



# WHO

REGIONAL OFFICE FOR EUROPE



GLOBAL PROGRAMME ON AIDS

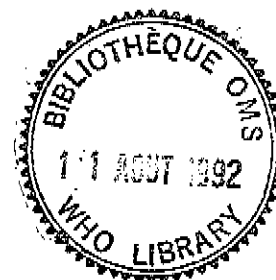
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## *AIDS HOTLINES FOR COUNTRIES OF CENTRAL AND EASTERN EUROPE*

Report on a WHO Workshop

Warsaw  
13-16 December 1991



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EUR/HFA TARGET 4

This activity was organized by the WHO Regional Office for Europe to promote work aimed at achieving the following target in the health for all strategy.<sup>a</sup>

## **TARGET 4**

### **REDUCING CHRONIC DISEASE**

*By the year 2000, there should be a sustained and continuing reduction in morbidity and disability due to chronic disease in the Region*

### **Keywords**

AIDS – prevent/control  
HOT LINES  
EUROPE  
CCEE

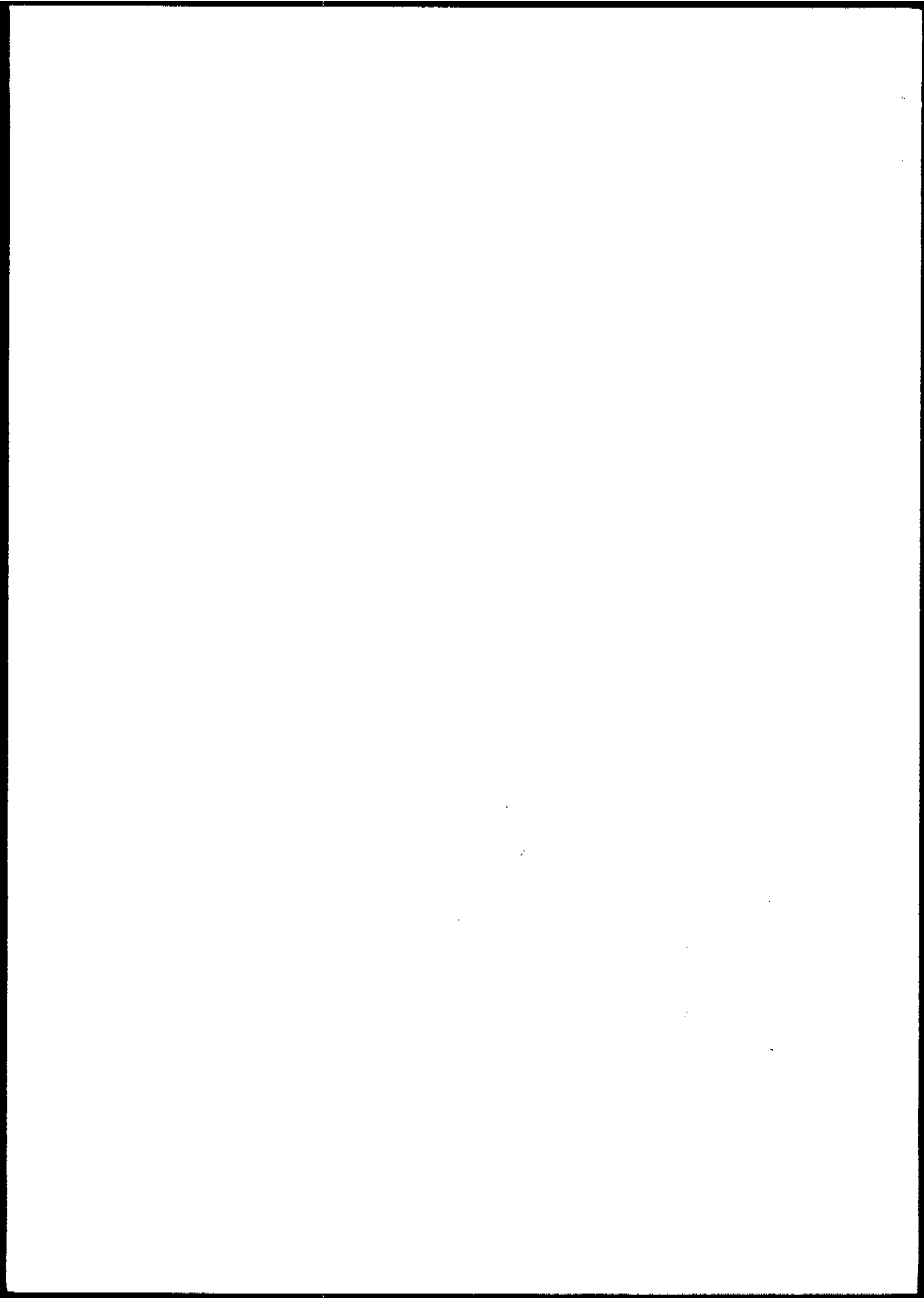
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<sup>a</sup> *Updating of the European HFA targets*. Copenhagen, WHO Regional Office Europe, 1991 (document EUR/RC41/Inf.Doc./1 Rev.1).

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## I. WORKSHOP PROGRAMME

### GENERAL INFORMATION

#### Steering Committee

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National Committee on AIDS Control, The Netherlands

Norma van Hoewijk, Secretary  
National Committee on AIDS Control, The Netherlands

Piotr Jaworski, Co-organizer  
Ministry of Health and Social Welfare, Poland

#### Chairpersons

##### Chairpersons:

- Dorota Cianciara, National Institute of Hygiene, Poland
- Henning Mikkelsen, WHO Global Programme on AIDS, Denmark

##### Facilitators:

- Shelley Gurney, National AIDS Helpline, United Kingdom
- Alan Jamieson, National AIDS Helpline, United Kingdom
- Kirsten Madsen, AIDS-helplinien, Denmark

#### Rapporteurs

##### Overall rapporteur:

- Rinske van Duifhuizen, National Committee on AIDS Control,  
The Netherlands

Working-group rapporteurs:

- Kerstin Dyrendahl, AIDS Helpline, Sweden
- Carsten Hinz, AIDS Hilfe Berlin, Germany
- George Sved, Swedish Federation for Gay and Lesbian Rights, Sweden

PROGRAMME

FRIDAY, 13 DECEMBER

- 10.00 - 11.30 Meeting organizers, facilitators, rapporteurs
- 12.30 - 14.00 Registration
- 14.00 - 15.30 Opening ceremony
- Welcome by Zbigniew Halat, M.D.
- Welcome by Svein-Erik Ekeid, M.D.
- Keynote speech 'AIDS Hotlines as a tool for AIDS prevention', by Hans Moerkerk, M.D.
- Keynote speech 'Results of the first and the second AIDS Hotline conferences', by Monique Middelhoff
- Keynote speech 'Maximizing the Existing Health Potential of People Living with HIV/AIDS', by Richard Rector
- 15.30 - 16.00 Break
- 16.00 - 17.30 First working group meetings
- 19.00 DINNER
- 20.30 - 22.00 Parallel video-sessions
- Group 1
- 20.30 Title: Right of Choice  
Target group: Youth  
Bulgarian videoprogramme based on interviews with several young people (20 minutes)
- 20.50 Three videospots  
Target group: youth  
Different Polish spots for youth 'Meeting at 9 p.m.', 'The Two', 'Wall' (10 minutes)
- 21.00 Title: Is it Freud?  
Target group: youth  
Polish videoprogramme on love, drugs and HIV (10 minutes)
- 21.15 Title: The intolerance  
Target group: general public  
A Polish videoprogramme about the relation between society and people with HIV/AIDS (10 minutes)

- 21.30 Title: Danish AIDS campaign 1987-90  
Target group: general public  
Introduction to the Danish model (20 minutes)
- Group 2
- 20.30 Title: Leben mit Drogen  
Target group: drug-users and counsellors  
German documentary (30 minutes)
- 21.00 Title: Personal Choice  
Target group: Prostitutes  
Bulgarian video programme based on interviews with  
prostitutes (11 minutes)
- 21.30 Title: living with AIDS  
Target group: general public  
BBC television programme (30 minutes)

**SATURDAY, 14 DECEMBER**

- 08.30 - 09.00 Meeting organizers, facilitators, rapporteurs
- 09.00 - 10.00 Plenary session: Basic information
- Spread of AIDS in Europe, use and limitations of  
data for Hotline counsellors, by Henning Mikkelsen
- Counselling and drug-use, by Kirsten Madsen
- Safer sex counselling, experiences from the Swedish  
AIDS hotline, by Kerstin Dyrendahl
- 10.00 - 10.30 Break
- 10.30 - 12.30 Working-group discussions
- 13.00 LUNCH
- 14.00 - 15.00 Plenary session: Hotline experiences in central  
and eastern Europe
- The Hungarian AIDS Hotline, by Zsuzsanna Sudar
- Experiences of the Institute of Venerology Medical  
Academy Poland, by Iwona Rudnicka
- Polish experiences with AIDS Hotline counselling by  
telephone, by Jan Krukowiecki
- 'Confidence telephone-line' for AIDS prevention in  
Bulgaria, by Darina Surcheva and Dimitar Kujumdjiev
- Problems of psychological assistance for  
homosexuals, by Kirill Zhuravlyov, USSR

15.00 - 15.30 Break

15.30 - 17.00 Working-group discussions

**SUNDAY, 15 DECEMBER**

08.30 - 09.00 Meeting Organizers, facilitators, rapporteurs

09.00 - 10.00 Plenary session: AIDS-Hotline management and organization

Good practice for AIDS Hotline counselling, by Alan Jamieson

Confidentiality and anonymity, by Shelley Gurney, National AIDS Helpline

Promotion of and publicity for AIDS-Hotlines: public relations at the Danish AIDS-Linien, by Kirsten Madsen

10.00 - 10.30 Break

10.30 - 12.30 Working-group discussions

13.00 LUNCH

14.00 - 15.00 Plenary session: the calls and the callers.

Sorry, I've got the wrong number! Experiences of gay Hotlines in Sweden by George Sved, Swedish Federation for Gay and Lesbian Rights, Sweden

Role-plays: two case-studies

15.00 - 15.30 Break: coffee and tea

15.30 - 17.30 Working-group discussions/role plays

**MONDAY, 16 DECEMBER**

08.30 - 09.00 Meeting organizers, facilitators, rapporteurs

09.00 - 10.00 Final working-group discussions

10.00 - 10.30 Break

10.30 - 12.00 Plenary session: reports of the working groups

12.00 - 12.15 Closing address  
Plenary

## II. OPENING SPEECHES

### Opening statement, by Zbigniew Halat, M.D.

It gives me great pleasure and it is an honour for me to welcome you to Poland, to Warsaw and to this workshop on AIDS hotlines for countries of central and eastern Europe. The workshop is convened in collaboration with the World Health Organization, the Ministry of Welfare, Health and Cultural Affairs of The Netherlands and the Ministry of Health and Social Welfare of Poland, and organized by the Dutch National Committee on AIDS Control.

I understand that this is the second such meeting in Europe, and the third in the World, organized with financial support from the Dutch Government. I wish to express my gratitude to the Government of The Netherlands for their commitment in this respect. I also want to put on record my appreciation of the fact that so many participants from the countries in Eastern and Central Europe have been able to come together here, in spite of all the practical difficulties we know most of you experience at present. Some sixty individuals from countries in central and eastern Europe have gathered here today including facilitators and temporary advisers from seven Western European countries.

The tremendous interest to participate in the workshop is an indication of the correct decision of the Global Programme on AIDS in the WHO Regional Office of Europe to give priority to the planning and development of AIDS hotlines in countries in central and eastern Europe.

This is a field where a tremendous amount of experience has accumulated recently in countries in western and northern Europe over a relatively short period of time. There is need to share knowledge of the success and the failures that has been gained, so that we in the countries of central and eastern Europe may profit by the experiences in western and northern Europe, and adapt your knowledge to our own realities.

It is often said that, at present, the only vaccine we have against transmission of HIV infection is information and education. However, the AIDS pandemic has underscored what we have known for a long time: that not every form of information influences people, increases knowledge, changes attitude, or makes a difference in changing behaviour. The AIDS pandemic has taught the world that there are great differences between old-fashioned health propaganda and the modern social marketing that is part of health promotion. It has illustrated the importance of target groups having confidence and trust in the source of the information. It has underlined that representatives of target groups should have a say in how their peers should be approached. It has shown the total superiority of one-to-one transfer of information in a counselling setting, and targeted campaigns should not be discounted as important consciousness-raising elements of a total information, education and health promotion strategy in HIV/AIDS prevention and control. However, before we start attempting to transmit information to achieve behaviour change, we must learn how to communicate effectively in a counselling situation. Counselling in any setting demands listening skills and empathy. Helpline counselling by telephone requires special skills. These skills do not come naturally to most of us; they need to be learned.

When a person has overcome his or her reluctance to call an anonymous telephone number and to start to talk to a stranger about sensitive issues like HIV/AIDS, sex and drug use, they do not usually want to be met by a person spewing out series of epidemiological statistics or masses of biomedical facts. What they want to meet at the other end of the telephone line is a sensitive, empathic person with active listening skills; a person with ability to guide the caller to decisions that are right for her or him.

