing it seems essential to side with the stronger partner, namely with the doctors and the medical system. Thus nursing and caring activities which are closely related to medical tasks (e.g. measuring blood pressure, giving injections, assisting in diagnostic procedures etc.) enjoys a higher prestige than helping with personal hygiene or feeding. The personnel from intensive wards, tumour centres or AIDS wards enjoy a higher standing than colleagues from so-called peripheral departments, who "only" provide general care. This struggle for standing and power extends outside the hospital. Those working at social stations or out-patient nursing services have a lower reputation than those working at university hospitals – not to mention the level of pay.

An important factor for nursing and caring personnel is the patient's evaluation of their work, expressed both verbally and non-verbally. This pro-

vides an additional, but no less effective form of 'reward' or 'reproach' for the work.

Germany can be referred to, with some justification, as a "developing country" as far as nursing and caring is concerned. The contrast is all too stark between the stagnation of care at a comparatively low level and the developments in medical treatment and research.

3. Caring for people with AIDS in Germany

The first people in Germany needing treatment and care for AIDS were in the hands of doctors and nursing staff who were fairly unprepared for the task. Clinics and social stations had inadequate knowledge and experience in dealing with AIDS patients. In the centres of population a medical infrastructure soon developed which enabled people with AIDS to find experienced doctors and hospitals. However, there was still no effective network of nursing and caring. The non-governmental AIDS-Hilfen were active in organizing psycho-social help for people with HIV/AIDS, but for a long time they did not see it as one of their main tasks to organize, finance and implement professional care.

In Germany, care outside of hospitals was seen for many years as at best a supplementary service to hospital treatment. Therefore both legal and funding bodies have tended to neglect it. This has in turn meant that there has been little motivation to care for AIDS patients (or other critically ill people such as tumour patients) outside the hospitals or even to look after those dying at home.

With the possibility of early medicinal anti-retroviral and prophylactic therapy the situation for people with HIV/AIDS has changed. AIDS is still regarded as being without a cure, but it has lost the character of being an illness which is always severe, necessarily requiring intensive stationary treatment, and leading rapidly to death. AIDS now presents a challenge above all to the field of caring and nursing.

A feature of providing care for AIDS patients is the erratic and unpredictable development of the illness. This affects the behaviour and attitudes of both the patient and the carers. In addition most of the patients are young adults who have been forced to the edges of society because of their lifestyle (gays, drug users, bisexuals). Often they are no longer integrated in a social network, having broken off contacts to their family, and seen friends and partners die of AIDS. Many face financial problems after having had to stop work prematurely, and now rely on social payments.

Above all these are generally patients who are well informed about their illness and its prognosis, as well as the options for treatment. They are in a position to determine the necessary care intervention themselves.

This can include:

- careful medicinal prophylaxis
- help with daily tasks
- intensive observation of the patient

with additional care in specific instances for:
- opportunistic infections
- infusion therapy
- inhalation therapy
- pain therapy
- round-the-clock care.

Some 80% of the disorders associated with HIV and AIDS can now be treated outside hospital. With the sometimes superfluous hospital treatment of AIDS patients becoming more and more expensive, the need to make savings has given added impetus to the trend towards providing treatment and care on a non-stationary basis.

Changes

1. The state model programme 1987 – 1991

"As much non-stationary as possible, as much stationary as necessary!" was the motto in 1987 of the German government's model programme to "Develop non-stationary assistance within the framework of social stations for people with AIDS". This model programme was part of the state programme to tackle AIDS immediately, involving various fields of action.

The social stations were the principal centres for non-stationary nursing, care and domestic services, and funds and personnel were to be provided to enable them to offer long-term domestic care for AIDS patients. A multiplication effect was envisaged. Centrally trained experts were to be located nationwide at the regular out-patient care stations, providing relevant further training for the carers and offering them the opportunity to acquire additional qualifications. Funding was provided for some 200 posts at 35 model stations.

However, it soon became clear that conceptional errors had been made when drawing up the plans. There had been misconceptions concerning both the day-to-day operation of the social stations and the demand for nursing and care services. With the conclusion of the model programme a number of significant, previously unseen problems relating to non-stationary nursing and care had been registered:

a) Non-stationary AIDS care is
- cost intensive
- time intensive
- labour intensive
- hard to predict and plan
- not feasible with the available personal and financial resources of the social stations

b) Non-stationary AIDS care includes three elements:

- the provision of suitable nursing/medical care in phases of acute infection
- maintaining the health status quo requires the provision of prophylactic measures to avoid complications and further hospital stays;
- depending on the level of independence of the patient, an organizational structure must be established to cope with the household, e.g. domestic care.

With people living longer with HIV/AIDS, non-stationary AIDS care is becoming increasingly the care of the chronic, very seriously ill. It is therefore involved in all the psycho-social conflicts which arise in nursing and therapy when the patient is cared for through to death.

There was also an underestimation of the amount and intensity of care necessary even for supposedly "easy" care tasks, where there are no current opportunistic infections, but still continual mental and physical decline. A large number of AIDS patients suffer from temporary or continual signs of cerbro-organic, neurological and mental changes. Such illness can often mean a rapid loss of independence in all respects, so that the nursing personnel and carers need to have profound knowledge of psychiatric care. The patients must be offered orientation which allows them to re-establish links to their surroundings, their friends and relations, and to regain independence.

Out-patient AIDS care thus involves intensive involvement with the patients and their friends and relations. It is characterized by detailed explanation, counselling, psychological help and guidance for care.

The conclusions to be drawn for the tasks facing the ambulant care of people with AIDS:

- On the one hand, retaining the maximum level of independence within the patient's world. "Activating care" therefore includes counselling, working out care measures with cover for deficits in self-care, instructions in the use of care aids.
- On the other hand, infections can often lead to an increased dependence on care. This involves intensive general and special care, which must also take account of the emotional burden on the patient and their close ones.

The importance of the relationship between carer and the AIDS patient also reaches a level which has long been recognized by experts to have the importance of medicaments.

2. The non-governmental response: Self-help takes on ambulant AIDS care

The model programme to set up non-stationary help for AIDS patients also allowed the participation of the AIDS-Hilfen and care projects set up by self-help groups.

Lack of funds meant that the AIDS-Hilfen and associated care projects had to mobilize those directly affected in order to provide care for people with AIDS. However, self-help is not sufficient to cope with these tasks. This explains

the various cooperation and coordination agreements between the care projects of the AIDS-Hilfen and other organizations. Some of these appear a bit strange, but they allow the creative and constructive coordination of a wide range of regional possibilities to care for people with AIDS.

With the conclusion of the model programme in 1991 the established welfare organizations began to retreat from the care of AIDS patients. But not the AIDS groups and their care projects. Despite the confusion at the end of the model as to how the complex care activities could be maintained without further subsidies and public funding, they felt particularly obliged to provide care. In addition, and in contrast to many social stations, they were also already providing a large amount of care.

The result was the development of care services which were brought together in 1991 under the umbrella of the Deutsche AIDS-Hilfe e.V. (D.A.H.) as a nationwide association.

2.1 The Association of Ambulant Care (AGAV)

13 care services throughout Germany are joined together in this association. Although they work under varying conditions, with different modes of funding, they have been able to develop a uniform approach to care, coupled with high standards of care.

Funding

All services are funded by local authorities and Laender. The funding differs considerably from Land to Land, and the usual contractual agreements which apply between health insurances and welfare organizations are often augmented by special rates for the care of people with AIDS. This is still often not enough to cover the costs of the complex organizational and care services needed.

Personnel and specialization

A service team of the AGAV consists of full-time trained staff, qualified in "domestic care", "nursing and care", "psycho-social support", "social work" and "caring for the next of kin". This "local" personnel is usually backed up by an administrative group, consisting of at least a manager and a book-keeper. They are responsible for negotiating with the people who hold the purse strings, monitoring the finances, and they represent the service in public. On various committees and elsewhere the leading members of the care service also have the important function of presenting the needs of people with HIV and AIDS to welfare associations, politicians and other potential partners.

As soon as the AIDS-Hilfen and the associated care services began to take on the provision of care it was recognized that this had a political element. Efforts were made to extend the limitations imposed by the health system. Thus today it has become fully accepted that the infusions required as part of AIDS care can be carried out and monitored by care personnel. People with AIDS can pass

away in their home, next of kin are cared for, night watches are held, and prophylactic measures are paid for.

In-job advice and training

All services offer personnel paid advice sessions and regular team meetings, which are intended to highlight and develop various critical aspects of the work. It should be noted that in Germany such support for caring and nursing personnel is by no means commonplace, although help for the helpers is regarded as the basis for work of a constantly high quality. Weekly team meetings are held to ensure internal communication and coordination. At a national level the exchange of information is possible at training courses, attended regularly by all services, which are tailored to meet the various special needs (e.g. administration, care, services). In addition to brushing up special knowledge, and acquiring personality-building abilities, an additional important aspect is the establishment of joint strategies and actions, ensuring e.g. that the same lines of argument are used in negotiations with funding institutions.

Caring for patients

The services in the conurbations care for between 8 and 15 patients. At times some services experience peaks, but the number of patients does not directly reflect the energy and the effort involved in the caring work. In the rural areas, trips can be as long as 1 hour (60 km) so that the capacity is correspondingly lower than in the cities.

The services in the cities, such as Munich, Hamburg or Berlin, put the daily requirement for nursing and care at six hours daily. Most people came into contact with the services through hospitals or verbal propaganda. The services of the AGAV are usually at the limits of their capacity, and therefore have waiting lists. The demand for ambulant AIDS care is growing.

Social stations also make use of the AGAV care services and "transfer" patients to them.

Conflict solving strategies

When care becomes a place of social learning for all those involved then the potential for friction and conflict necessarily increases. For the care personnel of the AGAV-Services this means:

Understanding oneself as a tool, which requires knowledge of one's strengths and weaknesses, in order to reduce as far as possible "repetitions" of earlier key experiences. These could express themselves, for example, in the feeling of having to take on particularly arduous and "difficult" care, or of being able to work with a pronounced emotional involvement in the care – despite clear signs of overloading etc.

An holistic approach to care on the basis of "caring for people of the same age", or often of "care by people also directly affected", as followed by the AGAV, must offer protection for all those involved and must ensure that involvement leads neither to mutual incapacitation nor goes too far.

For the patient the inter-disciplinary team therefore offers a release. The team not only supports its individual members, but also follows their work critically.

The instrument of collegial counselling and special sessions with advisors can help carers to examine role shifts, expectations, signs of affection and love, rejections, transference and counter-transference.

Planning and documenting care

In classical forms of self-help, in which ideally the competence of being directly affected is combined with expert knowledge, the situation of the person directly affected is the focal point of the work in an exemplary manner. The ups and downs of the illness justify care and medical measures which are open-ended. This means that the range of options for care, which can switch suddenly from a minimum, through intensive care to being present at the deathbed all had to be taken into account when planning the service, and are expressed in

- the staff numbers
- the qualifications of the personnel
- the timescale drawn up for individual care
- care planning and documentation, and in
- the formulation of the care aims.

In accordance with the WHO Programme "Health for all by the year 2000", the aims of the care were developed together with those directly affected. Responsibility is divided, in the sense of a "cooperation agreement", providing a working basis between professionals, those directly affected and the lay-carers, on which to decide what is acceptable, practicable and sensible, and also desirable and bearable on the part of the person directly affected.

The final point is the realistic assessment of the observation period after which the success of the care is to be checked.

The care provided by the AGAV care service is thus planned and documented. This is still not obligatory in Germany, and is not a criteria for registration as a care service, with the exception of those receiving public funding.