Various ways have been chosen in various countries and different settings to meet the needs and demands of the hotline callers or "customers". In some cases great stress has been put on the counsellors with professional training in health or social sciences or services. In other cases the stress is on volunteers with non-professional backgrounds; simultaneously stressing the need for the helpline to enable the non-health (or social service) professional to be really a professional counsellor rather than a counsellor with a professional background, and achieving this through intensive and extensive training, and on-the-job supervision.

Participants at this workshop will have the possibility to discuss the pros and cons of various solutions to a number of challenges and problems that have accumulated over the years of running AIDS helplines and other specialist telephone hotlines in western and northern Europe.

In this, let us remind each other, however, that the solution we choose for our own ventures must build on acknowledgement of the cultural and traditional sensitivities that are peculiar to each group targeted. Such sensitivities exist and need to be recognized. Breaking down social, legal, cultural, religious and traditional barriers may be needed concerning sexuality, sexual orientation and sexual practices, as well as concerning illicit use of alcohol, drugs and other substances. But in breaking down these barriers we must be willing to acknowledge that they exist and respect them for what they are, and on the other hand not be over afraid of breaking taboos. The very fact that there exists in the countries of Europe such variety of social, legal, cultural, religious and traditional attitudes is in itself one of the things that make Europe an exciting continent, and with increase in personal liberty in so many more countries, even more so at present than a few years ago. However, in relation to the AIDS epidemic the very expressions of freedom paradoxically put the population at risk calling for a firm public health and social policy response with concerted action of voluntary activities and statutory actions and duties.

There is an impressive array of participants and of advisers at this workshop. I am convinced that together you will be able to find answers on how to respond to this paradox of personal freedom and health-endangering behaviour. You will not give us the ultimate answer, but you cannot fail to give us important guidance. I wish you every success in your deliberations.

**AIDS HOTLINES, An important element towards an integrated system of HIV prevention, by Hans Moerkerk, M.D.**

It is a great pleasure for me to address you at this opening session on behalf of the Government of The Netherlands, one of the main sponsors of this meeting as a result of an agreement between the Regional Office for Europe of the World Health Organization and the Government of The Netherlands on financial support for HIV/AIDS related activities in countries of central and eastern Europe.

The bilateral and multilateral support programme for countries of eastern and central Europe as far as The Netherlands is concerned, is quite extensive; 100 million US dollars for 1992, mostly to be spent in Bulgaria, Czechoslovakia, Hungary and Poland as well as in Romania and the countries of the USSR and approximately 500 000 US dollars will be spent on AIDS prevention activities in 1991 and 1992 for activities on prevention and control of AIDS in countries of central and eastern Europe. Recently a contract between the Government of The Netherlands and WHO Regional Office for Europe was finalized.

Just as we give high priority to AIDS prevention in countries in Latin America, Africa and South-East Asia, we are aware of the emerging problems of HIV/AIDS in Eastern and Central Europe and should like to share our experiences and financial resources with you.

But we want to put activities financed by our government in a policy framework which is based on several criteria:

- AIDS prevention by educational activities is at this moment the only effective instrument we have in fighting AIDS;
- Involvement of groups concerned, like homosexual men, intravenous drug users, prostitutes, haemophiliacs etc. must be assured, and
- Respect for human rights and the principle of non-discrimination must be guaranteed by the recipient governments.

Guided by these principles, our government has entrusted the financing of many activities to the WHO Global Programme on AIDS in the Regional Office for Europe in which we have great trust and confidence. One of those activities is this conference, as was the recent meeting in Prague on HIV/AIDS and Human Rights.

The development of AIDS Hotlines always got a lot of attention in our country because we consider it as an important activity which can develop prevention, care, counselling and respect for confidentiality.

The first AIDS Hotline Conference was held in Amsterdam and the second one at Curacao at the Netherlands Antilles situated in the Caribbean.

As a result of both conferences several new Hotlines in Europe as well in Latin America could be started because it was clear that an AIDS Hotline should function as an important starting point for organized and planned HIV prevention and were able to show governments the need for good information and counselling, especially in those areas which are supposed to be of low-prevalence of HIV at that moment.

That is the situation now in Eastern and Central Europe where there is still low prevalences of infections, but where in the near future the epidemic will increase its impact considerably.

In recent years there has been a tendency in the eastern and central European countries, to relate HIV/AIDS prevention with existing laws on STD control in an attempt to stop the spread of the virus. Together with extensive epidemiological studies on the prevalence of the virus combined with testing programs like in the USSR, the authorities considered these measures of higher priority than health educational activities.

For several reasons, I believe this attitude has changed now.

First of all because increasing international contacts convinced many political and medical authorities that the law and compulsory testing are in fact artificial instruments which have only limited effects, are discriminatory in their nature and disturb the relationship with main target groups because they go 'the underground'.

But also awareness of the increased mobility of the population and the wish to reconstruct the society towards more individual freedom and responsibility, opened the door towards the development of health educational instruments which are needed for effective prevention of the spread of AIDS.

Allow me to offer you the conceptual framework of health education and health promotion on which AIDS prevention activities in my country were modelled.

The leading principle of the activities in The Netherlands, as well as other European countries like Norway, Denmark and Switzerland, is what I should like to call the pragmatic one. Pragmatic responses to HIV infection and AIDS focus to stop further infection and prevent unnecessary anxiety and social unrest. One of the main elements was and is the inclusion in all the activities groups and persons at greatest risk of HIV infection. Initially this concerned men who have sex with men and injecting drug users, subsequently followed by other groups such as prostitutes and their clients, migrants, refugees and tourists. Distinctions have always been made in this work between health information and health education. While the bare facts may lay the foundations for behaviour change, additional focused interventions are needed to support people in the changes they and their partners may need to make.

A health communication strategy on HIV/AIDS prevention consists of two stages. In the first phase the initiative is focused on specific target groups but gradually attention is diverted towards the general public thus moving the campaign into the second stage in which also increased attention is given to the target group.

The term health information refers to all activities that are aimed at enhancing people's knowledge of AIDS. Individual members of high-risk groups are made aware of their vulnerability and the rest of the population are made to realize that the disease is transmitted under specific circumstances only and that there is no cause for alarm. Health information is preferably communicated by experts. This information is a necessary precedent to health education and should be regarded as a one-way, awareness-creating communication process. In terms of time, health information is a relatively short-term strategy.

Health Education is to a greater extent based on a interchange of communication, for example in the form of workshops and discussions. Health education on HIV/AIDS needs a long term approach in which other health elements like sexuality, drugs, STD and lifestyles are to be included.

It implies the realization of not only one, but a series of campaigns and interventions. A common feature throughout should be a positive message which should tell people what they can do instead of what they should not do. In my concept explicit messages are to be preferred instead of vague expressions which can lead to numerous interpretations and misunderstandings.

An approach like the one described needs a systematic, step-by-step strategy. A hit and run approach, fast, powerful and aggressive, leaves little room for effective planning. But, it has to be admitted, a more time-consuming systematic strategy is not without problems: "The dilemma in AIDS prevention is on the one hand the necessity to stop infections as soon as possible and on the other hand the fact that effective results can only be achieved through well-planned and comprehensive action in the long run".

To illustrate the complexity of such an operation, but in the same time the urgency of such an approach, I should like to mention the way in which the category of homosexual men, one of the main affected groups, in western countries has to be reached.

First of all, one has to realize that in relation to HIV prevention, emancipation of gays and lesbians is an important condition! Unless the fact is recognized that there is a homosexual lifestyle which is not to be classified as a disease, but as just another way of responsible living, effective HIV prevention for this group is impossible.

That means that existing taboos and concepts in society have to be changed or eliminated. This calls for courage in political and societal responsible authorities which have to face a lot of negative reactions. An educational challenge in itself.

In the planning model for HIV prevention for men who have sex with men, there are three subgoals, one building on the other.

1. A behavioural change, achieved by motivating the individual to practice safer sex.
2. A change of lifestyle, created through communication that answers the questions of how and why sexual behaviour should be modified.
3. A subcultural change, that involves not only the individual, but the cultural patterns of the entire group. If the cultural environment learns to accept safer sex, the individual will feel more inclined to change his own behaviour: safer sex as a group norm!

It must be clear that in such a concept, acceptance of homosexual behaviour is an important condition. In fact the same can be said about bi-sexuality, prostitution and the use of drugs.

The importance of working on a long-term basis and of choosing communication channels encourages the creation of longterm effects. Campaigns must not become sporadic efforts: rather, one has to be constantly active in working with AIDS prevention. The French call this 'Frappez toujours'.

Evaluation has to be an integral part of HIV/AIDS prevention activities. This is not an easy task. We lack the hard figures on the effects of our work. We have mostly to rely upon surveys of samples of the population to track changes in knowledge, attitude and claimed practices before and after specific campaigns, supported where possible by data and measures of public response. These could be calls to Hotlines and literature ordering services, requests for HIV antibody tests and sales of condoms as well as surrogate markers such as reductions in sexually transmitted diseases.

As will be explained by other presenters during this meeting, AIDS Hotlines can play an important, initiating role in this process in which also the individual needs of the population can be taken care of. They also can play a vital role in the learning process towards solidarity, non-discrimination and respect for human rights. In countries where only recently the focus on human rights has played such an enormous role in changing political patterns, the plea for taking care of those principles in HIV/AIDS prevention will be understood.

Let me conclude with some general remarks about the global future with regard to HIV infection and AIDS.

As Michael Merson, Director, WHO Global Programme on AIDS, recently expressed on the occasion of World AIDS Day, we are facing only the beginning of the pandemic. Devastating effects already can be seen in countries like Uganda, Tanzania, Zaire, Zambia and Malawi. Many others will follow in Africa, Latin America, the Caribbean and Asia. But also in North America we face an increasing AIDS problem among the poor and discriminated people in the large urban areas.

Increasingly AIDS will become the disease of the poor and lesser educated also because their access to care and future treatments or vaccines will be low.

Politicians for a long time can close their eyes to such a development, because AIDS is for a long time invisible; the risk of reacting too late is an experienced fact already. I hope that the governments and the institutions in your society will not make this mistake.

Therefore, the initiative of the World Health Organization's AIDS initiative for Eastern and Central Europe needs strong support from the governments in the West. In creating a new Europe, we shall not forget, neither as individual countries, nor as members of the European Communities and the Council of Europe, our friends in the eastern part of our continent.

The Netherlands shall strongly support the wish to include Eastern and Central Europe in the concerted EC actions for HIV control and prevention. The extensive EC programme for eastern and central Europe gives us the opportunity to do so; my government wanted to tune such a development by now starting multi-bilateral activities through WHO and we hope that this example will soon be followed by other countries and the European Communities. Strong collaboration with the World Health Organization will be an absolute condition.

Let me close this presentation by wishing you a very successful meeting; although I can stay with you today and tomorrow, I have to apologize for leaving this conference Saturday evening to join another conference about AIDS in Africa.

Thank you very much for your attention.

**Results of the First and Second AIDS Hotline Conferences, by  
Mrs Monique Middelhoff**

Ladies and gentlemen,

It is a great pleasure for me to give you an outline of the results of the First and Second AIDS Hotline Conferences, which were held in 1989 and 1990. Already more than two and one-half years ago I was, as coordinator of the Netherlands AIDS Helpline, one of the organizers of the First European AIDS Hotline Conference, which was held in April 1989 in Amsterdam. Some of you I have met there for the first time as participants in 'our' conference and I am very pleased to see you here again, in a different role, prepared to share your experience and facilitate our discussions.

Introduction

Together with the Dutch National Committee on AIDS Control, of which the AIDS Helpline is a subdivision, the Commission of the European Communities (CEC) played a major role in the organization of the first AIDS Hotline Conference. The CEC also took responsibility to a large extent for the financial budget. Additional financial support was given by the Ministry of Welfare, Health and Cultural Affairs in the Netherlands.

About 180 participants from 20 European countries, including some countries of central and eastern Europe (CCEE), attended this open registration conference. Among them AIDS Hotline counsellors, persons concerned like HIV-infected persons and people with AIDS, and representatives of governments and organizations like the CEC and the World Health Organization (WHO).

Less than one year later, in March 1990, the Second AIDS Hotline Conference followed in the Dutch Antilles (Curacao). A second time the Dutch National Committee on AIDS Control played an important role in organizing this conference for islands and territories in the Caribbean and Latin-American countries. The CEC financed 50% of the conference budget. Financial support was also given by the Government of The Netherlands and the Pan-American Health Organization (PAHO).

Eighty representatives from 30 countries and territories in mainly the Caribbean and Latin-American region were invited and participated in the second conference with great enthusiasm and motivation.

Hans Moerkerk has already explained to you that the Dutch Government is so much involved in supporting and sponsoring Hotline conferences, like this one also, because the great value it attaches to well-functioning and accessible AIDS Hotlines where callers can discuss their private needs in a confidential, non-discriminatory way.

In this presentation I will not so much focus on the differences between the First and Second AIDS Hotline Conferences. Instead I will especially elaborate on the similarities in functions of AIDS Hotlines and the similarities in problems discussed and conclusions of both conferences.

A short description will also be given of the different types of Hotlines in Europe, existing at the time of the First European Conference.

#### Functions and types of AIDS Hotlines

Although there are great differences between the First and Second AIDS Hotline Conferences in size, design and working-model and not least in the part of the world where they were held, there are striking similarities in the functions of AIDS Hotlines, regardless of the different types of Hotlines.

All AIDS Hotlines have four major functions:

1. providing information
2. counselling
3. giving support to their callers and not least
4. acting one way or another as the intermediary between the public and the national AIDS programmes.

This feedback, or so-called "barometer" function, was seen as very useful by both conferences, for instance as a tool for measuring the effect of publicity and measures taken by the authorities, which sometimes can lead to unintended consequences like discrimination.

To get an impression of the situation regarding AIDS Hotlines and to illustrate the fact that "the" AIDS Hotline does not exist, for both conferences a questionnaire was designed with questions on administration and organization, target groups, staff and selection, training and supervision facilities and results of phone call registrations.

The same has been done for this Workshop, of which you can find the results in the background document. The response has been very encouraging and it is very good to see that so many initiatives have been taken in the last one or two years.

With respect to the First European AIDS Hotline Conference 32 questionnaires from 13 European countries were returned (80 were sent off in total). Though, as we can see now, there were already some AIDS Hotlines operating in Central and Eastern European countries, at that time none of these countries returned a questionnaire.

This left us with the impression that AIDS Hotlines were only functioning in most of the northern and western and in some of the southern European countries like Italy and Spain. Whether this picture still holds for other southern European countries like Greece, Portugal or Malta, is unknown.

The picture that emerged from the questionnaires returned, was that AIDS Hotlines in Europe appear to differ on several characteristics like target groups, professional organization, funding, call charges, services provided and catchment area of operation.

Roughly two types of Hotlines can be distinguished. Let us be very clear however that this distinction does not imply any judgment on quality!

The first one is mainly or exclusively concerned with the provision of the telephone service itself and with additional training and documentation activities. For the second type of organization, the helpline service is one among others like face-to-face counselling and care for people with AIDS.

A good exponent of the first type is the National AIDS Helpline in the United Kingdom. The NAH, which is a so-called "green line" or toll-free line, is open 24 hours a day, with an average of 8 lines at a time, works nation-wide, is financially supported by the national government and works with paid staff and counsellors. In 1990 the NAH answered about 750 000 calls in total.

I am convinced that the two representatives of NAH, present here, can tell you much more about their organization, which is certainly the biggest AIDS Hotline in Europe if not the world.

An example of the second type of AIDS Hotlines is the AIDS-Hilfe in Germany. Almost every city in Germany has its own AIDS-Hilfe, which works on a local or regional level. Most AIDS-Hilfes are partly funded by the local administration and partly dependent on private donations and work with paid staff and volunteers. The opening hours of the Helpline Service are in general only a few hours a day or even per week with only one or two telephone lines staffed at the same time. A representative of the AIDS-Hilfe from Berlin is also present here.

As is true for both the United Kingdom and Germany, both types of Hotlines may exist in one country. Half of all the questionnaires for the First AIDS Hotline Conference were returned from these two countries alone. This principle applies to other European countries as well. The different types can complement each other, can refer callers to one another and provide callers with the opportunity to choose the most suitable service needed at that particular moment.

After this outline on different types of Hotlines, on which information can also be found in the background document of this Workshop, I would like to address the second item of my speech.

#### Discussion and conclusions

Common denominators can also be found in the problems discussed and the conclusions on these topics of both conferences. I will highlight four of these, namely funding, publicity/promotion, professionalism and co-operation.

#### Funding

Though present as a secondary theme at the First AIDS Hotline Conference, the lack of funding has been especially a topic of discussion at the Second Hotline Conference.

As I have already said AIDS Hotlines are funded in many different ways, but it often seems to be a problem to acquire funds on a regular and recurring basis.

One thing that might help tremendously is to include funding of AIDS Hotlines as an essential part of the national AIDS programmes. WHO is one of the organizations that could play an important role in achieving this, as well as for instance the CEC.

However, I think it is a misunderstanding that money alone makes a good helpline service. A clear philosophy and a good plan are crucial starting points, which can support the inevitable process with potential donors.

In this respect it is worthwhile to mention the AIDS Hotline in Colombia, South America, which started entirely on a voluntary basis in the private house of one of the initiators and slowly built up a reputation as an important service. Of course this is not an ideal situation, but overall it was felt that there will always be tensions with regard to funding, no matter where the money comes from.

#### Publicity/promotion

For the effective functioning of an AIDS Hotline, it has to be well-known and accessible to callers. Hence publicity should be devised in such a way that it reaches the target group of the Hotline and educates callers in using the Hotline. Effective promotion may also attract new sponsors and volunteers.

Publicity is not necessarily a costly affair. Inventiveness and creativity in using existing distribution and communication channels, like radio and television networks, and a good relationship with, and even "courting" the media, is crucial for successful free publicity.

Since promotion should be a constant priority of an AIDS Hotline, it should be included in the planning for the Hotline itself and also in the National AIDS Programme.

#### Professionalism, training and evaluation

There is considerable variation in the view of AIDS Hotlines on the professional expertise needed within their organizations.

However most Hotlines agree that professionalism is more related to attitude and approach than with level of education or whether the counsellors are paid or volunteers. Selection and training play a central role in maintaining professional standards. In this respect three functions are considered necessary for all types of Hotlines:

1. continual training of counsellors
2. access to advice on specialized subjects
3. daily individual supervision.

After the process of selection, of which the criteria should be clear to all involved, initial training needs to focus on information and telephone techniques.

The continuing training, support and supervision of hotline workers after the initial phase, play a vital role in safeguarding the health and efficiency of all concerned. To guarantee professionalism it is also essential to have some kind of monitoring and evaluation system for the standards, procedures and the actual work done by the Hotline.

#### (Inter)national co-operation

As can be seen from the previous, at both the First and the Second AIDS Hotline Conferences many AIDS Hotlines are facing identical problems. Though all Hotlines seek their own solutions, which show considerable variation, much can be learned from one another. Co-operation on national and international level will not only have a motivating effect, it can also help to prevent the needless repetition of inventing the wheel time and time again. Besides, intensification of co-operation can lead to common standards of good practice and hence contribute to a better functioning of AIDS prevention in Europe. International organizations like WHO and the CEC can play a very useful role in this respect.

It is our sincere hope that this Warsaw Workshop will also lead to lasting contacts and networks of more - and less - experienced Hotlines.

On all these topics extensive information can also be found in the excellent report of the Hotline Conference in Curacao and the background document for this Workshop.

#### Conclusion

I do not think I exaggerate in my overall conclusion that both conferences were successful not only in bringing together considerable numbers of highly motivated people, but also in reaching important conclusions regarding the importance of AIDS Hotlines and the definition of good standards of practice in hotlines.

In my presentation for the Curacao Conference I mentioned that a Second European AIDS Hotline Conference might be of even greater importance in view of the democratic movements and socio-political changes in central and eastern Europe, that were taking place at that time and that would undoubtedly also influence the spread of HIV and AIDS and the necessity to react to this new threat.

I sincerely hope that this Workshop in Warsaw will prove to be useful and successful. Maybe within one or two years from now a truly Pan-European AIDS Hotline Conference can be announced.

Thank you for your attention.

**"Maximizing the existing health potential of people living with HIV/AIDS", by  
Richard Rector**

Four years ago I had the opportunity to visit Poland to address ministers from all over eastern and central Europe on the subject of AIDS. So today, it is both an honour and a privilege to return to Warsaw and participate in this AIDS Hotline Workshop. In less than two weeks I will celebrate my ninth year of being told that I had AIDS.

There is little doubt that these years of living with AIDS have been the most challenging, exciting and inspiring chapter of my life. I have watched, I have grown and I have learned. I have seen many glimpses of rare courage, integrity and compassion. I have admired power in the face of hardship, suffering, prejudice and mistreatment. I have gladly had my world made much richer.

But, many times I have stopped and asked myself if the cost of losing my friends, watching so many people die of the same disease that I have and seeing so much injustice and inequality in our world is really worth it.

Since my last visit to Poland in 1987, I have had the unique opportunity to travel and work on five continents and in over 50 countries. I have met many different types of people from many different walks of life, some who are now dead as a result of HIV. Each one of them has been my teacher, my friend and my hero.

Therefore, I would like to tenderly, respectfully and gratefully dedicated my work here in Poland to a dear friend, colleague and lover Dr Ian Schafer who died of AIDS-related complications on 5 November 1989 in Berlin.

I have been asked to share with you my thoughts, feelings and ideas about Living with AIDS and the Role of People with HIV/AIDS in Prevention and Care Programs. I could have set out to record the compassionate and human response to the AIDS epidemic - recognizing the tremendous work and tireless hours committed by individuals around the world. Had I taken that direction I would present only our successes and ignored the magnificent wall of opposition that those of living with HIV/AIDS are up against within the field of AIDS prevention and care. Looking at the results of AIDS-related efforts thus far, it seems that the topic of utilizing people living with HIV/AIDS must either be uninteresting for us to consider or we do not believe in working with people but prefer to work for people. Nevertheless, I recognize that this may be the first time some of you are hearing this message and will try once more.

Living with AIDS for nine years has taught me a lot. One of the guiding principles for AIDS prevention and care, including hotlines, must be to enable people to increase control over, and to improve, their health and further, to allow individuals and groups to identify and to realize their ambitions, to satisfy their needs and to change or cope with their environment. This principle highlights health as an essential element of the quality of life, both personal and social. Accordingly, AIDS hotlines must aim to enable people to maximize their health potential by giving them a new quality to their life and health, despite or because of an illness.

Maximizing the health potential of all people living in the era of HIV/AIDS is a perspective from which education, care and support must be established. It implies fighting against stigmatization and social disadvantages experienced by those of us living with HIV/AIDS, since active participation in social life is equally as important as physical and psychological well-being. Maximizing health potential further requires joint action by those of us living with HIV/AIDS and professionals engaged in different disciplines. This will involve a process of creating and developing potentials of health for, with and by people who live with HIV/AIDS.

In countries of eastern and central Europe you have a unique opportunity to learn from the mistakes that have been made in other parts of the world. AIDS helplines do not work in isolation and that they must be flexible enough to meet increasing information needs of communities they serve. And that as the number of those personally affected by the epidemic increases, so too, will the demands on helplines and hotlines to assist and to provide accurate up-to-date information to these people, information about programmes, services and treatments.

So, as we enter the second decade of HIV and AIDS let us look back, analyze and learn from our past and then look forward to face the challenges involved in maximizing the health potential of men, women and children with HIV and AIDS. I would like to review the impact of efforts made so far. First at the global level, secondly within organizations and institutions and finally at the individual/personal level.

The global level reveals:

A dramatic mobilization of persons with HIV/AIDS has led to a remarkable degree of interaction among and between people in countries and communities, quite extraordinary in scope and speed. In part because of this mobilization the science of HIV has become irrevocably international.

The language we use when talking about AIDS nevertheless still suffers from a lack of serious reflection and dialogue. In particular, the voice of persons with HIV and of communities perceived to be at increased risk go largely unheeded.

AIDS continues to be seen as a disease which concerns "other" people. Because of the power of fear and prejudice calls for isolation persist.

The problem of HIV/AIDS is increasingly becoming a "simple" matter of statistics, graphs, projections and "trendy" themes. Thus, leaving the real human tragedy in the shadows.

Within organizations and institutions we see that:

Individual human stories related to living with HIV have been incorporated into some programmes. However, our active participation in designing, implementing and evaluating full programmes is seldom sought. We have become a "simple topic" in the AIDS programme.

There is a "conspiracy of silence" around people with AIDS working in organizations, particularly within some gay and AIDS specific organizations.

The number of persons with HIV "actively" employed by organizations working in the field of AIDS is negligible.

Any representation of people with HIV on national AIDS committees and boards is often just tokenism.

Care and counselling are often still provided from the perspective of the medical profession, when diagnoses are made or AIDS-related illness present. The perspective of individuals is not taken into account and the continuum of our needs are neglected.

And all too often the organizations of people with HIV are manipulated as political pawns when highlighting the inadequacy of health and social systems.

The personal or individual level reveals:

Many individuals overlook the reality of HIV/AIDS until they are personally touched by the socio-economic and personal effects.

Current educational efforts have not prepared people to cope with a possible seropositive diagnosis for themselves or those around them. They often disregard the fact that target audiences not only include people without HIV but also persons who are already HIV seropositive.

Current services have neglected to assist seropositives in managing a possible diagnosis of AIDS. The participation of persons with HIV/AIDS in decisions about our care is not encouraged.

There is little doubt that the health potential of persons with HIV/AIDS has not been maximized. In part this is because our voice has not been heard with equal respect within the current structures established in the field of AIDS. Since the beginning, we have identified and articulated our role as active participants in designing, implementing and evaluating HIV/AIDS specific programmes, services and policies. We wanted to assist in shaping the perceptions and realities surrounding AIDS. And we sought a partnership built on equal credibility and equality. Many organizations involved in the field of AIDS, however, have become too institutionalized and have tended to lose sight of the communities and people they serve.