Theoretical foundations

The AGAV is the first and only group offering out-patient AIDS care which operates throughout Germany with the same approach, the same standards, the same theoretical foundations and with comparable care documentation.

The services are based on central aspects of the following approaches to care:

- Erich Böhm (Orientation and activating care)
- Dorothea Orem (Self-care ability versus self-care deficits)
- Imogene King (Care as interaction).

In terms of development standards, the stipulations of the ICN (International Council for Nurses) and the guidelines of the WHO on quality assurance in care were followed.

The approach to care

The AGAV defines care as social action between two or more persons, so that care is a matter for negotiation between those involved in the process.

AIDS care is not a matter of feeding and cleaning but, using the words of Erich Böhm, is care with "one hand in the pocket", thus activating the patient. The AGAV removes care from its traditional position of giving, and of knowing what is best for someone else, and gives the patient some responsibility and a role of their own: With the support of the AIDS care the patients are to be enabled as far as possible to live an independent life with their friends and relations. Care is thus an accompanying professional service, for regaining or stabilizing independence.

Such an approach also defines the position of the professional AIDS carers: They are the long arm of the patient, helping to maintain or to reconstruct what the patient understands as quality of living. Care must therefore be closely matched to accommodate the wishes, habits and dislikes of the patient, and if necessary re-negotiated from day to day. Care loses its quality and its credibility the moment it goes beyond the presentation of good arguments and begins to push things through over the heads of patients or in opposition to them.

This approach to care does not mean preaching harmony or self-exploitation, which seems to be an ever-present danger in the isolation of a one-on-one care situation in the cared person's flat. But it does mean a professional approach to care which does not need to build up self-assurance by exercising power and dominance, but which allows the carers to present their knowledge and ideas for discussion without losing authority or becoming unable to work.

In order to do justice to this complex activity the AGAV works with the relationship process between the carers and the person who is cared for. Each patient has a counterpart carer, who offers a primary relationship to the patient, independent of other colleagues involved in providing care. This involves the carer openly siding with the patient, which the latter can use in difficult conversations with parents, doctors etc.

The carer has an important role to play in the field of conflict between patient's desire for autonomy and their actual dependence – at least in part – when it comes to meeting their needs. The carer can be the motor to activation, or the only person towards whom the patients freely shows the weakness and fear they feel. At the same time the carers must come to terms with the patient's need to establish limits, and with patterns of coping which find expression in various ways, e.g. in jealousy and explosions of anger, and which keep redefining the possibilities and limits of caring.

Standards of care

The quality of AIDS care provided is always in danger of suffering under the organizational, financial and practical conditions already outlined. At the same time quality is the only way of remaining competitive and attracting funds at a time when resources are becoming scarce. The quality standards developed nationally by the AGAV reflect the experience of five years

professional care work for people with HIV/AIDS from the point of view of self-help. Thus the care work gains the transparency which makes it comprehensible for others – the so-called lay-public. Thus the standards for care represent a sort of "consumer protection" for the people affected by AIDS, allowing them to distinguish between inferior care and quality care. Standards are to prevent the patients becoming the "victim and plaything" of varying expert opinions or of the specific motivations of individual personnel.

When care services establish a consensus by means of standards then decision processes are faster, and work procedures can be made more precise, without losing quality. Funding bodies also need standards as an instrument for quality assurances, with which they can easily judge the value of services.

Features of the standards of the AGAV are:

- They take into account various care categories when describing the aims and the scope of the care and other services;
- The "moral-ethical" leitmotif attached to every standard;
- The holistic approach to care and other services;
- The communicative aspect of all the standards; the "negotiation" of care between the individual and the carers;
- They take into account "complications" and necessary "reorganization";
- Checklists are drawn up for each standard with practical tips in an appendix.

The standards of the AGAV are not restricted to describing processes. Against the background of their formally different general set-up and their experience, they formulate

a) at the level of the structural standard the organizational requirements, e.g. personnel, qualifications, material fundamentals etc. in order
b) to allow the staff at the process level to get things done together with the patient and their close ones using certain implementation procedures, so that
c) at the result level the planned results are there for all to see and to check using previously defined objective criteria.

Drawing up standards can give rise to lively and constructive discussions with the aim of achieving a satisfactory agreement about future work organization and ways of coping with practical problems. In the course of the work the standards must then be continually checked and their implementation controlled. They therefore represent a creative opportunity to refresh expert knowledge and to compare one's behaviour with other people's impressions.

As long as care work is defined solely by those providing the funds it will only be possible step-by-step to establish an ambulant care sector which combines the competence of the experts and those directly affected. At present, for example, psycho-social support, or company for the dying are still not seen as integral and professional components of all-round care, denying its own role and therapeutic effect beyond that of an auxiliary service for the medical sector.

Thus the AIDS-Hilfen and the associated care services have no option but to continue seeing the care of people with HIV/AIDS as political work, to stick to quality as the prime criteria, and to put more emphasis than in the past on the dignity of the individual. This is the only fitting response to the growing tendency of existing health policies to disguise the inadequate provisions for care services and nursing by transforming health to a luxury commodity, thus privatizing the risk of sickness.

Politically this means that the care services and the AIDS-Hilfen will carry on exposing the deficiencies of the health care system, and will demonstrate how creative care concepts can be developed for very ill and dying people, with the care of people with HIV/AIDS as an example.

Economically this means: Care services and AIDS-Hilfen will continue to work for the provision of a spectrum of services which focus on the individual as a whole and not as separate functions.

For care this means: Continuing to strive for the correct balance between closeness and professional distance.

Addressing people with HIV and AIDS this means: Raising the hope of involved, unprejudiced and competent care, which does not come with the features of welfare, and does not want be understood as charity. The hope of care which has the same basic tenets whether it is in a hospital or at home.

Reference

Besselmann, K.; Sellin, C.; Borchers, A.; Melchinger, H.: Modellprogramm "Ausbau ambulanter Hilfen für AIDS-Erkrankte im Rahmen von Sozialstationen" des Bundesministeriums für Gesundheit. Endbericht der wissenschaftlichen Begleitung, Köln, Hannover 1992

NON-GOVERNMENTAL ORGANIZATIONS IN EUROPE: NETWORKING AS A TOOL FOR INFORMATION, EDUCATION AND PREVENTION

Petra Narimani, head of dept. "International Relations", Deutsche AIDS-Hilfe

"We have learned that we cannot succeed alone – alone in our discipline, alone in our culture, alone on our country or region – yet we have difficulty finding a common language and working together. We have seen that isolation is inefficient and dangerous – and that the exchange, dialogue, tolerance and solidarity are sources of strength and pathways to more effective control and care."

This is what Jonathan Mann, Chair of the VIII International Conference on AIDS, said in his speech in Amsterdam, 19th July 1992.

The rapid development of many different networks (many of the European ones are united in EuroCASO) is an indication of the growing awareness and recognition that AIDS is an international issue. Collaboration at local, national and international level is essential in our efforts to impact upon the spread of the disease. As the EC countries are growing together (or at least make efforts to) and, at the same time, political changes in Central and Eastern Europe are creating new situations in which HIV transmission might considerably increase, the networks of AIDS service organisations and self-help groups should be joined, used and made more efficient.

Many self-help groups and organizations suffer from lack of opportunities, lack of resources, experiences, skills and strategies. We know how it feels not to be able to respond to the daily challenges, tragedies and needs even when we want to. Networking and exchange of expertise, energy and power is essential for communities to be able to create, set up and develop community-based groups and organizations into independent and strong units. The feeling of belonging to greater communities and networks empowers people to stand up against prejudice, lack of authorities commitment, and claim their right to actively care for themselves and their communities.

Networking can be highly effective in spreading information and education, in promoting the exchange of experience and skills between AIDS service organization, in advocating the rights of individuals and communities affected, the rights of access to resources, care and support, and the right to live free from discrimination. The problems we are confronted with in individual countries are rarely unique or completely new. That's why every country can benefit from access to a variety of solutions and programmes.

Networking is a process of self-empowerment, a response to AIDS at local, national and international level with special regard to people living with HIV/AIDS and all those affected by the disease. It highly supports sparsely

developed NGO sectors with limited resources, because it assures participation and integration in the regional networking structures by developing mechanisms for support, and exchange of experience with well-equipped so-called Western NGOs.

On the first "European Meeting of Self-Help Groups of People with HIV/AIDS" which took place in Göttingen/Germany on 18th – 22nd June 1992, the importance of interrelationships became quite obvious. In his greetings to the Conference, Horst Seehofer, Federal Minister of Health in Germany, said: "Information is always the most important tool to counteract a disease which does not stop at state borders. The motto is: Learn from each other to ease jointly the fate of the afflicted."

Delegates of more than 40 groups of people with HIV/AIDS from 22 European countries were given the opportunity to present themselves, to exchange experience and to get in touch with each other. This meeting (the documentation can be obtained through the Deutsche AIDS-Hilfe, Berlin) was a first important step towards an effective co-operation and a common lobby. The process of discussion must be continued.

European Community-Based Organizations (CBOs) and the Twinning Project

At the national level, there is a great number of networks such as "Positiv e.V. in Germany or "Body Positive" and "Positively Women" in Great Britain. All over Europe, there are also lots of national self-help groups of drug users (e.g. JES in Germany, MAINLINERS in Great Britain or ASUD in Paris), of gay groups, sex workers organizations etc.

Recognizing that the informal channels of exchange and the groups' activities have not been sufficient enough, EuroCASO has developed the "Twinning project". The idea is to set up a design which provides an opportunity for community-based organizations to form more committed and stable exchange interrelationships. East-West and North-South perspectives also play a part in launching this project.

The Twinning project is based on a cheap and simple model: It only needs funds for travel and, in some cases, administration. The twinning could consist of one return visit by two people from each CBO. The host CBO contributes with training, field activities, participation in workshops etc. When people affected by HIV come together, there is a great chance that they will develop relationships based on common identities, interests, experiences, skills, challenges, faith, dreams or ideals. Ever since the beginning the AIDS epidemic, people have come together and introduced informal and powerful twinning relationships.

E.I.G.D.U. – European Interest Group of Drug Users

In Europe, several million people use illegal drugs. Drug use should not be labelled a personal disorder or tragedy. Authorities in Europe normally put consumers of illegal drugs into prison or under certain restraints which criminalize them. It is, however, indisputable that criminalization and the "War on Drugs" are no solution to the problem. The black market, organized crime and widespread drug use are a consequence of the international prohibition of certain drugs. Thus E.I.G.D.U. claims for legal changes, an improvement of the situation of drug users in prisons, and adequate treatment options. These demands are part of a declaration which was passed by 26 groups (50 participants) on the "Second European Workshop for HIV-Affected Drug Users" in Berlin, 1st December 1991.
E.I.G.D.U. was established in 1990 after an initiative taken by JES (Junkies, Ex-Users, Substitutes) and the Deutsche AIDS-Hilfe, Berlin, Germany. Since then, the group has organized three European workshops which were financially supported by the WHO. On the last workshop in Verona in December 1992, a "Report on the Situation of Drug Users in Europe" was presented. It was compiled by members of E.I.G.D.U. and financially supported by the EC. At a board meeting in Oso in April 1992, E.I.G.D.U. decided to join EuroCASO.

EATG – European AIDS Treatment Group

The EATG which was founded in February 1992 is a co-operative network of people from different nations and HIV-affected communities. The goals of the EATG are

- to achieve effective treatment and access to experimental therapies for as many people with HIV as possible and
- to enable people with HIV to have maximum control over the treatment and research agenda.

In 1991, a "European AIDS Treatment Agenda" was published. In the same year, the "European AIDS Treatment News" was called into being, a newspaper which is issued bimonthly. The EATG is part of a European effort to enhance the networking and co-operation of ASOs as initiated by EuroCASO while putting special emphasis on the information about treatments and trials in HIV disease.

Network of Sex-Related HIV/AIDS Projects

The idea of forming a global network of sex workers, ex-sex workers and people working on sex work related HIV/AIDS projects was a result of the "International Conference of Non-Governmental AIDS Service Organizations" in Paris, 1990. For this network, too, the idea is to create solidarity, to make possible an exchange of skills, to provide resources, and to defend human rights. The realization of these plans is under way. At present, a secretariate is being set up.

ILGA – International Lesbian and Gay Association

ILGA is a worldwide federation of national and local groups. Founded in 1978, it dates back to the pre-AIDS era. ILGA Europe is active in campaigning for gay and lesbian rights and thus involved in AIDS policy issues, as many member groups and organizations are more or less AIDS Service Organizations.

Migrants organizations

In some European countries, migrants communities, too, have set up their own community-based organizations. Due to mobility and socio-cultural position, migrants are populations with specific needs for information on AIDS. In view of the constantly increasing mobility and recent economic and political developments, the international dimension of the AIDS epidemic and thus the international co-operation is becoming more and more important.

The "First European Conference on HIV/AIDS for the Muslim and South Asian Communities" in London, 9-11th September 1992, is a first step towards an international network of migrants groups. A pre-conference of European migrants self-help groups will take place in Berlin in May 1993, shortly before the IXth International Conference on AIDS.

From 9-11th May 1992, a workshop was organized on "AIDS Prevention towards the Turkish Population in Europe" in which 20 Turkish people from eight European countries participated. It was considered very important to organize a follow-up which takes place in Hannover in June this year. Such activities make it possible to make use of media and methods which have already been developed in some countries. This reduces manpower and financial costs.

ACT UP – AIDS Coalition to Unleash Power

ACT UP groups work according to the specific problems and needs of the individual communities. The activities of ACT UP are at the social, medical and political level. In order to improve the situation of HIV infected people, ACT UP initiates or takes part in action making and demonstrations. The ACT UP movement has its roots in the United States of America.

EuroCASO – European Council of AIDS Service Organizations

EuroCASO is a pan-European network of non-governmental, community-based organizations and an integral part of the global International Council of ASOs (ICASO). Being a "Forum for Networks in Europe", EuroCASO embraces gay groups, organizations of and for people with HIV/AIDS, sex workers organizations, drug users self-help initiatives and bodies for people belonging to ethnic minorities. It offers these groups the opportunity to present their work in the EuroCASO Newsletter, and tries to secure wide representation at the

Annual General Meeting. In the future, EuroCASO will organize pre-conferences for self-help groups prior to its own annual meetings. Moreover, human rights will become a focus of attention and EuroCASO wants representatives of self-help groups to take part in this work.

EuroCASO has a Secretariate, a Development Office, a Newsletter Committee, and a Working Committee which meets four to five times per year. Member organizations are those who have signed the EuroCASO-Charter. EuroCASO, which was established in Vienna in 1990, is, today, an important link for European and international bodies such as the EC, the Council for Europe, the WHO, UNESCO etc. It provides access to more than 380 ASOs in 30 European countries, organizes workshops, seminars and annual meetings, it lobbies international AIDS conferences and organizes protest campaigns against governments and authorities violating human rights of people affected by HIV/AIDS.

Closely related to EuroCASO are the International Steering Committee for People with HIV/AIDS (ISC+) and the Global Network for People with HIV/AIDS (GPN).

LEGAL MEASURES EMPLOYED IN GERMANY FOR COPING WITH AIDS

Friedrich Baumhauer, lawyer, former executive director of the Deutsche AIDS-Hilfe (1990-1992)

Epidemic control measures employed during the first years

The call for compulsory mass testing

The great flood of legal literature dealing with AIDS began to rise precipitously here in the year 1986. Until then in Germany, the only contribution to this topic was by the civil-rights expert Erwin Deutsch, from Göttingen, in his small essay "AIDS and Blood Donations," published in the Neue Juristische Wochenschrift.[1] This modest beginning, however, was soon followed by a whole series of many and various treatments, as well as by the first court decisions.

Under the impression of apocalyptic forecasts discussed in a great number of medical and epidemiological publications[2] – and as a result of moralistic politics which saw in AIDS a welcome vehicle for the suppression of what was, in its view, undesirable ways of life[3] – legal viewpoints quickly developed which demanded extensive intervention by the state. Such intervention would above all have been borne by those groups of the population especially afflicted by AIDS: i.e., the gays, drug users, and prostitutes, as they belonged to what at that time was known as "high-risk groups."

The degree of collusion between moralistic positions and alleged preventive medical measures became highly apparent in publications printed in AIDS-forschung (AIFO), one of whose publishers was Peter Gauweiler, the Secretary of the Interior of the German Federal State of Bavaria. One statement contained therein treats ...

"... stipulations concerning the legal regulation of the restaurant trade – which, in addition to protecting human life and health, are also required to promote public morals, prevent illegal prostitution, and (where possible) serve to facilitate official supervision, thereby including the route of infection especially in restaurants frequented by 'high-risk' groups."[4]

These publications presented blanket demands for intervention, in mistaken interpretation of the fundamentals of a state governed by the rule of law: fundamentals which in all cases, and especially in the area of the ad-

ministration of state intervention, call for careful determination of the appropriateness, the necessity, and the commensurability of any such measures. These proposed actions were furthermore intended to implement through rigorousness what they lacked in practicality. They concentrated on the search for so-called sources of infections, as well as on the conception, generally not specified in detail, of a requirement to "seal up" every last one of these sources.

An exotic climax, in every sense, was reached in this context in November of 1989 in a report by Gert G. Frösner of the Munich Max von Pettenkofer Institute, which also appeared in AIFO. This report, in practically exuberant terms, praised to the skies the Cuban AIDS prevention program – which includes mandatory testing of the entire population and internment of every HIV-positive citizen detected. In Frösner's opinion,

"... the responsibly functioning public health service of a socialistic country in which the personal freedom of the individual is subordinated to the common weal, is hardly in a position to react in any other way to the threat posed by AIDS."[5]

As a result of the Cuban experience, Frösner believes that work carried out to educate the general public against the dangers of AIDS "... does not appear to be a necessary measure – and, presumably, not the most effective means – for countering the HIV epidemic."[6] For this reason, Frösner also recommends for Western democracies the means of intervention used in "classical struggles against epidemics," to be employed in "judicious fashion," in addition to informative work.

The action of Bavarian administrative courts has been noteworthy in this regard, in their support of the above-described policy, and with the aid of unsupported claims and generalizations. In one example, the Bavarian Administrative Court of Munich, in a decision reached on 19 May 1988, upheld the subpoena of a former drug user which had been issued for purposes of performing a further HIV test: although the individual had been drug-abstinent for more than three years, and had received a negative HIV test report two years previously.[7] The justification provided by the court claimed that

"It is appropriate and in accordance with the intent of law that action be undertaken in accordance with Sections 31 ff. of the German Federal Act for the Control of Epidemics, even in cases of only extremely slight suspicion of HIV infection."

The essential factor for the judges on the court was "... the severity of the disease AIDS, which as a rule has a fatal outcome." The following fact, however, escaped the notice of the judges, or made no telling impression on them: that those persons who are allegedly endangered by infected persons are themselves – additionally and particularly – able to determine the degree of risk to which they expose themselves, and that the "cleansing actions" on which the court was required to rule provide the false and dangerous impression of a degree of protection which in fact does not exist.

Argumentation followed in accordance with the letter of the German Federal Act for the Control of Epidemics, in accordance with which the health officials must institute the required investigative actions, even in cases in

which suspicion of infection transmission is only suspected. The formulation of this stipulation grants public health offices in Germany no discretional leeway as to whether the type, cause, infection source, or spread of the disease should or should not be investigated. At the same time, however, the Bavarian Administrative Court of Munich blundered by citing the official justification for the draft of the Fourth Act for Modification of the German Federal Act for the Control of Epidemics from 1979, for purposes of supporting its decision cited above.[8] The fourth Act reads as follows:

"Investigations must accordingly be possible in all cases in which protective measures come into consideration in accordance with the stated stipulations (reference is to Sections 34 ff. of the German Federal Act for the Control of Epidemics)."

In accordance therewith, the legislature intended this stipulation only as an enabling norm, and not as a regulation binding health authorities to a course of action. The intention as enabling norm, furthermore, applied only insofar as it involved protective measures which must conform to the criteria of appropriateness, necessity, and commensurability.

Prime examples of the lack of observance of the above conditions by Bavarian health authorities are provided by their official injunctions issued on prepared stationary forms in cases of "suspicion of infection." The following injunction has been issued in this manner, printed as it is on the forms of official agencies, and served with registration by postal return receipt:

"I.1. The practice of prostitution by Ms./Mr. ....., born on ....., is tolerated throughout the entire Federal Republic of Germany, with validity beginning with the date of serving of this injunction, from this point in time onward, only under the condition that anal, vaginal, and oral sexual intercourse be conducted with condoms.

2. Ms./Mr. ..... shall be required, beginning with serving of this injunction, to undergo a blood test for HIV antibodies, insofar as such a test has not been performed within three months prior to the date of serving of this injunction. This blood test – which can be conducted by any physician officially licensed to practice the medical profession in the Federal Republic of Germany – shall be repeated at intervals of not longer then three months.
3. Ms./Mr. ..... shall be required, beginning with the date of serving of this injunction, to submit to the Public Health Office responsible in the area of her/his place of residence, the said physician's certificate on the results of an HIV test, and, if applicable, of repeated testing, and she/he shall be required to present this certificate to the police upon demand.
4. It shall be forbidden throughout the entire Federal Republic of Germany, beginning with serving of this injunction, for Ms./Mr. ..... to use such medical certificates with negative results of HIV testing for the purpose of advertising in any form. This injunction shall especially prohibit the display of such medical certificates in the rooms in which prostitution is practiced.

II. In the event of noncompliance with this injunction, the perpetrator shall be subject to a fine in the amount of DM 10,000 for each case of noncompliance under Sections I.1, I.2, or I.4 above, and to a fine in the amount of DM 1,500 for each case of noncompliance under Section I.3 above.

III. No fee shall be imposed for this injunction."

The above text is followed by ten pages of explanatory matter, beginning with the following statement:

"1. According to records maintained by the Public Health Office, Ms./Mr. ..... engages in the practice of prostitution. She/he therefore provides grounds for suspicion of transmitting infection in the sense of Section 2, Paragraph 3 of the German Federal Act for the Control of Epidemics."

Explanation is also provided of the reason why no fee is imposed for the injunction.