Through its short history, HIV has been seen as a disease of other people and continues to raise crucial health, economic, social, moral, humanitarian and legal issues. HIV has forced us to ask questions about the interaction of health and lifestyles, the role of institutions and communities, and even the value of life itself. HIV has unveiled the dimly disguised prejudices about race, religion, social class, sexual preference and nationality. Throughout the epidemic people have searched for someone to blame. People and communities thought that those of us infected deserved to be. Well, not all of us, the baby with HIV was the innocent victim and the rest of us were guilty.

- History records that "homosexuals with their promiscuous and deviant behaviour" were to blame. Even within the gay community people were blaming certain "types of gay men".

- Africa, an entire continent of diverse cultures and people, was blamed for the spread of AIDS.
- Drug users and bisexual men were seen as "the bridge" between AIDS and the heterosexual community.
- Prostitutes were blamed for spreading the disease to military forces and to other "customers in the general public".
- And women, in general, were only seen as a "vector of transmission" to unborn babies.

In allowing this blaming of "others", we have seen my home country - the United States - shut its borders to foreigners who are infected with HIV; we have seen men, women and children with HIV detained in camps; we have seen children with HIV denied an education in public schools; and we have seen families desert each other.

Nearly 10 years have lapsed since people with AIDS/HIV first raised our voice. With many of our forerunners now dead. People like Dr. Tom Waddell, Hans-Paul Verhoef, Henki, Lydia Wanagechi, Amy Sloan, Knud Josephson, Kevin Brown, Ryan White and Ian Schafer. Each in their own way raised their voice to ensure that people living with HIV were not seen as diseased individuals but were in fact seen as "healthy individuals" learning to live life to its fullest in spite of their disease.

As you begin to develop your AIDS hotlines, programmes and services remember that in our world, a world obsessed with power - never forget, that we - the men, women and children living with HIV/AIDS - constitute a unique and critical resource. The time is long overdue to acknowledge this and to incorporate us in all AIDS-related strategies. We are the ones living on the frontline and we can offer an expertise that cannot be learned elsewhere. We are people with skills and knowledge, talents and abilities, hopes and dreams. Much more needs to be done to make us full partners in the fight against AIDS.

Ladies and gentlemen, in travelling the road that lies ahead, let us never forget the inspiration people with HIV have given us, and let it strengthen us; and hold onto the remarkable history of our own individual and our collective efforts and draw from it the courage and confidence to make a difference in how our world views HIV/AIDS.

The future of HIV will depend upon the strength and commitment of our collective will and the wisdom of our vision of humanity, justice and solidarity.

Thank you very much.

### III. Plenary sessions

#### A. Plenary session: Basic information

1. The spread of AIDS in Europe, use and limitations of data for Hotline counsellors, by Henning Mikkelsen

Access to relevant, accurate and reliable information is essential to Hotline counsellors in order to respond to the needs of the callers. Creativity and innovative thinking is an asset when one is searching for sources of information. A good Hotline counsellor should always be curious. Considering the needs of the callers, you should search for information from many different sources.

Scientific information is important. Do not restrict yourself to medical information. Social sciences, psychology, anthropology, etc., may be equally important. Scientific information can be obtained in many other ways besides the traditional ones: visiting the library, subscription to newsletters, etc., it is highly recommendable that a network of experts in different areas who can provide detailed and updated information be developed.

Personal experience is another source of information. Do not forget to draw on your own resources in this respect, you may have a lot of experience in relation to sexuality, disease, death, etc. The same goes for your fellow colleagues. With regard to people who have lifestyles or live under circumstances which are different from yours, be it youngsters, migrants, gay men, drug users, sex workers and, in particular, people living with HIV/AIDS, you should take the opportunity to learn from their experiences, or even better, involve them in the work of the Hotline.

The callers represent an indispensable source of information. You should never forget that every caller is a unique human being. For that reason, active listening is one of the most important skills for a Hotline counsellor. Here, however, you have to restrict your curiosity, since the caller does not call to satisfy your needs in this respect.

Sharing information is important. You should consider how options and opportunities should be developed for sharing information and making information accessible to others, e.g., regular meetings, a Hotline diary, notice boards manuals, a well established filing and library system, etc. Further, systems for keeping the information updated should be established.

While many of you are currently experiencing a lack of information, you may soon enter the stage of being overloaded with information. You must be selective in your choice of information by considering carefully what kind of information you really need in your performance as a counsellor. Similarly, when it concerns the information needs of the callers. Be aware of the 'question behind the question'. Very often callers may start the conversation by bringing up a neutral question, e.g., 'How many prostitutes are infected with HIV in Warsaw?'. You may be unable to reply to such a question, yet the question may not reflect what the caller really wants to know or talk about, e.g., fear of being infected following contact with a prostitute, whether it is risky to have sex with a prostitute or how to prevent sexual transmission.

Be critical about the information you receive. Scientific information is not holy, seldom reveals eternal truths. Information is a tool and you are the person to decide whether or not it applies to the purpose. Consider, for example, statistics on the epidemiology of AIDS/HIV in Europe which are often misinterpreted. First, it should be noted that such statistics reveal only certain partial aspects. As it has been said about statistics: 'They are like a bikini. It is interesting what they reveal, yet equally interesting what they do not reveal'.

The number of AIDS cases gives some indication of the realities of HIV transmission in Europe, yet with great delays due to the long dormant period of HIV infection estimated on the average as 10 years. With regard to events of HIV transmission, the current number of AIDS cases reflects what happened 10 years ago, says little about the current rates of transmission and nothing about the future.

The statistical fact that the countries of central and eastern Europe so far have been classified as low HIV-endemic areas, does not justify any denial and complacency with regard to AIDS prevention. Besides, what I have already said, the process of rapid social changes may dramatically change the picture in the coming years. In some countries there has been a fall in the number of persons tested HIV positive in recent years. This may reflect an encouraging decrease in the rate of HIV transmission. Far more likely it reflects that persons with high risk behaviour for various reasons, be it fear of discrimination and stigmatization, denial of the realities of AIDS, fear of knowing about a positive result or simply because they do not find the test beneficial to themselves, refrain from being tested. Consequently, planning action in the area of AIDS prevention, should not be solely based on such statistics.

Finally, be aware of your limitations as a Hotline counsellor and remember that no one knows everything about AIDS. Be courageous, do not try to hide your ignorance. If you cannot help on every point, try to refer the caller correctly or ask the caller to call back later on while you, in the meantime, find the information. Information is important for a Hotline counsellor. It is far more important, however, that you are available and accessible, prepared and committed to help the caller in any way you possibly can, listening, sharing and caring.

## 2. Drug use and counselling at the AIDS-Linien, by Kirsten Madsen

I think the AIDS-Hotline in Copenhagen could have had good use of the experiences from others when we started up five years ago.

I hope that you in my presentation will find bits and pieces of our experiences that will be of use to you.

I am going to talk about counselling and drug use and about things we have done at the AIDS-Hotline in order to reach this population. I will in my presentation talk about:

1. Who they are
2. How to reach this population
3. How to train the counsellors
4. And finally some examples of specific counselling to this group as we have seen it at the Hotline.

Some figures from Denmark.

We are 5,5 million people in Denmark. We estimate that there are 6 000 to 10 000 drug users, generally between 15 and 40 years old. About 3 000 are in some kind of treatment, 2 000 are because of risk of HIV/AIDS on long-term methadon treatment in order to reduce needles. Also we have today an easy access to free needles and syringes in order to reduce the sharing of equipment. The drug users in Denmark belong to one of the largest populations in relation to AIDS. We do not have any exact figures, also because only about 10-15% have wanted to be tested. We know the first HIV-positive drug user was identified in 1984. Because of the late introduction of HIV in the group so far only about 50 drug users of a total number of about 900 AIDS cases have been diagnosed with the disease AIDS. We estimate that between 500 and 1 000 are HIV positives.

About attitude towards the drug users.

When we talk about drug users there is a tendency that we only think of the "hard core fixers" and forget the whole grey zone of young people experimenting with drugs. The young people we generally only tell about sexuality and safe sex, but not the risks involved in flixting with drugs like the so called "weekend-fixers" do. This experimenting group are not very likely to identify themselves as drug users, and do not feel the messages about clean needles are relevant to them. On the other hand we often forget to address sexuality and safe sex to the group who identify themselves as drug users. The focus is on the sharing of needles and not on safe sex. We see today that the message of clean needles generally has come through but not the message of safe sex.

We are asking a group who is heavily stigmatized in our society to control behaviours in situations where loosing control is part of the aim, namely to get high and to be intimate sexually. And the reason why they should change behaviour is in the media often expressed as to stop the spread to the "normal" heterosexual population. Not to save the drug users' lives. Drug users are often portrayed as totally irresponsible people, willing to kill in order to get drugs, infecting children with their dirty needles, they throw all over the place, criminals, haggard looking, who show up late for appointments at hospitals and then only to beg for free drugs. No wonder that drug users are very suspicious of public services and public servants.

This stereotype picture of a group, we want to reach, also at the Hotline, has to be changed into an individual portrait of many men and women, who have hopes and dreams like everyone else. If our expectations are so low, how can we as counsellors hope to make a difference?

We have tried at the Hotline different ways of breaking the preconceived perceptions and prejudices against drug users, by introducing prostitutes and drug users into the educational programme for the counsellors. This is one way of showing the human face of the group and also to acknowledge the group as "experts" concerning safe sex and drug use.

As I said before, the suspicion of public services, which the Hotline also could be seen as, are great within the drug using community. Therefore it is important, that we do not address the drug use as such. We are not here to tell whether it is good or bad to be a drug user. We are here to give accurate information about safer needles and sexual practices. This is very important to remember, so the users of the Hotline can call, without being confronted with irrelevant moralistic views. But also they feel that they can talk with a counsellor who is familiar with the community and its realities.

It is important to be a known face in the community. In an effort to strengthen the partnership with the local community, where the highest concentration of sexworkers and drug users are, we have made a campaign specially targeted towards this area. We have held public meetings, we have introduced posters, where the community have decided what was needed. The last two years for World AIDS Day we set up tents providing right-on counselling and information in the area. Also we have had top artists entertain the community members and a presentation on living with AIDS given by a person with AIDS in the local church.

We have tried to strengthen the peer feeling within the group of sexworkers by sending two prostitutes to a sexworkers conference together with a counsellor. We have helped get funding to introduce the idea of self-help groups and peer counselling for and by HIV-positive drug users. These are ways of showing true solidarity by giving power to the group itself.

These steps have been essential for gaining the level of trust so the drug users have utilized our service as a Hotline. But also it has given some inside knowledge to the counsellors involved and in this way making it an equal exchange.

The Hotline has many advantages when it comes to counselling this special group as well:

- you can be completely anonymous;
- you can avoid the intimacy of eye contact, which can be difficult for many;
- you can generally get the information here and now;
- it is free, except for the pay of the call which is low.

I will now give a few examples of some of the counselling for this group that have not been general for many other callers as well: problems with getting a doctor on call, because you are blacklisted as a drug user, and therefore might be deprived of the same services as other people with HIV and AIDS.

In the drug using group which is generally not a brochure reading group, there is much "pub talk" about HIV and AIDS.

Often dramatic stories are introduced as the truth about HIV and AIDS. Quite a few drug users tell that they have used us for checking out information. One example has been that heroin could slow down the process of getting AIDS, that men could not get AIDS from women, etc.

A girlfriend who injects in a wrong way, and produces a lot of blood in the room. Do you dare to assist and how. Here we must remember that drug users are as scared as the rest of us.

A drug user who feels heavy pressure from the treatment center to get tested, but is scared. He or she can use the Hotline to discuss pros and cons and reach a decision that he or she can live with.

Relatives of drug users, who now find it unbearable after living many years with the pressure of a drug user in the family now also have to deal with HIV.

Desperation when you have finally almost quit using drugs and then test positive.

With these calls, like many others, our main function is to be openly listening and show understanding. It might sound insignificant, but everyone working at a Hotline, will know that this might make the whole difference.

### 3. Safer sex counselling - experiences from the Swedish AIDS Hotline, by Kerstin Dyrendahl

The Noah's Ark-Red Cross foundation is an organization based on voluntary action, founded to work with prevention of HIV infection and support to infected persons and their close family and friends. The national AIDS Hotline is one of the "branches" of the foundation.

At the Hotline we have provided nationwide information since spring 1987. The amount of calls each week has changed over the years. In the beginning, due to the societal information campaigns, many people phoned. During 1989-1990 HIV and AIDS was no longer "hot stuff", the problem seemed ignored and we did not receive as many calls as earlier. Lately, several well-known persons have come forward talking about their HIV infection. Some of them have since then died. Based on that, mass media turns once more the attention to the subject, with the result that people become interested in learning more. The number of calls to the Hotline increases. Most of the calls contains questions on whether or not a behaviour is risky.

#### Safer sex counselling

When discussing methods, maybe the first thing to do should be to change the headline. Much more important than giving advice is providing information on a level appropriate to the person asking for it. What language to use when talking about genitals, intercourse, etc., choosing one's words carefully, not to insult on one hand, not to arouse on the other. The information has to be simple and clear, correct and understandable. This forces us to listen carefully to the caller and adapt to his/her language - as far as possible. It is also very important not to forget checking up on how the caller receives the information and if the content is understood. Ask questions like "Do you know where you have your mucous membranes?", or "Does this make sense to you?", "Further questions?". Basic knowledge of the body is essential for the understanding when, where and how HIV can become a threat. Inform the caller about this particular virus and its living conditions to clarify the infection routes! We have found it important to compare HIV with some other well-known microbes for instance to describe that it is not possible to be infected by taking a swim in a pool. Having acquired the information above, the caller should be able to discuss safer sex, for instance questions like;

- what makes a sexual intercourse risky?
- is it easier for a man to infect a woman, than vice versa?
- what role does the body fluids play?

- how come some people discuss French kisses among the transmission routes?
- petting?
- how to use condoms?

Having learned that quite a few behaviours could be risky, it is important to give the caller an opportunity to discuss lifestyle and sexual behaviour, what is safe, safer, safest? We try to encourage people to find ways to express their sexuality without feeling anxious afterwards. The caller should become able to make his/her own decisions based on known facts. Not only risks but also the seriousness of the situation affects the way to give information. It is not the same thing to discuss kisses among young teenagers as discussing it with a person who has an HIV-infected partner, even if the content of the message is the same. One problem is that many people do not phone the Hotline until after a risky behaviour, looking for advice on how to handle the situation.

This raises many questions on relations, i.e. which should not be discussed under this headline. Knowledge in safer sex and transmission routes gives the caller guidelines on how to handle practical matters to avoid spreading HIV, if infected. To many people phoning the hotline, this seems to be the very first moment they consider themselves at risk. Until now HIV infection has always been somebody else's problem. Talking about "risk-groups".....

People working on the Hotline are not trained sexologists, but mature persons extremely good at listening to peoples' problems and questions, using their knowledge, imagination and cultural competence to guide callers on how to stop HIV transmission.

**B. Plenary session: Hotline experiences in Central and Eastern Europe**

**1. The Hungarian AIDS Hotline by Zsuzsanna Sudár**

We are very glad to be here and to share our experiences with you. As you know the first AIDS cases were reported from Hungary in 1986. AIDS education and prevention began in Hungary then, and due to the early beginning of AIDS education there is a quite low number of AIDS cases so far. The centre of AIDS prevention and counselling is the Ministry of Welfare, under whose supervision the National Institute for Dermato-Venereology works, and, besides dermatology, co-ordinates HIV testing, care of STD patients and counselling of HIV seropositives. The AIDS Hotline has been working at this institute since 1 January 1987. Due to these organizational aspects which we mentioned we co-operate mainly with governmental organizations. Non-governmental organizations for AIDS prevention exists in Hungary also, these organizations were established recently and there is no co-operation between us in this moment. The AIDS Hotline works at the State Institute for Dermato-Venereology. Persons who answer the questions are dermato-venereologists of the Institute and medical students who participated in special training concerning AIDS. The Hotline can be called from all parts of Hungary at the caller's cost. We receive the calls every workday from 8 a.m. to 4 p.m. The advertising of AIDS Hotline is parallel with leaflets in AIDS prevention published by the Institute for Health Promotion. The telephone number of the AIDS Hotline appears in every pharmacy and it can be found in the telephone directory.

All calls received by us are registered. We register the gender of the callers and the questions asked by them. No personal data are registered. We ask for information concerning life-style only when it is necessary for answering their problems. As many as 3102 questions were received in the course of the period between 1 January 1987 and 31 October 1991. This low number is due to the interest of the Hungarian population in AIDS prevention, and due to the feeling of safeness of people in the AIDS question which safety originates from ignorance of hazards.

A very interesting fluctuation could be observed in the frequency of calls: the greatest interest was on Monday and Tuesday in weekly distribution, possibly due to the experiences of the weekend. The number of calls increased in spring, probably because of the beginning of relations. However, the autumn peak is due to worries about the careless relations during the summer. In spring 1990 there was a decrease in number of calls and that was because there were general elections in Hungary. In autumn 1991 interest increased because it was the first occasion in Hungary that World AIDS Day got so much publicity. The interest in AIDS questions became very high in the last few months. This is due to the large increase of educational activity via mass media and newspapers.

After this detailed analysis of organizational aspects we try to summarize very briefly our experiences during processing of the calls registered. More than half of the callers inquired about HIV testing. Most of them asked where HIV testing was performed or when seropositivity could be present after a specific date when penetration occurred. There was a great interest in the possibility of anonymity during HIV testing. We got a lot of questions concerning clinical symptoms of AIDS and when these signs would appear. These people generally found something wrong and worried whether they could be symptoms of AIDS: the number of questions about the transmission of HIV was approximately the same, whereas less people were interested in the possibility of prevention. Sixty-five per cent of people who showed interest in HIV transmission was male. We got a lot of questions about the hazards of kissing, and orogenital contact besides the general possibilities of penetration. Some people inquired about the transmission of HIV by mosquitoes. These questions were very frequent especially in summertime. Also some callers asked how long HIV survived in body fluids after leaving the human body. These questions may lead to the consequence that people try to think about HIV transmission as a process. We got very interesting questions about other ways of HIV transmission as you can see in our next slides. In the first slide there are supported ways of HIV transmission by body fluids and sexual contacts. In the second slide there are a large number of infections contracted by people with AIDS. Here we must speak about gays. Only a few callers reported themselves as homosexual. This may be due to other ways for gays to get information about AIDS, for example gay organizations. The number of callers who reported themselves as drug users were very few, too. This is due to the very strong isolation of drug-users and the traditional method of drug use in Hungary which is the continuation of alcohol and sedatives. The small number of seropositive drug users may be due to this tendency also.

Apart from the tangential contact to prevention of almost all questions which can be asked concerning AIDS we got only a few questions about prevention. Our experiences show that people turn to the Hotline with their worries and conscience problems after an occasional contact. There were some questions about the correct use of condoms, while other callers wanted to hear about other possibilities of avoiding HIV infection.

Some calls were also received not directly concerning actual health protecting topics but for precise information about a special problem. The majority of these callers inquired about epidemiological and statistic data in Hungary while others were interested in details of diagnostic methods. Some callers asked for general information about AIDS disease. Especially youngsters turned to us with sexual problems asking for individual support.

Few callers had an irrational phobia about AIDS and we were unable to calm them. Some people used the Hotline to proclaim their antisocial conceptions. Others regarded the Hotline as a possibility of realizing their perverse desires.

Summarizing the calls we should make the conclusion that knowledge of the public about AIDS is insufficient. The relative increase of questions about prevention may mean that people are beginning to realize the hazards of AIDS. They have begun to be interested in avoiding HIV infection in their everyday life instead of regarding AIDS as a special problem of homosexuals, for example. The increase of registered calls during the last few months indicates that the Hotline is becoming a general way for people to get information about AIDS and in many cases to get urgent counselling.

## 2. Experiences of the Institute of Venerology, by Iwona Rudnicka

The Institute of Venerology is a part of the Medical Academy in Warsaw and works with medical education, improving physician qualification in dermatology and venerology, treatment of STDs and prevention of STDs including AIDS.

There are many kinds of prophylaxis such as information about STDs and AIDS in posters, books, calendars, leaflets, films. The physicians of the Institute give lectures about STD and AIDS to schools, factories, lodging-houses. The President often takes part in TV and radio programmes. One prevention of STDs and AIDS is free condom distribution.

Since 1970 we have a confidential telephone and since AIDS appeared we have also answered questions about HIV and AIDS. The confidential phone is open every day from 4 p.m. to 9 p.m. In fact it is possible to get information all of the time, because the doctor who is on duty answers the confidential phone, too.

People find out about the phone from newspapers, leaflets, posters, calendars, radio and TV programmes. Sometimes the phone number appears on buses. Increasing calls are due to this information in papers, on TV and radio.

After the call we note the sex, age and problem of the caller.

In 1990 we noted 1551 calls and answered 1593 questions. Sixty-three per cent of callers were male and 37% female. Forty per cent belonged to the group of 20-30 years old, 37% were between 30-45 years old, only 12% were younger than 20. People asking about AIDS are older than people with venereological problems.

The calls were divided as follows:

- 65% AIDS
- 17,5% STD
- 5,5% dermatological problems
- 3,5% sexual problems

Among the calls concerning HIV/AIDS about 25% ask where and when people can be tested. In this group there were questions about anonymous testing.

Twenty per cent concerned AIDS phobia, 12% asked when HIV antibodies appear in the blood, 11,5% asked about symptoms of HIV infection and AIDS and differences between HIV and AIDS, 9% were anxious after sex with an unknown partner, 6,7% asked how the virus is transmitted and what risk behaviours are, and 4,3% did not know exactly how the virus is transmitted.

Men more often than women had an AIDS phobia and were afraid after sexual intercourse. Women more often did not know what behaviours risk HIV infection and were more interested in anonymous testing.

Only 2% of the calls concerned prophylaxis of HIV infection including safe sex. These people asked how to stay HIV negative.

Only two persons asked about treatment in AIDS. People from risk groups rarely phoned. Last year there were five drug users, 18 homosexual men. They asked when and where they can get blood tests. Five callers were HIV positive. They asked about treatment, safe sex, safe behaviours.

Often talking by phone is not enough. In this case the doctor makes an appointment to examine and speak to the patient.

Many times people are advised to consult a psychiatrist, psychologist, sexologist.

### **3. Polish experiences with AIDS Hotline counselling by telephone, by Jan Krukowiecki**

In June 1986, Out-patient and In-patient Departments for HIV/AIDS patients was opened. One year later, in June 1987, the AIDS Hotline phone started. Its number is published in daily newspapers. The telephone is answered by the nurse working in the Out-patient Department, and once a week a doctor on duty answers the telephone for two hours. Doctors note the numbers of the calls and very briefly the subject of conversation.

The nurse calls the doctor to the telephone when the client asks for it. Every year about 200 calls are registered.

The greater part of callers ask about AIDS and HIV symptoms.

Very often clients ask about ways of infection. A lot of callers want to know the address where HIV testing is done.

The counsellor tries to talk in such a way as to find out if the client has real fear of being infected or not, explains the ways of HIV transmission and answers every question. But questions concerning either the AIDS symptoms or acute HIV disease are rather neglected and not very precisely explained by counsellors. The callers, if they belong to a high risk group or already had contact with a risk person or a HIV-positive person are asked to come to the Out-patient Department for pre-test counselling. During our work we also had some calls from health care workers and medical staff. They wanted to know about the possibility of HIV transmission from their patients.

In conclusion knowledge of AIDS problems is still very poor even among medical staff and health care workers.

#### 4. Confidential telephone line in AIDS prevention, by Dr Darina Surcheva

There are Hotlines (in seven towns) and the telephone net was established by the Bulgarian Red Cross.

The main goal of these telephone lines is to give psychosocial support in bad or crisis conditions and difficult situations and to decrease and to help to manage the callers' stress. The different problems are discussed: medical, social, moral, juridical, etc. In 1986 a special "AIDS Hotline" was established. It is especially active around World AIDS Day.

##### The Hotline

1. works twenty-four hours a day,
2. assures anonymity, and
3. confidentiality,
4. does not exert pressure on callers, and
5. makes sure that staff are especially chosen and trained.

The approach is to listen to the caller and to accept his/her problem, and to give all needed information for the problem-solving. Counsellor and caller together look for the best possibility to find a way out of the situation or to find an alternative. The counsellor must mobilize the caller's will and belief in him/herself. This work requires much professional skills, confidence, knowledge of the world (experience) and personal qualities. All this requires special training for the staff and therefore the telephone line is staffed by specialists only: medical doctors, psychiatrists, sexologists, sociologists, psychologists, jurists, teachers, etc., who are well trained in different courses. Their work is unpaid or partly paid. We can judge of the effectiveness of the Hotline from the repeated telephone calls, the number of subscribers to the telephone lines and the callers' gratitude.

In most cases the callers are young people: 36,4% between 20 and 30 years old, and 17,1% between 30 and 40 years old. The most callers are single: 47,6%, married: 36,8%, and separated (divorced): 15,6%. Most questions are about the possibility of being infected with HIV or routes of transmission, the incubation period, the test quality, the first symptoms of AIDS, places for anonymous testing and confidential counselling, how to tell

the family, safer sex, etc. These questions and problems are a result of the great fear of being HIV infected or sick from depression by receiving positive HIV-test result, from the discrimination and isolation of HIV-positive people, from the increase of prostitution and homosexuality after the democratic changes, etc. In 36,5% of the phone calls the callers require advice, in 25,8% listening, and in 22,4% to relax. Most phone calls are after the weekend. On Thursdays and Fridays they are usually about the routes of transmission and safer sex. It is important to note that in the last year phone calls from homosexuals increased. All phone calls are registered, but only on age, sex, education, profession, family status and questions. The goal of this registration is, after analysis of the data, to find the gaps in health education and promotion and direct further work (prevention) to these fields and populations groups. Now, with the establishing of gay NGOs, they will be included in these telephone lines. The trust and confidence will be greater and in this way HIV/AIDS prevention will be more effective and the public benefit greater.

To promote the telephone lines, mass-media: radio, TV, magazines, posters, etc., are used. Especially young people receive leaflets and brochures with information about the work of the telephone line, the telephone number in different towns, working hours, and the kind of information which they can receive.