The proponents of such state-enforced measures never took into consideration the idea of acceptance – in the interest of coordinated and, over the long term, more effective public health policy – of the uncontrolled presence of individual "sources of infection." They also failed to the same extent to realize that – in light of the routes of infection already known by this time – the danger for the individual likewise depends on his or her own behavior. These proponents therefore demanded application of the German Federal Act for the Control of Epidemics without proper reflection or differentiation. Their intentions were often associated with the demand for new legislation, since they claimed that the German Federal Act for the Control of Epidemics did not suffice to provide effective protection from AIDS.[9] Inflexible invocation of reference to the "especially great risk of infection"[10] insinuated uncontrollable paths of transmission, and demands for "safety in every individual case" inhibited carefully considered deliberation in the interest of effective overall strategy.[11]

There were of course more circumspect voices, although they very slowly and hesitantly asserted themselves in legal literature. German Federal Attorney General Manfred Bruns, for example, called attention again and again, in a series of articles, to the legal reservations which such action raised, and to the dangers to public health policy of trying to implement state-controlled prevention measures.[12] His argumentation centered on deficiencies, from the aspect of prevention, in the eloquence of the test results, partly as a result of the seroconversion period of up to six months which is currently required. He also pointed out the psychological effects of mandatory government measures on public readiness to accept appeals for prevention. In the final analysis, he felt that spread of the disease would be promoted by propagation of the tests as a preventive measure: mass mandatory testing would merely accord the public a deceptive feeling of security. Bruns therefore argued that such measures could not be implemented with justification based on the German Federal Act for the Control of Epidemics.[13]

Finally, the German Federal Ministry of Health and most of the German Federal States decided on a prevention policy which featured mandatory official measures only as the last resort in individual cases. The attempt was then

made by more aggressive proponents to force the German government to stricter measures by bringing the matter before the Federal Constitutional Court, the highest instance in Germany. It was alleged that the government had neglected to fulfill its obligations in protection of life and health – as stipulated in Article 2, Section 2 of the German Basic Law (embodying the German federal constitution) – from dangers arising from AIDS.[14] The Federal Constitutional Court ruled, with reference to precedent cases, that the federal government was indeed basically obligated to fulfill such obligations. The court, however, restricted any possible intervention by the judicial system to cases in which "... the government bodies may have remained totally inactive ..." or in which "... the previously implemented measures had obviously proved insufficient ...."[15] The judges of the highest court continued that it was

"... not evident that the legislature or the executive had failed to fulfill any of their responsibilities for protection which derive from the Basic Law, insofar as they had chosen – in accordance with the current status of professional discussion, including international viewpoints – to prevent infection by AIDS primarily by taking informative action for the public on the possibilities of infection."[16]

It may indeed be concluded that this decision basically ended the discussion as to whether it were necessary to resort to compulsory measures in the struggle against AIDS. There is accordingly no legal foundation for including AIDS in the catalog of Section 3 of the German Federal Act for the Control of Epidemics, which lists diseases required to be reported to the government, nor is there justification for implementing other measures in accordance with Sections 30 ff. of this Act.[17] The courts had, however, failed to answer the question as to what extent such measures were admissible.

Otfried Seewald has conducted a study to provide a solution which may be termed dogmatic in the administratively legal sense. The so-called right to avert danger – a concept to which the German Federal Act for the Control of Epidemics also belongs – allows in general the implementation of mandatory official measures only against those persons from whom a danger emanates, or who occasion a danger. German law terms such agents Störer, or instigators. Such instigators must accept restrictions of and encroachment upon their rights in order to fend off or restrain dangers which they would otherwise occasion. Persons not instigators – and persons with HIV, or persons who may be only suspected of harboring infection, are not instigators in this sense – basically cannot be subject to such measures.[18] This initially dogmatically appearing viewpoint attains a certain appeal by virtue of the fact that it, contrary to all other positions involved, takes into account the fact that the behavior alone of persons with HIV does not suffice – within the context of the relevant transmission routes of AIDS – in order to occasion a danger of infection transmission: the participation of the other, allegedly endangered person is also necessary. This participation is necessary to establish the route of transmission: i.e., the commission of penetrating sexual intercourse without a condom, or the mutual use of a hypodermic needle not verified to be sterile, in the IV application of drugs.

In his study of the decision of the Bavarian Administrative Court concerning the admissibility of measures of intervention based on epidemic law which are

instituted against a person suspected of being infected, Seewald furthermore points out a number of inaccuracies in the decision of the court: shortcomings which in fact admit doubt as to the sustainability of this decision.[19]

This argumentation is not entirely conclusive, even though it is correctly based on the fact that the danger of transmission – insofar at least as it involves the transmission paths of sexual intercourse or IV drug consumption – cannot arise without the correspondingly endangering participation of the "endangered" person, who must commit the same violations against "safety standards." German law dealing with the right to avert danger does not take into account the concept of participatory culpability, or its equivalent, to the extent that this concept has extensive significance in civil law. The one-sided shift of blame – be it ever so unpractical and "unjust" according to common sense – may be said to be extensively characteristic for law dealing with police and regulatory measures. After all, the matter involved here is less that of arriving at a reasonable – i.e., "just" – compensation of interests, than it is a matter of achieving quick results in the sense of warding off danger.

Results which are appropriate as well as sustainable within the context of prevailing jurisprudence can be obtained only by means of exact and non-prejudiced examination of commensurability on the basis of administrative law. Determination of the appropriateness of a measure attains central importance in his context, if the legal intents as established in Section 10 of the German Federal Act for the Control of Epidemics are carefully examined. In accordance therewith, the required – and, for that reason, also appropriate – measures must be implemented in order to avert danger to the health of the individual and of society (Section 10, Paragraph 1 of the German Federal Act for the Control of Epidemics).

It is no wonder that these two cases of legal intent – i.e., preclusion of danger to the individual and to society – may well come into conflict with each other in certain situations. In such situations, careful deliberation must take place as to which objects of legal protection are endangered, and to what degree of intensity. There is neither a fundamental prerogative in favor of society – despite regular assertions to this effect – nor is there such a prerogative in favor of the individual and his rights.

If, however, the rights in jeopardy are essentially equivalent, efforts taken toward protection of the majority of society must be considered to enjoy priority even though a deficit of protection may result for individual cases. Government measures which might protect individual persons from AIDS, but which would thwart an inherently conclusive and effective concept of prevention, could not therefore be legally admissible – unless a case of obligation to render aid is involved in accordance with Section 323c of the German Criminal Code.

Most of the proposed or demanded measures calling for government-enforced mandatory action – such as mass testing of so-called high-risk groups – legally fail owing to their deficiency of appropriateness. The German Federal Act for the Control of Epidemics also stipulates that no measures can be legally admissible if they attempt to circumvent by means of "dragline research" the express renunciation by the legislature of the requirement to report diseases in accordance with Section 3 of the German Federal Act for the Control of

Epidemics – and such circumvention is precisely the case in the attempt to enforce mandatory tests for HIV antibodies among certain sectors of society.

In the final analysis, mandatory HIV tests, and encroachment upon the rights of a citizen based on such tests, do not as a rule pass the test of commensurability. Careful deliberation must likewise take place of protected rights in the case of verification of commensurability in a narrower sense: in this context, between rights to life and health as they are legally protected, and rights which may be consequently restricted – in this case, those entailing the concepts of freedom and self-determination. It must be taken into consideration in this connection that extensively organized informative and educative campaigns have already provided the general public with the possibility of self-protection against HIV infection. To this extent, more rigorous measures are neither necessary nor are they commensurable, in light of the extremely abstract danger involved. Public health officials are allowed to encroach upon the rights of citizens to avert a danger only in cases which can be specifically described and in which an immediate and present danger exists for an endangered person who is not able to influence such a danger by his or her own actions. Even in such cases, the obligation to initiate action exists only insofar as that nothing of the stated nature oppose consideration of the opportunity to be gained for society in general.

Even though the Bavarian Administrative Court has in individual cases upheld[21] the legality of measures taken in accordance with the so-called Bavarian Catalog of Measures (20 and 67), grave reservations must therefore be lodged against the admissibility of these measures[22].

A particularly disturbing example of this nature may be found in the practice of a number of German Federal States which have attempted to persuade asylum applicants to tolerate an HIV antibody test, in the context of action taken on the basis of the German Law for Acceleration of Asylum Procedures. Authorities threaten such candidates with deportation before their asylum application is decided, in the event that they refuse their consent to the HIV test. Even if the request to take the test were justified, its combination with substantive asylum law – and the current practice amounts to nothing other than such a combination, since the chance for an asylum-candidate to have his or her application approved is significantly impaired once the applicant has been deported – constitutes an offense on the part of the authorities: it at the very least fulfills the conditions for duress under Section 240 of the German Criminal Code, if not for assault according to Section 241 in conjunction with Section 234a of the Code (defining the offense of abduction). Entirely apart from commission of these offenses, the residence of asylum-seekers who have not been HIV-tested does not represent a danger which could justify encroachment upon the rights of this sector of society to the extent as grievously as indicated in the above – especially since there is as yet no sign of a convincing concept of prophylaxis with regard to HIV-positive asylum applicants.

Bavaria Versus the Rest of the German Federal Republic

In May of 1987, the German Bundestag, upon being so commissioned by all represented parties, organized the Official Investigating Committee of the German Bundestag on AIDS, for investigation of "The Dangers of AIDS and Effective Means to Restrain its Spread." The committee was specifically commissioned to prepare proposals for action to be submitted to the parliament. Of the eight extra-parliamentary members of the commission, three came from the University of Munich alone: a fact which ensured weighty representation of the so-called Bavarian Line i.e., of prophylactic policy based on epidemic control measures of mandatory nature. Despite this influence, the reports of the AIDS committee contained no recommendation for new laws or any other proposals which entailed mass testing of the entire population or of even only certain sectors of the population.

Instead, the AIDS committee issued an interim report on 16 June 1988 which supported the government in its already existing concept of informative and educative efforts. The committee recommended the HIV antibody test only for the following:

- In cases of stable partnerships, as a survey test, or in cases of nonpromiscuous lifestyles
- For women who wish to have children and for whom an HIV risk exists
- In conjunction with examinations to detect problems during pregnancy, in cases in which HIV risk exists.[23]

The AIDS committee expressly emphasized the necessity of relieving those sectors of society most severely afflicted by AIDS i.e., male homosexuals, IV drug addicts, and prostitutes, from the pressure imposed by measures of prosecution implemented by the government. The committee made the following recommendations:

- Deletion of Section 175 from the German Criminal Code, and assessment of the possibility of substitution instead of a uniform protective stipulation for male and female youth in the German Penal Law on Sexual Offenses[24]
- Improvement of the situation of professional prostitutes through elimination of social and legal discrimination[25]
- Revocation of the practice of considering the possession of sterile disposable syringes by drug addicts to be proof of the possession of narcotics.[26]

These recommendations represented a definitely clear repudiation of those approaches which advocated a policy of prosecution and social rejection. Furthermore, public discussion concerning AIDS calmed after the two reports of the committee were published.

In the second volume of its report, the final publication in May of 1990, the committee elaborated on its following finding: that, in accordance with judicial experience gained concerning the influence on human behavior by legal norms, specific individual measures – i.e., those which attempt to elicit detectable behavior only from ill or infected individuals, and not from society as a whole – must be assessed as ineffective in the context of general epidemic control.[27] The report also emphasized that law is expected to encourage the formation of moral standards, whereby the responsibility to refrain from discriminatory action against those involved must be placed on an equal rank with the responsibility to prevent behavior which encourages the spread of infection.[28]

By the end of its study, however, the committee was not able to arrive at a jointly held viewpoint concerning the employment of compulsory measures. The final report expressly presented the various and divergent opinions which had come to light during deliberations of the committee, and which centered on the question as to what extent epidemic-control intervention may or must be implemented.[29] By the time the committee report had been published, however, the respective positions on prophylactic strategies had become so firmly established that the committee was no longer able to contribute noteworthy impulses in this regard. Considerable uncertainty appears to exist on this question only in the newly admitted Federal States of Germany.

Rights of self-determination and tests for HIV antibodies

The HIV test in hospitals and in doctors' offices

The procedures for conducting tests for asylum applicants as described above is only the tip of a huge iceberg. To be sure, success has been achieved, for the time being, in neutralizing the call for compulsory measures and mass testing by public health offices. Nevertheless, the German judicial system as well as public health policy have both failed in the matter of defending the patient's right of self determination against demands – arising above all from the medical side – for subjection to HIV antibody tests.

With firmly established judicial precedents which has developed over decades regarding the requirement for the patient to consent to medical procedures for therapeutic or diagnostic purposes, the legal situation by now should by all rights be perfectly clear.[30] Now, for whatever reason, it appears that all of this no longer applies for the patient who is expected to take an HIV antibody test.

Despite the significant consequences and risks of psychic and social nature which are associated with presentation to a patient of a positive HIV test result[31] – consequences which may extend to specific alterations in the legal status of the patient concerned[32] – a number of authors do not consider it legally necessary for the patient to expressly consent to the taking of a blood

sample for an HIV antibody test. These authors proceed on the basis of the still valid assumption that, in the case of a "conventional" blood test – which does not include an HIV antibody test – the patient's consent to venipuncture for taking of a blood sample represents his or her implied consent for the performance of any other type of laboratory test. The authors reach the same conclusion with respect to the patient's consent, however, if – even without appropriate notification by the physician – the intention exists to perform an HIV antibody test.

The facility is astonishing here with which the proponents of such a lax attitude toward actions associated with the right of self-determination have disregarded principles established over long years of judicial precedent.[33] On the one hand, they assert that matters of practical or economic concern in everyday work in a hospital environment justify action in setting aside the elementary rights of the patient. Where these grounds do not suffice, such proponents resort to presumptions and allegations concerning the actual intentions of the patient: e.g., that a patient's request to have a comprehensive precautionary health checkup will routinely and automatically authorize and obligate the physician to perform the HIV antibody test.[34]

Even dogmatic constructions, furthermore, are employed to avert any culpability on the part of the medical staff in cases of HIV tests which have been secretly performed. It did not take long, for example, for word to get around among medical staff concerning prevalent judicial opinion in such cases: i.e., that culpable bodily harm owing to lack of the patient's consent for an HIV test has not taken place in the event the decision to perform this test is made only after the blood sample is taken. Or that intent to commit an offense which is formed after the deed is committed (dolus subsequens) cannot be legally associated with the previous deed.[35] This reasoning continues by claiming that even an intent which plans to have an HIV test conducted along with other laboratory analysis, which is formed before the taking of the blood sample, and which is not previously revealed to the patient, does not contribute to the commission of a punishable offense, since explanation to the patient on the blood test to be conducted in the laboratory is not related to protected rights [36], and is therefore superfluous.

All of these viewpoints call attention to an extraordinary judicial divergence of opinion as compared to viewpoints proposed in other publications on the requirement to inform and to gain the patient's consent in cases in which HIV and AIDS are not involved. Böllinger, for example, evaluates this phenomenon not as a coincidental development, but as a contribution to "systematic, superfluous social rejection of those infected with HIV."[37]

As a result of this unfortunate development, attention cannot be often enough called to the relevant legal view summarized in the following concerning the requirements for valid consent to have a blood sample taken for an HIV antibody test:

To begin, an indication is required in the event that the patient herself or himself does not expressly wish the HIV test. Protection of the staff in the hospital, or prevention of transmission at all, does not represent such an indication, since staff knowledge of the HIV antibody status of a patient represents no additional protection for the staff under the assumption that conven-

tional hygienic rules are consistently observed (already an essential prerequisite in a hospital). According to the results of an American study, assumption should even be made of the very contrary.[38] In addition to the diagnostic function of the HIV test in the event of specific evidence pointing to an acquired immunodeficiency syndrome (AIDS), the following may be considered as indications in this sense:

- The desire of a couple to have children, if there exists an increased probability that one partner has an HIV infection
- The desire of an expectant mother to learn the probability with which the expected child will develop immunodeficiency after delivery.

In all cases of such valid indications, however, the essence involves the interests of the patients or their partners. In the event, on the other hand, that the alleged interests of outside third parties are incorporated into the indication, this as a rule creates an irrelevant precondition for the HIV test, with the result that the consent of the patient is invalid.

Furthermore, the patient must be informed of the purpose of the HIV test – a purpose which may not be irrational. Although this statement may be banal, it is nevertheless essential, since it is not rare that the only consequence of a positive HIV test result is the recommendation provided to the patient with respect to his or her behavior: i.e., that he or she not take part in so-called unprotected sexual intercourse. In the case of sexuality outside a permanent relationship, as well as within a so-called open relationship, this is a type of behavior which serves the purpose of preventing infection. The diagnostic HIV test, in addition, must likewise contribute to a decision on modes of therapy or behavior which would be different for a negative test result than for positive findings.

Finally, the patient must receive comprehensive information on the side effects and the risks of the medical action: i.e., the HIV antibody tests in this context. If this aspect is frequently also neglected in the context of legal discussion, this shortcoming lies in the certainly not entirely unconscious narrowing of viewpoint to the venipuncture procedure. This restricted viewpoint shuts out the entire problem complex associated with disclosure of the diagnose to the patient, and with the following reaction by the patient. It is only by viewing the entire process with blinders of this nature that it is possible to overlook the grave risks following disclosure of a positive test result to the patient: the increased risk of suicide; the possibility of depression; the danger of social rejection, significantly higher as it is for AIDS than for comparable diseases; as well as the consequences for the legal status of the patient, who from this point onward will be unable to conclude private health or life insurance policies.

In a pioneering decision already in 1987, the State's Attorney of Mainz, Germany, confirmed all of the guidelines summarized above – as well as the legal consequences of disregard of these guidelines: i.e., with confirmation of the basic liability of punishment for bodily harm for illegally taking a blood sample.[39] The ruling confirmed that the taking of a blood sample for purpose of differential diagnosis, with following use of the blood for an HIV antibody

test, represents only relative slight encroachment upon the patient's bodily integrity – if such an act be considered merely in its isolated sense. Nevertheless – so continues the reasoning of the Mainz ruling – the consequences of positive results (also including the indirect results) must be considered to be of grave significance for the patient involved – with severe enough results arising alone from the order to take the blood for purpose of the HIV test. The directive to have the sample taken already places a stigma on the patient of belonging to the so-called high-risk groups which include drug addicts, homosexuals, and prostitutes. This ruling even views the disclosure of a positive test result to be able to suddenly change the life of the patient involved in an existentially threatening manner. It furthermore leads in certain cases to extremely acute psychic situations which can escalate to the point of suicide danger. The patient would in addition experience as a matter of course considerable social consequences, either in the profession he or she intended to enter, or in the profession already practiced. The patient would thereby be subjected to social isolation and stigmatization to a degree experienced with no other disease. In the opinion of the State's Attorney, these circumstances dictate the express provision of information to the patient, with necessity of appropriate consent granted to take the blood sample.[40]

Although the actual procedures with such blood samples frequently take place in an entirely different fashion, this ruling illustrates the extraordinarily problematic relationship which basically exists between physician and patient involved here: one in which the physician routinely issues appeals for the patient's confidence, and in which the patient in turn is frequently robbed of his right to self-determination.

AIDS and criminal law

From Munich and Kempten, through Nuremberg, and finally to Karlsruhe

While the Official Investigating Committee of the German Bundestag on AIDS was still deliberating the exemplary action of law on human behavior and society, the criminal judiciary in Germany had already set its course. After lower-court decisions had been rendered in Kempten[41] and in Munich, the Regional Court of Nuremberg-Fürth considered the case of an HIV-positive American. The American had allegedly taken part several times in so-called unprotected sexual intercourse in a gay sauna – without, however, the existence of verification that he was responsible for HIV transmission. In one case, confirmation was provided that transmission had not taken place. In another case examined by the court, the sexual partner could not be located, and nothing could therefore be learned of his subsequent fate.

The American had been persistently instructed by a physician that he, as "a virus carrier," would be allowed to practice anal intercourse only with a condom. On the basis of information received from Dutch brochures, the Ame-

rican chose to practice the method of coitus interruptus – admittedly not an optimal mode, but at least one which somewhat reduced the danger of transmission.

This case had become a topic of treatment in legal literature even before rendering of decision by the court of first instance. Rolf Dietrich Herzberg, lecturer in criminal law in Bochum, Germany, had already expressed his views on this topic, and had personally recommended that such an action be considered worthy of punishment by virtue of its representing grievous bodily harm. Herzberg saw in such an approach the opportunity to retard the proliferation of AIDS. In the prevailing concept of criminal intent as shared by the body of German legal precedents, however, he saw no possibility for realizing this approach. Herzberg reasoned that, if charges were nonetheless brought against the perpetrator for grievous bodily harm – as was actually the case in the Nuremberg proceedings – this would be possible only by circumvention of received precepts of German criminal jurisprudence. In order for an offense to embody conditional intent, the precedents of jurisprudence require the existence of "... the acquiescing in or taking seriously of the risk ..." on the part of the perpetrator, "... in addition to an understanding of the forbidden and unshielded consequential danger ..." – i.e., the danger of virus transmission in this case.[42] Herzberg did not believe that such an eventuality would successfully prevail in German jurisprudence.

In what practically amounts to emotionally touching helplessness, Herzberg recommends concealing this result – unsatisfying as it is for him as well as for many others – from the HIV-infected parties involved, in order to preserve at least a small remnant of belief in the alleged AIDS prophylactic effect of criminal law.[43]

The courts, however, have entertained fewer scruples. After the Nuremberg Regional Court sentenced the accused to a prison term of two years for attempted grievous bodily harm, the German Federal Court of Justice – in a leapfrog appeal – upheld this conviction, thereby and in fact ignoring the received precepts of German jurisprudence concerning conditional intent. The Federal Court of Justice ruled that the perpetrator had acted with intent to harm, in accordance with the following:

"... by virtue of the fact that he recognizes the onset of the consequences entailed by the offense as feasible and not entirely remote, and thereby acquiesces in such a manner that he tacitly accepts the consequences of an offense, or that he at least accedes to such consequences in order to achieve the desired objective, much as the perpetrator may not actively desire the onset of such consequences in and of themselves; conscious negligence, on the other hand, is involved if the perpetrator does not concur with the consequences of an offense which he has recognized as possible, and if he seriously – not only vaguely – trusts that the consequences of the offense will not materialize."[44]

Even the uncontested protestation of the accused – i.e., that he avoided ejaculation in his partner for purposes of reducing risk – failed to persuade the federal judges to concede to the perpetrator that he had not concurred with the consequences of the offense in the form of virus transmission. In a series of commentary published on this ruling – including commentary by authors who

were basically in agreement with the ruling – astonishment was registered over the deviation from precedent which was evidenced by the Federal Court of Justice in this ruling.[45]

The Federal Court of Justice likewise ignored the position – as represented by the defense and, in particular, by German Federal Attorney General Manfred Bruns in various presentations previously published – that the sexual partners of the accused had acted at their own risk, by virtue of agreeing to go along with unprotected sexual intercourse in a gay sauna. Even Wilfried Bottke – in detailed knowledge of gay sexual practices which is astonishing for the profession of lecturer in criminal law – realized that, at least in "dark rooms," any participant must assume that his sexual partner may well be HIV positive.[46] For this reason, Bruns concentrated on the fact that – in accordance with our jurisprudence – suicide and self-inflicted injury committed intentionally under the perpetrator's own responsibility, or committed with tacit acquiescence, are not punishable offenses.[47] This position therefore sees that if a person engages in high-risk behavior – i.e., as is represented by so-called unprotected sexual intercourse in spur-of-the-moment sexual contact, or in the very frequently occurring promiscuous situations in gay saunas – he acquiesces in the risks of self-injury involved in HIV infection, in view of the more desirable advantages. This standpoint holds that such a person makes use of a "tool" – namely, the HIV-infected partner – who therefore only participates in the nonculpable, attempted act of self-injury, and who must therefore also be considered to have acted in a nonculpable manner.