5. Problems of psychological assistance for homosexuals, by Kirill Zhuravlyov

The Centre of Crisis Psychological Phone Assistance "Hotline AntiAIDS" was formed in 1991. There are 30 workers, more than 2/3 of them volunteers (people of different professions). Seven per cent of all the appealing to us are connected with psychological problems of homosexuals.

A specific of psychological assistance methods for any social group depends on the social attitude to the group. How to prepare special methods of assistance for homosexuals, if they do not differ from heterosexuals by any psychological test? In such cases, their psychological problems are caused by the conditions of GAY beings in society. Methods of psychological assistance are prepared on this basis. It causes the need for research on the reasons for the psychological problems. In this instance the reason is a social attitude to homosexuals and their way of life.

The existence of sexual minorities is characterized by the process including three phases:

1. A society influence directed on the sexual minority group (GAY discrimination)
2. Some processes inside the group, caused by the social influence, and the transformation of the group.
  - a. unification of the sexual minorities representatives into social groups (forming of social structures on sexual basis)
  - b. sexual minorities transform in a separate social stream, becoming a social minority
  - c. discomfort of every representative of the minority causes discomfort in relations inside the group.

3. A group influence directed on the society: social movement, formed by homosexuals (GAY movement).

This process results in three conflicts:

1. conflict between the group (the personality) and the society
2. a conflict inside the group
3. a conflict inside a personality.

Let us examine these three main types of conflict:

1. The problems of recognition.

Naturally, it is difficult for the man to admit to such aspects of his personality, which are not traditionally accepted by the society. And the negative attitude of society he feels on the part of acquaintances, colleagues, relatives.

2. An urge to change oneself.

Sometimes it happens that tendencies to self-antagonize supported by society are stronger than personal physical needs. Then a conflict connected with an urge to change sexual orientation develops. One can change his life, but suppression of physical needs results in permanent stress, neurotic conditions, sociable disharmony. Practically, people with such inner personality conflict do not contact psychotherapists.

3. Aggression directed at homosexuals as psychological self defence against his own homosexual feelings. (This conflict is typical for heterosexual people).

Mass consciousness resists homosexuality. And when it projects on the individual consciousness of a man with some instinctive homosexual feelings it results in inner personality discomfort, which transforms into homophobia in society.

Taking into consideration that these conflicts are provoked by the society's rejection of GAYS, one can find some correct methods to psychologically assist homosexuals. During volunteer training attention is paid to such things as: GAYS are not a separate race, nation, or subculture, but a part of every nation, of every social strata. And to discriminate against this minority is to discriminate against all society. We raise the cultural level of every Hotline employee to make him understand and acknowledge another way of life, in order to achieve our aim: the humanization of interpersonal relationships.

**C. Plenary session: AIDS-Hotline management and organization**

1. Good practice in telephone helplines, by Alan Jamieson

What are AIDS Helplines?

What is their importance?

What is good practice and why it is important for AIDS Helplines?

These are the key questions which I hope to deal with in this brief presentation. The aim is chiefly to identify areas which require consideration rather than provide answers to the questions which need to be asked.

### What are helplines?

AIDS Helplines are human service organisations which offer confidential, compassionate, non-judgemental, anonymous client centred service to individuals who telephone with questions or anxieties about HIV infection or AIDS. As such they form an important point of human contact between national AIDS programmes and the public.

Their availability and accessibility via the telephone and the service they offer by listening to and helping callers play a vital role in communicating information and in personal education, both of which are crucial factors in the fight against HIV infection and AIDS. AIDS Helplines are particularly good at encouraging people to take individual responsibility for their sexual behaviour. They also fulfil a "barometer" function of measuring the effectiveness of education campaigns for the public. The services provided range from pure information to telephone counselling and long term emotional support. Such services are offered to the general public or to designated groups within communities such as gay men.

We need to remember that telephone helplines are a relatively new creation going back 20-30 years. They have been affected by rapid advances in technology and considerable cultural changes in terms of attitudes to, availability of, and use of, the telephone.

### Importance of helplines

Overall a telephone helpline can provide a unique service. It is personal, confidential and anonymous, capable of a variety of approaches to a subject and experience shows it is particularly suited to dealing with such "taboo" subject areas as sex, sexuality, HIV infection and AIDS. The number, type, and variety of telephone helplines has increased dramatically over recent years and services include small groups based in members own homes and large national organisations. All have been founded as a response and education. They all provide easy and confidential access to individual help.

### Good practice of helplines

The expansion of helplines to cover a variety of subject areas led to concern among voluntary and counselling organizations in the UNK about the standards of help being offered by helplines.

Good practice is seen as essential for all workers and helplines in order to ensure the provision of responsible and effective quality service to callers. The principles of good practice are more a set of aims than a set of rigid rules namely something to aspire towards rather than something to be obeyed. People working in telephone helplines offer support to callers in some or all of the following ways:

by responding to the immediate feelings and concerns of callers;

by exploring, with the caller, practical and/emotional issues he/or she wishes to talk through;

by providing information when it might be useful to the caller;

by letting callers consider and choose for themselves what they want to do or have happen next.

The guidelines cover:

purpose  
management  
confidentiality  
promotion and publicity  
information resources  
recruitment and selection of helpline workers  
training  
supervision and support  
the call

I now consider each of these briefly.

#### Purpose of the helpline

When setting up the helpline it is essential to consider why anyone should use your helpline rather than other services. Is there a need? If you create a helpline how will it relate to others? There is also a need to be clear about what you offer to callers. Is it information? Emotional support? Telephone service only? Is it client centred and non-directive? Or is it directive? Is it an information helpline? Or is it a telephone counselling line?

What are its limits and how much and how deep can the support offered to callers be?

#### Management of the helpline

By management I mean the taking of overall responsibility for the smooth operation of the helpline. Any group involved in management needs to bear in mind a number of important questions: is the nature of the helpline clear both to workers and to users?

Are policies regarding confidentiality, referral, relations to other organisations clear? Are the resources adequate? Is there sufficient training, accommodation, funding, workers, etc.?

Is it clear what workers can expect in relation to training, support and service? Are lines of responsibility within the helpline clear to all who work within it?

#### Confidentiality

It is vital for helplines to be clear about policy regarding confidentiality both to the workers and the callers.

Most helplines want to be able to guarantee that everything the caller says will remain confidential. It is necessary to be clear about whether there are any exceptions to this and also to be clear about to whom information is confidential.

#### Promotion and publicity

There is little point in going to the trouble and probably expense of setting up a helpline if no one knows of its existence.

Therefore carefully planned promotional activity is essential if the helpline is to be properly used by those for whom it is intended. In doing this it is important to try and ensure that any publicity generated accurately reflects the service provided so there is no risk in raising expectations with callers beyond those that the helpline can reasonably expect and meet.

#### Information resources

It is necessary to define very clearly what information resources are to be maintained by the helpline, then to ensure that they are accurate and up to date. It is important to ensure that workers within the helpline know how to access the information and also how to gauge the appropriateness of information for particular callers.

#### Recruitment and selection of workers

The object of any recruitment and selection exercise is to create a suitable team of workers who can provide the service that is advertised and offered to the public. Thereafter it is important to try and create teams of workers who can work effectively within the limits of the helpline service. Essentially you need to be clear about the kind of people you are looking for. A good worker is someone who is committed to the aims of the helpline; is comfortable with and comes across well on the phone; is able to respond sensitively to participate in training and supervision; is emotionally stable and self-aware; is someone who will not take advantage of callers; is someone who will not depend on the helpline to meet her/his own emotional needs; is someone who is able to take responsibility for calls and knows his/her limitations; is someone able to work as a member of a team. All this requires a great deal of preparation and thought beforehand.

#### Training

Training is essential. It is important to be clear about what it is that you want the training to achieve. There are three elements:

- Induction training where the introduction of the helper to the work of the helpline is achieved.
- Basis training where helpers develop listening and responding skills and their knowledge of the information that is available to callers.
- On-going training to enable established workers to develop their skills and potential.

Good training will always include both practical and theoretical components. The experiential aspects of training in this type of work are vital.

Good practice requires that attention be given to listening and responding skills, understanding the process of the call, the distinct nature of working on the telephone, skills relating to the beginning and ending of calls, and awareness of difficult types of calls e.g. suicidal, sexually manipulative, aggressive etc. Thereafter attention needs to be given to the discussion of ideas and feelings that arise from the work.

#### Supervision and support

Helplines should have a clear policy for supervision and support so that it is available to all helpers. It is essential for the wellbeing of helpers who are offering emotional concern and support to callers who may often be in considerable distress. Helpers are bound to be emotionally affected from time to time and will be in need of this kind of support. It further serves a staff development need and contributes considerably to the health and wellbeing of the helpline itself.

#### The call

Understanding the process of the call is important.

Calls generally have a beginning, a middle and an end and how these are handled is important in terms of the quality of service offered to callers as well as to the effectiveness and satisfaction of workers.

So, from giving a welcoming response and creating initial trust, the task is to help callers explore their difficulty and then provide them with information and support in helping them to make a decision about what they decide to do next. This sounds simple but in fact it is a highly skilled task.

This is a very brief summary of some of the key points relating to AIDS helplines and the principle of good practice which can apply within them. Much greater detail is available within the booklet Telephone guidelines: Guidelines for good practice which is available to you.

In conclusion there seems no doubt that the telephone will continue to be an important medium for offering information, counselling or emotional support of the type mentioned. We therefore all have a responsibility, from whatever service we come, to ensure that what we do is of the highest standard.

It is very easy for standards to slip and short cuts to be taken. We must take seriously our responsibilities to callers. Their needs are of paramount importance and call for the highest possible standards of work. It is hoped the guidelines will help you to attain those standards.

## 2. Confidentiality, by Shelley Gurney

Telephone counselling is a service to help people through a present upset or worry; it can be the first contact by a client, and is often only the starting-point, the first step in the process of dealing with and overcoming a problem.

If this first contact is experienced as a safe and positive one for the caller, she/he is more likely to take up a referral to other agencies who may be able to offer further help.

This is important since most telephone counselling is one-off experience, the caller has not usually rung before and is unlikely to ring again, preempting the possibility of on-going work.

This situation is often like crisis counselling, where time is at a premium and the counsellor has only a limited period in which to establish a relationship.

It is within this context that I am considering the importance of confidentiality.

The first step in creating a relationship between a caller and the helping agency is establishing basic trust - one meaning of 'confident' in the Oxford English Dictionary is 'trusting'.

Unless the caller can trust the agency she/he will not be prepared to discuss issues of an intimate and personal nature - issues which may involve some secrecy and feelings of shame and guilt (if they relate to sexuality and sexual practices) and may also involve illegal acts (e.g. drug use) and whose revelation therefore may put the caller at risk, e.g. mistrust of staff agencies.

Telephone counselling can guarantee the caller a greater degree of (and even total) anonymity, which can encourage greater confidence and willingness to talk about problems knowing that there can be no repercussions from personal revelations.

The callers can choose the space from which to make the call. They can feel less threatened in places with which they are familiar, and which are their own territory. However, many callers may not feel safe calling from their own homes and use public call boxes or their workplace phone.

However, anonymity and confidentiality are not synonymous and callers may still need to feel reassured and understand the specific terms under which the agency can guarantee confidentiality, particularly in small communities.

If we accept the necessity of confidentiality in providing an effective service then each individual agency will need to develop an agency policy of confidentiality which defines the extent of confidentiality both within and outside the agency.

Confidentiality in the context of counselling has been defined by the British Association for Counselling as treating 'with confidence personal information about clients, whether obtained directly or indirectly or by inference. Such information includes name, address, biographical details, and other descriptions of the client's life which might result in the identification of the client'.

It is important to consider what information is considered confidential. Does this relate to personally identifiable information such as names and addresses, or to more general content information?

To whom is the information confidential? It is probably unrealistic for an agency to offer its clients 'total' confidentiality, i.e. between caller and counsellor. In order to best support callers, helpers and other workers - to allow for mutual development and support - confidentiality can be kept within the confines of the agency, its past, present and future workers. There can be 'layers' of confidentiality which extend from individual to other team members, through line management and into staff support practice and internal and external training. A strategy which defines confidentiality as a restriction on the communication of personally identifiable information, i.e. preserving anonymity, can allow for considerable communication between staff members within a totally confidential client/counsellor relationship.

However, helplines may not be able to offer their callers continuity in terms of counselling staff and may need to share information about callers. Similarly some agencies may operate in close contact with others, e.g. medical or social services. Inter-agency co-operation is important and information about callers may need to be shared between agencies. Does confidentiality extend to preclude discussions with other organizations? There may be workers whose work overlaps between two agencies with clients in common.

Can callers and calls be discussed outside the agency in general terms, e.g. with family and friends, who may also be potential users of the service? Are such discussions useful and respectful of the callers or frivolous?

The policy needs to be clearly understood by all staff - confidentiality is easily breached and can never be mended. Staff should be able to communicate the policy clearly to all clients including any limitations on the degree of confidentiality being offered.

How does the agency approach confidentiality to its workers? Especially if offering further services? How much confidential contact is acknowledged? How are workers protected?

There may be certain circumstances in which an agency may consider breaching confidentiality and disclosing information to a third party.