The Court held, on the other hand – and in oblivion to any form of reason entailing AIDS prophylaxis – that the already infected partner possessed "... a higher degree of specialized knowledge ..." concerning the dangerous situation involved. The ruling stated that the already infected partner is accordingly better able to assess the risk concerned, and is therefore under the obligation to inform his noninfected partner of his infection, or to employ protective means.[48]

The elaboration provided by the Criminal Division of the German Federal Court of Justice – entirely discriminating as it was in comparison to the ruling of the court of first instance, as well as in its rejection of the intentions to achieve general prophylaxis and public-health action as entertained by the Regional Court – therefore provided a hypocritical impression: indeed, even the federal judges did not remain unaffected by the general atmosphere of hysteria which prevailed at that time. By pulling out all the stops, the high court arrived at the fabrication of culpability of unprotected sexual intercourse – but they also reduced the perpetrator's sentence to 18 months. It is undisputed among criminologists, however, that – at least among those sectors of the population who abide by the law – it is not so much the severity of a sentence which acts to deter crime, but – if at all – the not insignificant probability of prosecution and sentencing.

In any case, German AIDS-Hilfe organizations, AIDS counseling centers, as well as all those not merely theoretically involved with AIDS prevention, experienced this ruling of the Federal Court of Justice in the sense of a catastrophe. The court decree more firmly established the previous one-sided shift of responsibility for the proliferation of AIDS to persons with HIV – and

contributed to the entirely counterproductive effect of giving the rest of the population a false sense of being absolved from any such responsibility. Entirely apart from these aspects, however, it became clear that counseling sessions would in the future be much more difficult to conduct, by virtue of the fact that those seeking advice would be forced to discuss criminally punishable forms of behavior.

The fear was indeed well founded that the attempt was being made to achieve by criminal justice what had previously failed with the instruments of epidemic law: the systematic prosecution and social isolation of persons with HIV.

Fortunately, the following developments did not entirely bear out these fears. To be sure, a number of convictions for attempts to commit grievous bodily harm as a result of so-called unprotected sexual intercourse did in fact take place immediately following this ruling by the German Federal Court of Justice. At the same time, though, the fearfully expected wave of denunciation and prosecution did not materialize. Additional high-court decisions overturned individual attempts by Bavarian criminal justice to extend culpability even further: i.e., to merely the "... unreasonable request of the carrier of HIV virus ..." to engage in sexual intercourse with another person without protective means "... while concealing his infection ...."[49]

Despite a certain relief, long-lasting anxiety among persons with HIV, as well as a collective scapegoat feeling, still remain – the effect which was, to be sure, intended by its instigators.

The legal situation of persons with HIV and AIDS in everyday life

Fear of losing work

Experience has shown that fears of persons with HIV have to a great degree, and not without grounds, been primarily concentrated on losing their work. Even many employers with good intentions – out of consideration for the irrational fears of their customers and business associates – have seriously considered whether or not they should continue to employ HIV-positive staff at all, and have even wondered the same about members of so-called high-risk groups.

In Berlin, the Labor Court has ruled on a case in which an employee had informed the owner of his company that he was HIV-infected. The owner informed other members of the staff, who immediately demanded the dismissal of the infected colleague. The other staff lent weight to their demands by threatening to quit themselves if the ill employee were not fired.

The employer then dismissed the employee, but the Berlin Labor Court declared his dismissal ineffective. The court justified its ruling by citing long years of precedents in German labor adjuciation, in which such so-called "coercion dismissals" are admissible only if the coercion situation has not aris-

en from the side of the employer himself. In this case, the pressure had arisen precisely from the employer: the company owner had – without necessity or any other logical justification – informed the staff of the HIV infection of their colleague. The court additionally ruled that it had properly been the responsibility of the employer to protect his employee from unjustified demands for dismissal, as was here the case with the employee under attack.[50]

The judges of the Labor Court set a tone of considerable significance here: that at least they had not considered departing from established judicial precedent in view of the development of AIDS. This fortunate tendency has continued to develop – whereby, to be sure, special-protection rights for HIV-infected employees have not conversely been established. An employee with HIV-related disorders, for example, can lose his job in the same manner as an employee suffering from any other type of disease, if he stays away from work frequently or for long periods as a result of his illness.[51] The Regional Court of Brunswick, Germany, ruled in 1989 that, if a company doctor informs the employer of the HIV infection of one of the employees, the physician is guilty of violating professional secrecy and must pay damages to the employee who has suffered a loss.[52] In this particular case, prosecution did not take place because the statutory period for filing suit had lapsed.

At the beginning of 1988, Werner Hinrichs published a much-respected contribution to the objectification of the working atmosphere in the corporate sphere, and to the clarification of numerous legal questions in the interests of those suffering from HIV and AIDS. His article was entitled "Protect The Healthy But Do Not Isolate The Ill: Aspects Of Aids In Labor Law," and was published for the German Trade Union Federation. Hinrichs pointed out that there is generally no justified interest on the part of the employer to determine from job applicants whether they are HIV positive – neither through questioning during job interviews, nor by HIV tests at checkups performed before hiring. It is furthermore allowed for the applicant to reply falsely when questioned as to her or his HIV status, without legally suffering negative consequences. There is no legal resort, on the other hand, if the job applicant is required beforehand to present a negative HIV test report to a prospective employer. Hinrichs therefore especially emphasized the responsibility of company Works Councils to protect applicants in such cases.[53]

The situation in hospitals

Whereas it is by now no longer a disputed fact that, in almost all professional fields, there is no danger of HIV transmission at work, controversy still prevails in the hospital area as to which consequences should be drawn on the basis of alleged or actual danger of transmission. This situation has led to considerable anxiety among hospital staff and among patients: HIV-positive patients as well as those not tested or who are HIV negative. There have until now been no court rulings on this point. In the above-mentioned case involving violation of professional secrecy – which took place in a hospital – the Regional Court declined to rule in any manner whatsoever on the question of whether the hospital management as employer possibly might be able to have a justified

interest in knowing the HIV status of one of its staff. The German Association of Social-Insurance Underwriters for Industrial Occupational Accidents (Berufsgenossenschaft), in its department responsible for public health and welfare services, has listed AIDS in its catalog of occupational diseases, as occupational disease no. 3101, in accordance with Annex 1 of the Ordnance on Occupational Diseases (BeKV). The following was contained in an official notification issued by the Association of Social-Insurance Underwriters for Industrial Occupational Accidents in 1988:

"In the case of a verified HIV infection, and of professionally related contact with blood, the probability of causal connection must as a rule be affirmed, except for cases in which the probability of infection outside the profession is so great that, for this reason, an occupational infection cannot be considered as sufficiently probable."[54]

This published notice involves a legal formulation which merely creates operative facts to the benefit of parties insured in the German national accident-insurance program, which elements allow in turn the insured party to lodge insurance claims. As a result, this formulation by no means provides a statement on the probability of HIV transmission in the area of hospital work.

Until now, the cases of verified HIV transmission in hospital work were either the result of disregard of hygiene rules, or took place as a result of occurrences with the nature of accidents, such that even knowledge of the positive serostatus of the patient would not have enabled prevention of infection. Only one case is known of transmission from medical staff to patients: in the frequently publicized case of the dentist in the United States who had infected patients with HIV as a result of flagrant disregard of the rules of hygiene. The appeals for systematic HIV antibody tests to be conducted among medical staff, or for hospital patients, are all therefore devoid of logically reasonable grounds. Or, they assume that hygiene rules belonging to the basic principles of the medical profession are regularly being disregarded: i.e., that physicians systematically violate the fundamental rules of their profession.

The same applies to proposals leading toward requiring hospital staff or patients to inform the hospital management in the event that they are aware of being HIV-positive. Even if a number of authors have attempted to inflate this matter to the status of a legal obligation, such demands only signify a confession of insufficient hygiene, and once again amount to transferring responsibility to persons suffering from HIV.

HIV-positive civil servants?

Since members of the legal profession in Germany are particularly closely associated with the civil service, legal literature has accorded a special role to discussion on the question as to whether applicants with HIV could be allowed to attain lifelong tenure as civil servants, and as to whether an HIV test should be required for applicants for civil service work. Very early, AIFO authors repeatedly emphasized that the government could not afford to hire civil servants who would, with greater than otherwise normal probability, soon

become unable to work. Their recommendation was to disqualify HIV-positive applicants from becoming civil servants.[55] This position was confirmed by a ruling of the Bavarian Administrative Court dated 9 November 1988, which was, however, accompanied by supplementary elaboration to the effect that, at the same time, the employer insofar enjoys no judgmental leeway.[56] In other words, the employer could not be forced to completely forgo appropriate testing, and could at the most be held to restrict such screening to those applicants for whom "... according to the impression received by an examining physician, particular evidence exists which links then to membership in one of the risk groups."

The extent to which the Bavarian Administrative Courts were prepared, within the context of AIDS, to forsake the principles of a state governed by law is revealed in the recommendations with which the court attempted to deny the discriminating character of its proposed procedures. The court established that the question of membership in one of the risk groups could "... furthermore be posed in a completely general and neutral manner, without forfeiting the desired effectiveness." The court continued: "If the applicants provide no answer to the questions, then the office gathering information may draw its own conclusions therefrom."[57] These statements represent judicial recommendations to employ assumptions gathered from reactions to veiled hints – to be used, in turn, as the basis for procedural differentiation in the context of selections for public office – office which is open to all on an equal basis as constitutionally guaranteed in Article 33, Section II, of the German Basic Law.

Significant social dimensions become evident in this question, as part of a matter which involves not only the government civil service, but also the entire field of labor law. The question is: to what extent in the context of tests administered to job applicants are prognostic statements admissible which result not from the ascertainment of manifest diseases, but which arise from diagnostic techniques which are more and more sophisticated, increasingly farther oriented into the future, and possibly based at some point in time on gene technology? What degree of coincidence, or whose peremptoriness will in the future determine whether screening for job applicants will be restricted to, say, merely tests for blood sugar or blood pressure – or whether highly sophisticated medical apparatus and laboratory technology will be employed in diagnosis in order to guarantee that the applicant will be able to "amortize" the costs of training and upkeep which the employer invests? Attention has appropriately been called to the fact that, in any case, up to 80% of the civil servants who leave their jobs every year in general public administration, are granted early retirement because of premature disabilities – without in fact AIDS having, up to now, played any kind of role whatsoever.[58]

In their extensive study carried out in 1990, the authors Peter Lichtenberg and Werner Winkler called attention to the grievous constitutional-law misgivings which have arisen as a result of Bavarian adjuciation:

"Neither the protection of public administration from financial and organizational burdens, nor the defense from infections in the sense of Section 1 of the German Federal Act for the Control of Epidemics convincingly suffices as justification – especially in view of the fact that the eloquence of

the HIV test is considerably restricted in extent when applied for civil-servant applicants as the minor group which they represent."[59]

On 27 March 1987, the Conference of the Ministers of Health of the German Federal States (GMK) issued a policy statement against HIV tests for civil-service candidates, with justification on the basis of social considerations and of the devastating example such tests in public service would furnish for other employers. As a result, Bavaria remains the only German Federal State which continues to deny civil-service status to candidates owing to positive HIV test results conducted on a mandatory basis.

Private health and life insurance

Probability and prognosis represent essential factors in the insurance business. It was natural that the private health and life insurance companies reacted with particular alarm when extensive details became known on the manifestations and effects of the HIV infection. The source of alarm was not so much the expectation of increases in insurance benefits, as such, which the companies would be forced to pay: it soon became evident, indeed, that this development would for the time being proceed in a foreseeable manner. The sole important factor, rather, was for each insurance company to maintain its clientele on as low-risk a level as possible in relation to its competitors.