In what circumstances can confidentiality be breached? Common arguments include:

- it is in the client's best interest, e.g. threatened suicide
- the client may be putting others at risk, e.g. illegal acts

- professionals involved may 'need to know', e.g. medics, dentists, health care workers
- disclosure is in the overriding public interest.

In such circumstances the client's consent to a change in the agreement about confidentiality should be sought whenever possible unless there are good reasons for believing that the client is no longer able to take responsibility for his/her actions.

Any breach of confidentiality is an extremely serious matter and should whenever possible be discussed with a supervisor/line manager. Clients must be informed of the action and advised of the implications and consequences of disclosing information.

Finally it is worth considering what written information and records are required to be kept by the agency.

Records may need to be kept for continuity and statistical information. Agencies may need to consider for what purpose they keep written records:

- what information is needed?
- can this information be made anonymous (not personally identifiable)?
- who has access to the information and where and how is it stored (cleaners, office/administrative staff)?
- for how long is it kept?
- how is it destroyed? (is it destroyed?)

What is the agencies' recording system? Is it centralized? Can individual workers keep individual detailed notes which can be cross-referenced?

How is HIV status recorded and is this necessary?

And finally what is the legal position with regard to withholding information?

### 3. Public relations at the Danish AIDS-Linien, by Kirsten Madsen

I am going to talk to you about a different approach to public relations work as we have practised it at the AIDS-Hotline in Copenhagen. I hope you can use some of the ideas, if you are setting up an AIDS Hotline.

First I will give you a short introduction to the situation in Denmark, because the frame is of course important for how you as a Hotline can implement your "local campaign". This is also to emphasize that coming from a social democratic society, with free medical care and which has a reputation for not having many taboos about sex education as an example, makes it, of course, a lot easier, than making public relations in a society, where for example, even showing a condom can be controversial.

First some statistics. We are 5,5 million inhabitants in Denmark. We have so far had 905 persons diagnosed with AIDS, of which 40% have been diagnosed only in the last two years and 60% have died. Through the last two years every second day one person has received the diagnosis AIDS and every day one person is told that he or she is HIV positive. Three-quarters of the AIDS-diagnosed people are men and we estimate that 3 500 - 4 000 men are infected through homosexual contact. A thousand to 1.500 are estimated infected either through heterosex or drug use.

The government in 1987 decided by law that the fight against AIDS should be done voluntarily, anonymously, and with honest and direct information and education.

The Hotline where I work can be seen as an important part of this information and education. We are both a telephone and an on-site one-to-one counselling and we also try to take initiative in new projects. We are 5,5 paid staff and 50 volunteers. I will show you a few slides of what the Hotline looks like as well as some of the staff and volunteers.

The callers were - when the Hotline started in 1986 - asking a lot about sexual transmission and questions like whether mosquito bites, using the public toilet, swimming pool, eating of the same plate could cause infection with HIV.

As time has gone by more callers and people on the one-to-one counselling at the AIDS Hotline are personally touched by HIV and AIDS. Either they know someone who is infected or sick, they themselves are HIV positives or they have had a real risk of being infected. The callers are often very concerned about the reaction of their surroundings. I think the Hotline has a moral obligation to utilize this knowledge about different callers, in a more general manner, through public relation work. Callers can be seen as an indicator of what is needed in public relations.

My responsibility at the Hotline is public relations. Traditionally, public relations has been advertisements in papers and magazines, making brochures and TV spots. Often all this is done by a professional advertising company.

We see at least five problems in this approach:

1. it is expensive and we have only 50 000 dollars per year, which for Danish standards is little;
2. it is difficult to distribute materials to where they are most needed;
3. there is an overload of written materials that deal with the same subject;
4. you do not reach the nonreading community;
5. it is a passive way of giving and receiving information.

At the Hotline we found that in the late eighties there were enough organizations who made publications about safe sex, etc., and also that it was a real problem to distribute the information where it was most needed. What was even more lacking, was the outreach to people who do not read these sort of materials or read at all. We found that many were willing to volunteer their services in the P.R. work, and I must add here that there is not a big tradition for volunteers in Denmark. Because it is people who are sensitive to issues around HIV and AIDS, it is also an ethical quality control, to include some of the people who could actually be your callers or target group.

All this has caused us to try other ways of doing public relations than is traditionally seen in Denmark.

We try to initiate new groups where we see a need. We saw a need for support to relatives to people who had died of AIDS. Also we knew it was hard to make the press write anymore about HIV and AIDS so something new had to be introduced. Therefore we decided to "steal" the american idea of the Names Project which is a project about making a personal memory quilt to someone you have loved that died of AIDS. By sewing the quilts together we can use them for displays. So far this has been a very successful project. We found that relatives, lovers and friends got great support, by meeting other people who had lost one to AIDS. Many people in Denmark do not like to seek help when it is called counselling. With the Names Project you start doing something practical, visible and artistic, that has to do with the one who died that you loved and now miss. His or her death will get some meaning as the quilt will be displayed in connection with AIDS information events. Sewing a memory quilt can also bring family and friends together.

The Names Project is now a well established group on its own feet with less and less support from the Hotline. It has attracted a very mixed group of grandmothers, gay lovers, sisters and friends, who have been able to share feelings, which is not so easy to do in cold Denmark.

From a public relation standpoint, this project has been covered by TV, magazines, books and museums to a degree that we often have to make a "waiting list". Part of the success is that here is something visual that is not scary but still deals with death. We have arranged lots of public meetings, volunteer appreciation parties, support parties, etc. We have tried to pull people in from other countries to get inspired and learn from their experiences. But also to show the global picture of AIDS. We try to pull people in from the community and let them present what they see as the problem. We have done this especially in an area where we see a lot of sexworkers and drug users. We have asked different groups from this area what they could use us for and this has resulted in specially designed posters and a demand for having people from the Hotline come to the different institutions to tell staff, volunteers and users about AIDS.

In making our printed materials, we have tried to use people that are sensitive to the issue. For instance the postcards and posters are made by a person who died of AIDS this year. We try to attract people's attention by making something beautiful they want to keep and something that has a message they can play with and which is not too obvious and carries simple messages about condom use, etc. AIDS is many things and changing behaviour for one is not just done by telling about condoms.

I started out saying something about distribution problems. It is important to show faces behind the AIDS Hotline too, so we have been a small team who has visited bars and pornoshops to distribute materials. This is of course very time-consuming and you need a lot of humour. But if there is time, I think this is also a very mutual learning experience, to get a feeling of what the man in the street feels about AIDS, and for him to see that we are not necessarily strange looking transvestites or whatever picture he might have had in his mind. I will show you a few slides with different "streetwork" events. What I have been trying to say and show is that public relations can be a vital part of a Hotline and also have the effect that the volunteers and staff will be proud of being a part of the organization which is very important in order to keep already trained volunteers and staff.

I will end my presentation by showing some slides from parties hosted by the Hotline to show the importance of putting joy into the work as well.

Thank you very much!

D. Plenary session: The calls and the callers

1. 'Sorry, I've got the wrong number', by George Sved

The SFGL (Swedish Federation for Gay and Lesbian Rights) has about 5 000 members. There are 25 local departments, three counselling centres, 15 gay/lesbian switchboards (helplines), six radio stations and three bookshops.

The list below shows the questions that are most frequent.

MEN:

1. Sorry, I've got the wrong number
2. I am not gay, but ...
3. I am so worried, I have a cold since Friday, fever, diarrhoea
4. How is it transmitted? Symptoms?
5. What is safer sex?
6. Testing?
  - Where? When? Anonymity? Result? How? Legislation?
7. The bisexual dilemma
8. I am HIV positive, but my boyfriend is ..
9. Harassment at work
10. The physician
  - fear of the health care system in general

- the AIDS Media-Doctors
  - the certificate; sick-leave/take leave
  - the commands/regulations
  - contact tracing
11. To live with HIV
- to be alone
  - to have sex
  - to be in love
  - to hide
  - to be afraid of living and dying
  - to arrange the funeral or a travel around the world on your credit card
  - to make up the last will
  - insurance and work
12. The surviving relatives
13. It's your fault - gay pride.

WOMEN:

1. To have been unfaithful
  - where is the closest testing-site
2. The Nurse at Primary Health Care Centre
3. "Liberated Libby"
4. Prostitutes
5. Lesbians
  - risks for HIV for women engaging in lesbian sex
  - vaginal secretion, periods
  - bisexuality
  - IV drug use
  - insemination/children

- other sexually transmitted diseases; herpes, chlamydia.

#### IV. Working group reports

##### 1. Working group: A

Rapporteur : George Sved  
Chairperson : Kirsten Madsen

##### First session

The group consisted of about 15 persons with very different backgrounds. The introduction round showed that expectations mostly were to learn from each other, share practical information and experience on Hotlines and to create a social network.

##### Special interests

- Special hotlines for some target groups like health care personnel and HIV-positive people?
- How to influence governments to abolish legislation that is counter-productive to AIDS prevention.

##### Second session

The session was used to discuss two major topics; general versus specialized hotlines and safer sex. It became obvious that different kind of Hotlines run by government agencies and NGOs aimed at specific target groups are necessary because at the moment there is a lack of trust between the different parties.

On safer sex, the discussion was most about how to bring the message, having almost nothing to offer.

For instance the quality of available condoms is sometimes very bad and lubricants are not available at all, not to mention waterbased lubricants. It was felt that protection with bad condoms used the right way is much better than no protection at all.

A central issue was also the AIDS phobia on different levels as well as homophobia.

##### Third session

The group had a very active discussion. The impact of fear for HIV infection and AIDS was highlighted from different angles.

The 'afraid-callers' seem to be quite universal. Their repeated calls to different Hotlines is time-consuming and often manipulative. In spite of quite good theoretical knowledge of HIV/AIDS, fear and prejudice is often present also in the medical profession. One group member told that their Hotline was kicked out of the building when it became public that they were drug users counselling on AIDS.

It proved also important to give HIV a human face in order to overcome fear, in order to replace fear by a wish to come close.

#### Fourth and fifth session

The group started with discussing the possibilities for setting up Hotlines. In many countries the telephone system is not perfect. It is not unusual that lines interfere, and several conversations can be overheard at the same time.

Telephone lines are scarce in many countries, and you may have to wait for years to get a telephone. Due to this, many people do not have telephones, and costs for the call can also be high (especially for long-distance calls). Not all areas are automatic, which means calls from rural parts of countries must be ordered and can be overheard by a local switchboard operator. Thus there are difficulties in setting up Hotlines but it can be done.

Promotion issues were also discussed especially in the light of balance. Some felt they had reached out well, and did not want to 'overdo' the promotion because of the lack of technical resources and the lack of manpower. Others felt that much more needs to be done.

When discussing the budget that Western countries and WHO allocated to central and eastern Europe, it was felt that it would be a great help if funds could be earmarked for AIDS activities not only for governmental agencies but also for NGOs and if the activities could be better monitored. Funding for existing, well functioning services should be a priority.

A round was made on the testing policies in the different countries and some group members were astonished to experience under what circumstances HIV tests were used.

The picture that emerges is:

A lot of false positive test results due to lack of confirmatory tests, and testing without informed consent or other compulsory forms.

In discussing the test issue also a wide range of questions on safer sex and counselling skills and methods were dealt with.

#### Sixth closing session

Discussion on the follow-up and conclusions of the workshop. The different remarks:

- Planning a two-week seminar for Hotline volunteers from Russia and other republics.
- Better counselling skills are important for the Polish participants.
- Drug users' problems in connection with Hotlines were not addressed sufficiently. It is felt important to liberalize legislation on drug use in eastern European countries. Harm reduction and not marginalize drug users should be the policy.

- Inspired to work in a wider sense with changing attitudes and information among teachers and health care personnel.
- Very useful. Will start with my friends and colleagues. Please do not leave us alone now. We need training.  
  
In the beginning optimistic. After role-play more 'pessimistic' because of complexity of practising counselling with regard to HIV/AIDS.
- Would like to have guidance from existing Hotlines on questions and answers. Believe us that at this time a big state-owned line would not be called by prostitutes and gays. More training on counselling content, not on organizing. How to come closer to a very scared and shy person? Thanks to WHO for organizing a conference and the importance of Hotlines in the countries of central and eastern Europe was recognized. Western countries should be patient. We will be more experienced in three or four years. We also need some form of recording.
- I feel it important in Hungary to give publicity to AIDS Hotlines in order to give information to general public on AIDS (the risk groups are informed). Workshop was useful - same questions, same problems in the countries of central and eastern Europe.
- It was a good workshop, networking was very useful, both nationally and internationally. More information is wanted from the Global Programme on AIDS of the WHO Regional Office for Europe direct to helplines if possible. A profile of counsellors would be helpful (what information the counsellor must know, skills etc.).
- The workshop has been worthwhile. Recommend my government some sort of follow up. Socially very pleasant conference.
- Very useful to see there are many ways to do things. Confronted with own prejudice to the countries of central and eastern Europe. I have enjoyed the group.
- Important that invitation was sent direct to individuals.
- Many people working in the national AIDS programme are homophobic, will never be trusted by oppressed gay and lesbian people.
- One country's decision not to grant citizenship to HIV-infected people was regretted.
- Thinking about preparing a centre in Warsaw for lesbian and gay switchboards and for AIDS prevention as a result of the workshop.

2. Working group: B

Rapporteur : Kerstin Dyrendahl  
Chairperson : Alan Jamieson

First session

The group split up in pairs and then introduced each other saying who they were, what they did, why they were here, what they wanted from the workshop and what they brought.

Participants then worked in small groups to identify their own needs and expectations of the workshop.

These were:

- networking
- more information about AIDS
- more information about AIDS Hotlines
- relation between AIDS Hotlines and other Hotlines
- information on evolution of Hotlines
- structure and staffing and organization
- intensity of work hours/calls/problems
- more basic information on HIV/AIDS
- the role of personal counselling/anonymous counselling
- is just a Hotline enough?
- recruiting and training counsellors
  - how? for how long? in what skills?
- counselling the counsellors
- who is calling? why?
- registration and analysis of calls
- information about documentation
- how to reach specific groups?
- marketing and public relations
- effectiveness of clear messages

- funding
- cost efficiency.

Second session

Trying to discuss yesterday's list, the group started with whether or not deep kissing might transmit the virus (HIV).

Other questions discussed: how to acquire basic information and how to interpret it before informing others.

Various methods were presented. In Poland for example there is a national institute that is responsible also for validating of the facts (interpretation of articles in magazines).

Discussion followed on how to develop a good manual and keep it updated.

- How to recruit and select counsellors?
  - Who should become a HIV counsellor?
- Should he or she be physician or not?
- Should HIV-positive persons' experiences be used?
- Who is too young to answer?
- Could a gay answer?
- Should the Hotline reflect the spectrum of the society?

It was also felt important that if no tradition of counselling exists in a society one should try to create one in a changing society.

The training of hotline counsellors was also discussed.

- skills
- methods to answer
- training models, role plays, peer monitoring, etc.

mentorship/support/supervision

- credibility (of both the counsellor and the organization responsible for the Hotline) and empathy are considered more important than professional background.

Every country or organization has to find its own model because there is no 'THE HOTLINE'.

Anonymity creates possibilities to pose the questions needed.

There is a risk with scientific translation of texts. Texts must use the language of the target population.

#### Third session

An example of fund raising in the UNK was presented. How to find money within the countries of central and eastern Europe.

Know the local setups.

Small initiatives are important like:

- buses in streets
- concerts.

Sex education traditions were also discussed: in school, in the family. Sometimes none seem to exist at all.

Ways of promotion.

- on goods, newspapers, stickers, posters, buses, TV/radio, sex shop, through friends.

#### Fourth session

Management of calls.

First the response to callers was discussed in small groups. Different points of view existed on how to respond, anonymity or not.

But there was agreement on: friendly tone, good articulation, adapted language, empathy, patience, listening to questions 'behind'. In summary: interested, welcoming ('opening the door'), creating trust and setting the scene.

A good call should have a clear structure: beginning - middle - end.

Discussion followed on the importance of a clear registration system, not only to clarify and make results visible but also to support, for example, promotion strategies for the Hotline.

#### Fifth session

Role plays showed examples of finding good and bad answers.

Discussion followed on:

- How to advise the caller what to do. The counsellor can only support the caller in finding a solution.

Two groups worked on whether the Hotline be autonomous or be a part of a treatment centre.

Group I - two views were expressed:

1. Autonomous Hotlines give better accessibility to general public
2. In a treatment centre medics will be counsellors and they are able to give best possible advice.

Morals were also discussed:

- basic shared values
- need to be defined
- others will change with the progression or regression of society and with time.

Is promotion based on moral principles? Or on the need for safer sex?  
Or do both these factors prevail?

Group II

Need to consider what underlines the need for the helpline whether it is in an STD clinic or is a gay or body positive or drug help line.

Co-operation between all lines is aimed for but at this moment one has got to be happy with what exists. The future is not known, and we are therefore not in a position to know what is better.

#### Sixth closing session

Individually:

Think of one positive thing you received from this workshop

- (more) supportive
- learning from experience
- techniques
- role of Hotlines
- operation of Hotlines
- more information on training
- learning from West AIDS Hotlines should be confidential
- good group experience

What will you do differently as a result of this workshop and what else would help you?

- create a working model
- involve more physicians

- give more information to callers
- more training for counsellors
- more supervision
- learn new skills
- support helplines training
- change education material away
- change registration forms
- more support to callers, comfort them
- make better contacts with seropositives
- networking
- keep contacts
- money
- good reference
- material
- (information and training)

3. Working group : C

Rapporteur : Carsten Hinz  
Chairperson : Shelley Gurney

First session

After the introduction of the facilitator and the rapporteur by themselves, two participants introduced themselves one to another. Then, each participant introduced his 'partner' to the whole group.

In three groups of four persons, the participants cleared their expectations on the workshop apart from the general themes given in order of appearance:

- personal contact with people from other countries working on the same theme
- technical problems in setting up a Hotline
- how to reach target groups
- fighting bureaucracy

- how to find reliable specialists/organizations to refer the caller to
- right level of language for good communication with the caller
- what kind of support to offer to seropositives
- what kind of callers to expect
- other themes of the target groups, e.g. coming-out, emancipation of gays
- prevention not separated from emancipation
- how to attract people
- fighting conservative politics
- how should authorities encourage and enable people to run Hotlines, how to start them
- co-operation of authorities with, e.g. gay groups who want to run a Hotline
- how to change policies/legislation to enable activities of, e.g. gays
- problems concerning different languages/cultures in the region of the Hotline
- discrimination of languages/ethnic groups within Hotline.

#### Second session

The group exchanged experiences concerning:

- \* Lack/availability of general information on sexuality, i.e.
  - sex education programmes in schools
  - appropriate books/material
  - competent educators/teachers
  - increasing influence of religious forces
- \* Possibilities/limits of Hotlines, i.e.
  - referral systems
  - how to find/motivate members of the target groups for work in a Hotline
  - how to enable/train professionals (medical doctors, psychologists, etc) towards special needs of the target groups

- coping with/fighting the limits set by legislation
- \* Lack of communication/co-operation between
  - groups, who want to run a Hotline and authorities
  - groups with a different approach towards the 'Hotline', e.g. whether it should work for the general public or for specific target groups.

### Third session

Three small groups worked on different issues, which are important when planning or starting a Hotline:

1. referral systems/how to find out their reliability
2. selection and training of staff
3. collection of data/information needed for work.

After 30 minutes work in these subgroups, each group presented the outcome:

1. A National AIDS Committee should be able to
  - recommend reliable specialists
  - build up training programmes for specialists, where they get to know people belonging to the target groups and where they are provided with special information/issues concerning, e.g. lifestyles of target groups
  - give licences to the specialists, who have attended these seminars
  - have the activities funded by governments, helped by WHO.
2. A psychological profile has to be worked out which clears the conditions for appropriate communication with callers belonging to different target groups.

Professional background, social level or sexual orientation of the counsellor are of minor importance.

The team of counsellors should regularly exchange experiences and information, especially concerning referral possibilities. The question of (dis)advantages of volunteers and/or paid staff remained for discussion.

3. The most important aspect/criterium has to be the credibility of the Hotline. Discussion on how far the counsellor can/should enter the privacy of the caller without scaring him/her.

Direct questions only as much as necessary for the counselling.

#### Fourth session

Before starting to work in sub-groups, each participant was asked to give a short comment on what is still missing for him/her, and what kind of expectations have already been met.

##### Benefits on

- personal contact that may serve to solve problems coming up in practical work later on
- confidentiality/communication
- social aspects of AIDS/sexual orientation
- information from activities in other countries that may help in negotiations with their own authorities

##### Open aspects

- general Hotlines versus target Hotlines
- practical financial/funding problems.

Two small groups worked on the following topics:

1. registration of data/confidentiality
2. general Hotlines versus targeted Hotlines.

Results presented to the whole group:

1. There was agreement that some collection of data is useful
  - to present the work of the hotline to the public
  - to justify funding
  - basic information for lobbying
  - monitoring effectiveness, i.e. reaching target groups

The collection should be made as sensitive as possible.

The purpose of the Hotline is help the caller, i.e. above all, confidentiality has to be assured.

2. The decision towards a general hotline or a target hotline finally depends on the conditions in each country. It is important to choose an appropriate name depending on the language, to mention in a specific way the services offered in the advertisements, e.g. psychological, medical, social, legal. The (volunteer) counsellors have to be trained on these subjects by experts so that the experts only must be present personally at certain advertised hours for any specific questions.

A targeted Hotline is important for, e.g.

- lifestyle problems apart from AIDS
- easier access to AIDS-related lifestyle questions
- AIDS problems can sometimes not be separated from lifestyle aspects.

A general and targeted Hotline could be run together, with different opening hours and shared expertise.

As long as only one Hotline is possible, a general hotline has priority, but if specified hotlines are possible, it is better to separate them to avoid confusion for the caller.

#### Fifth session

The group first separated into two small groups and worked on practical aspects of questions that could come up in a Hotline.

Each group choose three possible questions and discussed possible answers:

1. 'To tell or not to tell I am seropositive'
2. 'How should I go on living as a seropositive'
3. 'What does safer sex mean, how to practice it?'

The whole group worked out that there is not one correct answer, but that it is necessary to concentrate on the personal situation of each caller.

The two common issues were recognition of the importance of

- information regarding the prevention of further infection
- providing the caller with information relevant to his/her personal benefit.

#### Sixth closing session

In the last working group session, the participants resumed the main achievements of the workshop:

1. to make contact with other people working on the same issue
2. to exchange experiences with people at both national and international levels

Support and encourage starting activities of one's own:

1. Hotlines
- Agreement of the importance of standards and the necessity of profound preparation, e.g.

- training for counsellors (counselling does not just mean to provide the caller with information, but putting emphasis on personal problems and enabling the caller to find the conclusion on his/her own)
- setting up information (translating from clinical terms into a language the caller understands)
- getting to know material, e.g. for translation
- Criteria for setting up a reliable referral system
- Being clear what kind of service is appropriate in relation to the individual requests of the caller
- 2. Agreement of the importance of general sex education programmes and the need to target young people in particular.
- 3. The importance of national and regional networking for
  - training programmes for counsellors
  - lobbying to change the legislation for discriminated minorities
  - putting pressure on national governments to add "the free choice of sexual orientation" to the basic human rights in the constitutions.
- 4. The importance of specific activities for target groups which proceed emancipation of minorities.

#### V. Working group results, conclusions and recommendations

The summarized results of the three working groups and the workshop as a whole, are presented in this chapter.

#### Conclusions

- \* It was very stimulating and encouraging for the participants to meet other people confronted with similar experiences, problems and challenges when combating AIDS in their individual country;
- \* Before an AIDS Hotline is able to operate appropriately some basic criteria have to be fulfilled (non-judgemental approach, respect for human rights in general and more specific: no discrimination based on sexual preferences);
- \* An AIDS Hotline should involve members of specific target groups as much as possible (people with HIV/AIDS, men who have sex with men, women, drug users);
- \* There is a great lack of possibilities for the practical execution of a kind of AIDS Hotline (recognition at the policy level, funding, space, skills, etc.).

The workshop answered a lot of questions, but at the same time launched new questions and needs.

In all of the central and eastern European countries that participated there is a great need for:

- basic information about: AIDS, (homo)sexuality, counselling, the role of the Global Programme on AIDS of the WHO Regional Office for Europe, etc.;
- concrete guidelines for telephone counselling;
- some kind of training as follow-up of the workshop;
- funding and skills to negotiate funding;
- participation in (inter)national networks.

The participants of the workshop agreed on a statement concerning the rights of homosexuals.

Recommendation

Attached.

Annex 1

Recommendation

Participants at the "Workshop on AIDS Hotlines for Countries of Central and Eastern Europe", Warsaw, 13-16 December 1991, examined the London Declaration on AIDS Prevention, unanimously adopted on 28 January 1988 by the World Summit of Ministers of Health on Programmes for AIDS Prevention, which emphasized the need in AIDS programmes to protect human rights and human dignity.

They also reviewed Resolution WHA41.24 of the Forty-first World Health Assembly on Avoidance of Discrimination in Relation to HIV-infected People and People with AIDS, urging Member States to protect human rights and dignity of HIV-infected people and people with AIDS, and of members of population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment and travel.

The group further considered the Prague Statement, unanimously endorsed by participants of the Pan-European Consultation on HIV/AIDS in the Context of Public Health and Human Rights, held in Prague from 26 to 27 November 1991, urging Member States to ensure that all laws, policies and practices which directly or indirectly affect HIV/AIDS prevention and control or concern the legal emancipation and empowerment of women and vulnerable population groups take full account of principles of human rights, ethics and humanity, pointing out the need to pay special attention to the needs and rights of men who have sex with men, drug users, sex workers, prisoners, migrants, refugees and ethnic minorities.

The participants unanimously decided to recommend that Member States of countries of central and eastern Europe, in view of the potential risk of a rapid increase in HIV transmission among men who have sex with men, take immediate action to review and revise all existing laws, policies and practices which discriminate on the grounds of sexual orientation, and counteract discriminatory attitudes among the general population along the guidelines suggested in the Prague Statement.

Annex 2

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