Insurance companies accordingly issued instructions – either explicitly or implicitly – to their salesmen to become especially aware of any indications of membership in one of the "risk groups" while present in the ambience of applicants for private health or life insurance.[60] If an insurance salesman visited the home of a man over 30 who had never married, for example, the applicant could expect that the salesman would pay special attention to any traces of feminine deportment – or that he would note the presence of, say, a conspicuous collection of musical recordings by the German singer Marianne Rosenberg: a reliable indication, according to widespread popular belief, for the owner's belonging to the "risk group" of homosexual men.[61] Insurance salesmen, however, owing to the workings of their commission system, are chiefly interested in having applicants sign an insurance policy, and not in preventing such a conclusion. In addition, they cannot expect to suffer any immediate disadvantage from any early or excessive benefits which their company might be forced to pay. It therefore appears that such instructions issued to insurance salesmen may be disregarded as minor in consequence.

In the end, the insurance trade came to an internal agreement – again, in the interest of uniformity in competition – and issued a routine policy declaration to the following extent: in cases of life-insurance policies over DM 150,000 presentation of negative HIV test results would become a stipulation for conclusion of the policy.

In the case of all other policies in which health factors of the insured party play a role – and this applies in the opinion of insurance companies also to private accident-insurance policies – the standard stipulation is binding as set forth in Section 16 of the German Act on Insurance Policies (VVG): i.e., that the insured party, upon conclusion of the policy, shall reveal to the insurance

company all conditions known to the insured which are of relevance for "... assumption of risk." Since the law stipulates that, in case of doubt, those conditions shall be considered of relevance for assumption of risk which the insurance company expressly poses in writing, all application forms now include questions concerning an HIV test and its results. In the event that the applicant provides culpable answers to these questions – i.e., that he or she intentionally or negligently provides false information – the insurance company shall be entitled to withdraw from the contract and shall not be obliged to render payment of insurance benefits.

This legal situation – which by now has been upheld in a number of judicial rulings[62] – as well as the consistent practice of insurance companies not to sign policies with HIV-positive applicants for health and life insurance, mean that it is practically impossible for persons with HIV to provide insurance coverage for themselves, or those close to them, beyond the limits of government-sponsored social insurance. It is also impossible for them to obtain major bank credit required for professional or private planning, since such loans are routinely secured by life insurance specifically required for the loan.

Aliens in Germany with HIV: sometimes tolerated, and sometimes repatriated

The status of aliens with HIV who do not have citizenship in a country of the European Community is particularly insecure with respect to their residence permission in Germany. In a number of decisions, various German courts have ruled in thoroughly contradictory fashion. In 1985, for example, the Administrative Court of Saarlouis, Germany, ruled that HIV infection

"... justifies the repatriation of an alien — regardless of his individual behavior – on the grounds alone of the danger of AIDS (e.g., also in case of his treatment by a physician or in a hospital)."[63]

The court acted here apparently more under the influence of reporting in the tabloid press than on the basis of well-founded legal principle. The Frankfurt Administrative Court struck the same note, as late as 1989, when it ruled that HIV infection represents

"... such a high degree of peril to the public health of the Federal Republic of Germany that, on this ground alone, the residence of an alien in the Federal Republic cannot be (further) tolerated."[64]

In contrast, however, the Higher Administrative Court of the German Federal State of Baden-Württemberg ruled in the summer of 1987 that the extension of residence permission for an HIV-positive alien is

"... not precluded solely on the basis of legal grounds (negative barrier) if, on the basis of his residence heretofore, it can be assumed that he despite his HIV infection does not jeopardize the public health in the sense of an offense meriting repatriation as set forth in Section 10, Paragraph 1, Clause 9 of the Aliens Law (old version)."[65]

This differentiated conception of the matter is based on the behavior of the alien, and not on the HIV infection; it appears to represent the predominant outlook in Germany today. At the same time, however, it does not yet repre-

sent the exclusive legal view: indeed, the opinion is still encountered – although not undisputed – in commentary to alien law that the public health is likewise jeopardized in the case of an incurable communicable disease, even through no evidence exists that the alien actually transmits a disease to others by virtue of his behavior.[66]

The Bavarian Catalog of Measures contains its own section on alien law and stipulates that HIV-infected aliens must in all cases be refused residence permission. If an alien submits an application for a residence permit in Bavaria, and if she or he is not a citizen of a country of the European Community, or not the citizen of Austria or Switzerland, then he or she must submit to an HIV test.[67]

High-court adjudication has not yet taken place in Germany to settle the question of whether and under what conditions the authorities may request an HIV test from aliens who apply for a residence permit, or the question of what consequences a positive test result may have in this context. In a comprehensive study in this area, the attorney Bernd Aretz, former member of the board of German AIDS-Hilfe, has arrived at the conclusion that,

"... in view of the number of aliens entering the Federal Republic of Germany, the number of infected Germans, and the number of those aliens who are either not allowed to be tested or who are not allowed to be repatriated upon presentation of positive test results, ... those aliens who are infected and who could theoretically be repatriated are not of numerical consequence. Compulsory measures taken with respect to aliens on the basis of an HIV infection impair the social climate to such a degree that approaches to restrain the proliferation of the infection – by aliens as well – are significantly impeded.[68]

It is doubtful whether this insight will prevail in court decisions or especially in the administrative practice of German immigration offices – particularly in view of the tendency existing at these points of extensively exploiting every possibility to deny issuing residence permits to aliens.

Conclusions

The judicial reaction to the phenomenon of AIDS is remarkable owing to various of its aspects. The initial hesitance on the part of public health policymakers – which was at the beginning forced to develop a prophylactic concept against a disease which was new and unfamiliar in every respect – was matched at the same time by extraordinary commotion on the part of legal policymakers and jurists. Despite isolated warnings about "apparent and deceptive activism" and reminders to preserve "politico-legal circumspection,"[69] demands arose ever more frequently for rigorous application of existing law, or creation of new law: proposals characterized not only by panicky but also by legally dogmatic reactions. The list of references entitled "AIDS and Law" compiled by German Federal Attorney General Manfred Bruns by now encompasses around 500 titles, not including legal decisions. All of this

commotion, however, has had no noticeable effects on the epidemiological situation. Even in Bavaria – i.e., precisely where the most systematic efforts were directed through the legal means of coping with this disease – there has been no evidence of special epidemiological developments: neither for the better nor for the worse.[70] At the same time, however, one may indeed speculate on whether the acceptance of preventive appeals would not have been taken more effectively to heart, had the judicial flash in the pan not taken place to repeatedly alarm the social groups involved, as well as society at large.

It has been only recently that certain publications have moved to the fore which have primarily treated the social situation of persons with HIV, and which have endeavored to find ways and means to support and protect these people. Nevertheless, structural discrimination has developed in Germany with respect to persons with HIV – one which justifies speaking of a special legal status: special in the sense of being inferior.[71] This development can well have consequences for the future – and not only for persons with HIV. Gene analysis and manipulation now make it possible to forecast the quality of economic utility of a human being. If persons with HIV are today classified as unsuitable for civil service, or dangerous for certain areas of society, then they have been placed in a pioneer role by virtue of the fact that most of them belong to groups of society which at any rate had been considered to be deviate. The legal differentiation elaborated on in the above takes as its point of departure not the modes of behavior of certain persons, but their personality characteristics, and can easily be obscured with respect to these groups of society. Once such differentiation has become established as part of legal standards, then nothing stands in the way of their being applied to other groups of society. The politico-legal calm which has set in recently must not be allowed to deceptively lull society into ignoring the fact that legal measures which persecute and isolate minorities exert, now as before, an attraction on a great number of politicians and jurists. Only very slight changes in the political landscape would be required to reactivate such tendencies.

Special AIDS legislation is not required to counter such an eventuality. Indeed: it is to be feared that, given the current political constellation, such a development would lead to a legislative package containing not only supporting but also discriminating elements. Nor is an anti-discrimination law required, as is currently being called for from various sides. The fundamental function of a free society based on the rule of law is, after all, the prevention of discrimination. The Fundamental Rights Article of the German Basic Law – particularly its Sections 1 (Paragraph 1), 2, and 3 – already express this clearly. Even if such guarantees of basic rights initially only indirectly restrict the power of the state, they at the same time represent an injunction for the legislature to take action wherever structural discrimination becomes apparent – i.e., "structural" in the sense of involving deficiencies in the regulatory mechanisms of the legal system. In such circumstances it does not suffice for the government to issue declamatory demands for the end of discrimination. Evidence from the USA confirms this: that anti-discriminatory laws have by no means contributed to improvement of the situation of the nonwhite population there. Experience gained in the Federal Republic of Ger-

many provides further verification from the attempts to abolish discrimination against women – that even incipient traces of the improvements desired become apparent only in situations in which absolutely specific standards are established. One example in Germany here is progress made from the basic prohibition against indicating the desired sex of applicants, in advertisements announcing vacancies on the employment market. In other words: anti-discriminatory legislation points out the problem, but does not solve it.

What we in Germany require is concrete legal norms for protection against damages as a result of the misuse of data related to the individual person – and this includes data on personal characteristics such as HIV serostatus. The already existing Data Surveillance Act, and other comparable legislation for protection against data misuse, prohibit only the detrimental utilization and forwarding of data related to individual persons. From the elaboration above, it should be clear that the detrimental acquisition of such information must also be prohibited, in the two following areas at least:

1. In the context of employer-employee relationships, it must be prohibited to gather data on physical disposition insofar as such data extends beyond the determination of currently existing disorders. Such prohibition should include public-service law, i.e., the law governing civil servants. Feasible here are not only civil-law sanctions – e.g., claims for restitution oriented to resulting loss in income – but also criminal-law sanctions, in the event that difficulties in the establishment of the specific loss are to be prevented.
2. In the context of physician-patient relationships, infringement of the right of informational self-determination – with the definition of "infringement" here also to cover the conduct of HIV tests, as supported by the great predominance of legal opinion – must be punished in a manner similar to that applicable for the prohibited forwarding of medical data in the context of a breach of professional secrecy.

Since the problem complex involved here does not admit restriction – either to the relationship areas outlined above, or to the phenomenon of HIV/AIDS – the opportunity most admirably presents itself of establishing fundamental prohibition of violation of the right of informational self-determination, beginning at the point of the prohibited acquisition of data related to the individual person. Owing not only to the fundamental tone which such legal supplement would set, but also to the structural legal grounds concerned, such changes should most properly take place in the German Criminal Code itself, and not merely in special supplementary laws devoted only to data protection.

Notes

1 Deutsch, Erwin. "AIDS und Blutspende", Neue Juristische Wochenschrift (NJW), 1985, 2746
2 Cf. Koch, Michael G. AIDS – vom Molekül zur Pandemie, Heidelberg, 1987
3 Cf. Walter, Alfred. "AIDS als Versuchung, Munich, 1989, especially p. 114 ff.
4 Lippstreu, Wolfgang. "AIDS und Gewerberecht", AIFO, 1987, pp. 469 – 475
5 Frösner, Gert G. "AIDS-Bekämpfung: II. Die unterschiedliche Seuchenbekämpfung in verschiedenen Ländern", published in AIFO, 1989, p. 597 ff. (598)
6 Ibid., p. 599
7 Bayerischer Verwaltungsgerichtshof München. Ruling of Bavarian Higher Administrative Court, 19 May 1988, Az. 25 CS 88.00312, published in NJW, 1988, pp. 2318 – 2321
8 Bundestagsdrucksache, 8/2468, Anl. 1, p. 25
9 Cf. e.g., Albrecht, J. "Diskussionsbemerkung zur Veröffentlichung von I. Schäfer", Das öffentliche Gesundheitswesen, 1987, p. 670
10 Zitzelsberger, Walter. "Ausländerrechtliche Aspekte der "AIDS-Problematik", published in AIFO, 1988, p. 49 ff. (51)
11 Gallwas, Hans-Ulrich. "Gefahrenerforschung und HIV-Verdacht", printed in NJW, 1989, p. 516 ff.
12 – "AIDS, Alltag und Recht", printed in MDR, 1987, p. 353; – "AIDS im Betrieb und im Arbeitsleben", printed in MDR, 1988, p. 95; – "AIDS und Strafvollzug", printed in Strafverteidiger, 1987, pp. 504 – 507; in other sources as well
13 Bruns, Manfred. "AIDS, Alltag und Recht", MRD, 1987, p. 354 ff.
14 Bundesverfassungsgericht. Ruling of the German Federal Constitutional Court dated 28 July 1987 – BvR 842/87; NJW (Neue Juristische Wochenschrift), 1987, pp. 2287 – 2288
15 Ibid.
16 Ibid.
17 Cf. Hoffmann, Jochen. "Verfassungs- und verwaltungsrechtliche Probleme der Virus-Erkrankung "AIDS unter besonderer Berücksichtigung des bayerischen Maßnahmenkatalogs", NJW (Neue Juristische Wochenschrift), 1988, pp. 1486 – 1494
18 Seewald, Otfried. "Zur Verantwortlichkeit des Bürgers nach dem Bundesseuchengesetz", NJW (Neue Juristische Wochenschrift), 1987, pp. 2265 ff.
19 Verwaltungsgerichtshof München. Ruling of the Higher Administrative Court of Munich, NJW (Neue Juristische Wochenschrift), p. 2318
20 "Bekanntmachung des Bayerischen Staatsministeriums des Innern vom 19.05.1987 zum Vollzug des Seuchenrechts, des Ausländerrechts und des Polizeirechts", published in various sources, also in AIFO, 1987, pp. 346 ff.
21 Bayerischer Verwaltungsgerichtshof, published in AIFO (AIDS-Forschung), 1988, p. 283; Verwaltungsgericht München, StV (Der Strafverteidiger), 1988, p. 165; Bayerischer Verwaltungsgerichtshof, published in NJW (Neue Juristische Wochenschrift), 1988, p. 2318; Verwaltungsgericht München, AIFO, 1988, p. 694; Verwaltungsgericht Augsburg, AIFO, 1988, p. 569
22 Cf. Hoffmann, op. cit.
23 "AIDS: Fakten und Konsequenzen", Zwischenbericht der Enquête-Kommission des 11. Deutschen Bundestages: "Gefahren von "AIDS und wirksame Wege zu ihrer Eindämmung", published in Zur Sache – Themen parlamentarischer Beratung, Nr. 3/88, p. 22
24 Ibid., p. 23
25 Ibid., p. 25
26 Ibid., pp. 24 ff.
27 "AIDS: Fakten und Konsequenzen", Endbericht der Enquête-Kommission des 11. Deutschen Bundestages: "Gefahren von "AIDS und wirksame Wege zu ihrer Eindämmung", published in Zur Sache – Themen parlamentarischer Beratung, Nr. 13/90, p. 316
28 Ibid., p. 322
29 Ibid., pp. 355 ff.
30 As only one source for many others, with numerous additional references: Bundesgerichtshof. Ruling of the German Federal Court of Justice, 16 October 1962, NJW (Neue Juristische Wochenschrift), 1963, p. 393; Bundesgerichtshof. Ruling of the German Federal Court of Justice, BGHSt 12, 379 (383) = NJW (Neue Juristische Wochenschrift), 1959, 825

31 Cf. the ruling of the Mainz State's Attorney, in NJW (Neue Juristische Wochenschrift), 1987, p. 2946; JA, 1988, p. 112, with reference to Solbach; NStE StGB 223, Nr. 3, as well as Deutsche AIDS-Hilfe e.V. (publisher): "AIDS und HIV im Recht", Bamberg, 1991, p. 263 ff.
32 For example, not to be in a position to open a private health or life-insurance policy. See additional references below.
33 See note 15
34 G. Pfeiffer. "AIDS und Recht; Das Parlament – Beilage: aus Politik und Zeitgeschichte, Nr. B 48/88 dated 25 November 1988, p. 21 (23)
35 Janker, H. "Heimliche HIV-Antikörpertests – strafbare Körperverletzung?" NJW (Neue Juristische Wochenschrift), 1987, p. 2897 (2899)
36 Janker, op. cit., p. 2902 (without a specific reference as to which protected rights are involved)
37 Cf. Böllinger, op cit.
38 Gerberding, J.L. et al. "risk of exposure of surgical personnel to patients's blood during surgery at San Francisco General Hospital", NEnglJMed 322:1788-93 (June 21), 1990
39 Staatsanwaltschaft beim LG Mainz. "Einstellungsverfügung vom 14.08.1987", 2 Js 55.752/87, printed in NJW (Neue Juristische Wochenschrift), 1989, pp. 2946-2948; also in RAR (Rundbrief AIDS & Recht der D.A.H.), no. 2/1989, pp. 1-3
40 Ibid.
41 Amtsgericht Kempten. Ruling of Local Court in Kempten on 20 June 1988, Az. Ls 11 Js 393/88 printed in NJW (Neue Juristische Wochenschrift), 1988, pp. 2313 ff.
42 Herzberg, Rolf Dietrich. "Die Strafdrohung als Waffe im Kampf gegen AIDS?" NJW (Neue Juristische Wochenschrift), 1987, pp. 1461-1466 (1466)
43 Ibid.
44 Bundesgerichtshof. Ruling of the German Federal Court of Justice, 4 November 1988, Az. 1 StR 262/88, printed in several sources, including NJW (Neue Juristische Wochenschrift), 1989, pp. 781 ff.
45 For example, in: Bottke, Wilfried. "Rechtsfragen beim ungeschützten Geschlechtsverkehr eines HIV-Infizierten", published in AIFO, 1989, pp. 468 ff.
46 Bottke, op. cit., p. 471
47 Bruns, Manfred. "Nochmals: "AIDS und Strafrecht", NJW (Neue Juristische Wochenschrift), 1987, pp. 2281-2282
48 Bundesgerichtshof. Ruling of the German Federal Court of Justice, op. cit., source 44
49 Bayerisches Oberstes Landesgericht. Ruling of Supreme Regional Court of Bavaria, 26 October 1989, NJW (Neue Juristische Wochenschrift), 1990, pp. 281 ff.
50 Arbeitsgericht Berlin. Ruling of the Berlin Labor Court, 19 May 1987, Az. 24 Ca 319/86, printed in NJW (Neue Juristische Wochenschrift), 1987, p. 2325
51 Landesarbeitsgericht Berlin. Ruling of Berlin Higher Labor Court, 10 June 1987, Az. 10 Sa 11/87
52 Landgericht Braunschweig. Ruling of the Brunswick, Germany, Regional Court, 5 October 1989, Az. 4 O 240/89
53 Hinrichs, Werner. "Gesunde schützen, Erkrankte nicht ausgrenzen – Arbeitsrechtliche Aspekte von AIDS", special printing taken from Arbeitsrecht im Betrieb, no. 1/88, p. 8
54 Mertens, Gerhard. "Berufskrankheit AIDS", published by Berufsgenossenschaft für Gesundheitsdienst und Wohlfahrtspflege, as special printing taken from Mitteilungsblatt, no. 21
55 For example: Kathke, Norbert. "Die Begutachtung von anti-HIV-positiven Personen durch das Gesundheitsamt", AIFO (AIDS-Forschung), 1986, pp. 665-668; as well as in Seume, Manfred. "Der HIV-Antikörpertest bei Einstellungsuntersuchungen von Beamtenbewerbern", AIFO, 1987, pp. 703-707
56 Bayerischer Verwaltungsgerichtshof München. Ruling of Bavarian Higher Administrative Court in Munich, 9 November 1988, Az. 3 CS 88.01854, printed in AIFO (AIDS-Forschung), 1989, p. 89-92
57 Ibid., p. 92
58 For example, Haesen, Wilfried. "HIV-Test bei Beamtenanwärtern?" published in Zeitschrift für Rechtspolitik (ZRP), 1989. pp. 15 ff.
59 Lichtenberg, Peter, Dr. Dr. and Dr. Werner Winkler. "Die Immunschwäche AIDS und das Beamtenrecht unter besonderer Berücksichtigung des HIV-Antikörpertests als Einstellungsvoraussetzung", published in Deutsches Verwaltungsblatt (DVBl), 1990, pp. 9-18
60 Cf. Wolff, Volker. "Suchtrupps", printed in Capital, no. 3, 1987
61 We chose to allow this ironically exaggerated form of expression, as it used only at this point, to remain

62 For example, Oberlandesgericht Düsseldorf. Ruling of Higher Regional Court of Düsseldorf, Az. 4 U 38/91, printed in Rundbrief AIDS und Recht of the D.A.H. (RAR), 1/2, 1992, pp. 17 ff.; – Landgericht Frankfurt in VersR 1992, p. 563

63 Verwaltunggericht Saarlouis. Ruling of Administrative Court of Saarlouis, Germany, 2 October 1985, Az. 10 F 35/85, printed in AIFO (AIDS-Forschung), 1986, pp. 260-262

64 Verwaltungsgericht Frankfurt. Ruling of Frankfurt Administrative Court, 8 February 1989, Az. VI/1-H 3719/88, printed in Rundbrief AIDS & Recht of the D.A.H. (RAR), 1989, pp. 8-9

65 Verwaltungsgerichtshof Baden-Württemberg Mannheim. Ruling of the Baden-Württemberg Higher Administrative Court in Mannheim, 30 July 1987, Az. 11 S 805/87, printed in NJW (Neue Juristische Wochenschrift), 1987, pp. 2953-2954

66 Cf. Kloesel-Christ. Deutsches Ausländerrecht, 2nd edition, § 10, Rdr. 65

67 This is the so-called "Bavarian Catalog of Measures": Bekanntmachung des Bayerischen Staatsministeriums des Innern vom 19.5.1987 zum Vollzug des Seuchenrechts, des Ausländerrechts und des Polizeirechts, Az. IE/IA/IC – 5280 – 8.2./7/87, Abschn. B

68 Aretz, Bernd; Ulrike Meuser; and Hannes Flotho. "Rechtliche Beurteilung der HIV-Infektion von Ausländern in der Bundesrepublik Deutschland, Marburg, 17.2.1989, Drucksache der AIDS-Enquêtekommission, Nr. 390

69 For example: Koch, Hans-Georg. "Rechtliche Probleme bei AIDS", special printing from Freiburger Universitätsblätter, Heft 97, November 1987, p. 66

70 Cf. the monthly case statistics published by the German Federal Health Office (Bundesgesundheitsamt, AIDS-Zentrum)

71 Baumhauer, Friedrich."HIV-Positive = Sonderrechtsstatus?" D.A.H.-Aktuell, Nov/Dec 1989, pp. 14-15

AIDS-FORUM D.A.H.

BAND XII

Aspects of AIDS and AIDS-HILFE in Germany

- On the History of the AIDS-Hilfe
- Reactions of the Gay Community to AIDS in East and West Berlin
- Gay Men and Health Promotion
- Harm Reduction and the Political Concept of the "War on Drugs" in Germany
- JES – History, Demands and Future
- Therapy Studies, Ethics and Design – Involving Directly Affected People in Clinical Trials
- Caring for Out-Patients with AIDS
- Non-Governmental Organizations in Europe: Networking as a Tool for Information, Education and Prevention
- Legal Measures Employed in Germany for Coping with AIDS

ISSN 0937-1931

Deutsche AIDS-Hilfe e.V.