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REGIONAL OFFICE FOR EUROPE



GLOBAL PROGRAMME ON AIDS

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NATIONAL AIDS PREVENTION AND CARE PROGRAMME REVIEW

Report on a Consultation

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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.^a

TARGET 5

REDUCING COMMUNICABLE DISEASE

By the year 2000, there should be no indigenous cases of poliomyelitis, diphtheria, neonatal tetanus, measles, mumps and congenital rubella in the Region and there should be a sustained and continuing reduction in the incidence and adverse consequences of other communicable diseases, notably HIV infection.

ABSTRACT

The National AIDS Prevention and Care Programme Review Consultation was held to gain a more detailed understanding of National AIDS Programmes by examining the historical development, successes, constraints and lessons learned of selected country programmes. This insight will enhance the role of the WHO Global Programme on AIDS as an information broker to facilitate the exchange of experiences between National AIDS Programmes in the Region.

Participants concluded that all Member States must share the responsibility for ensuring human rights and counteracting discrimination and complacency. National AIDS Programmes must be developed to view the causes and effects of HIV infection within its broad social and economic context. Only an intersectoral approach can appropriately respond to the challenges of the pandemic.

Key recommendations included: an intensification of WHO's work with the media; strengthening and development of mechanisms to share experience between established and newly-formed National AIDS Programmes; evaluation of National AIDS Programmes should be strengthened; NGOs should be included in programme planning; and young people should be supported towards healthy lifestyles.

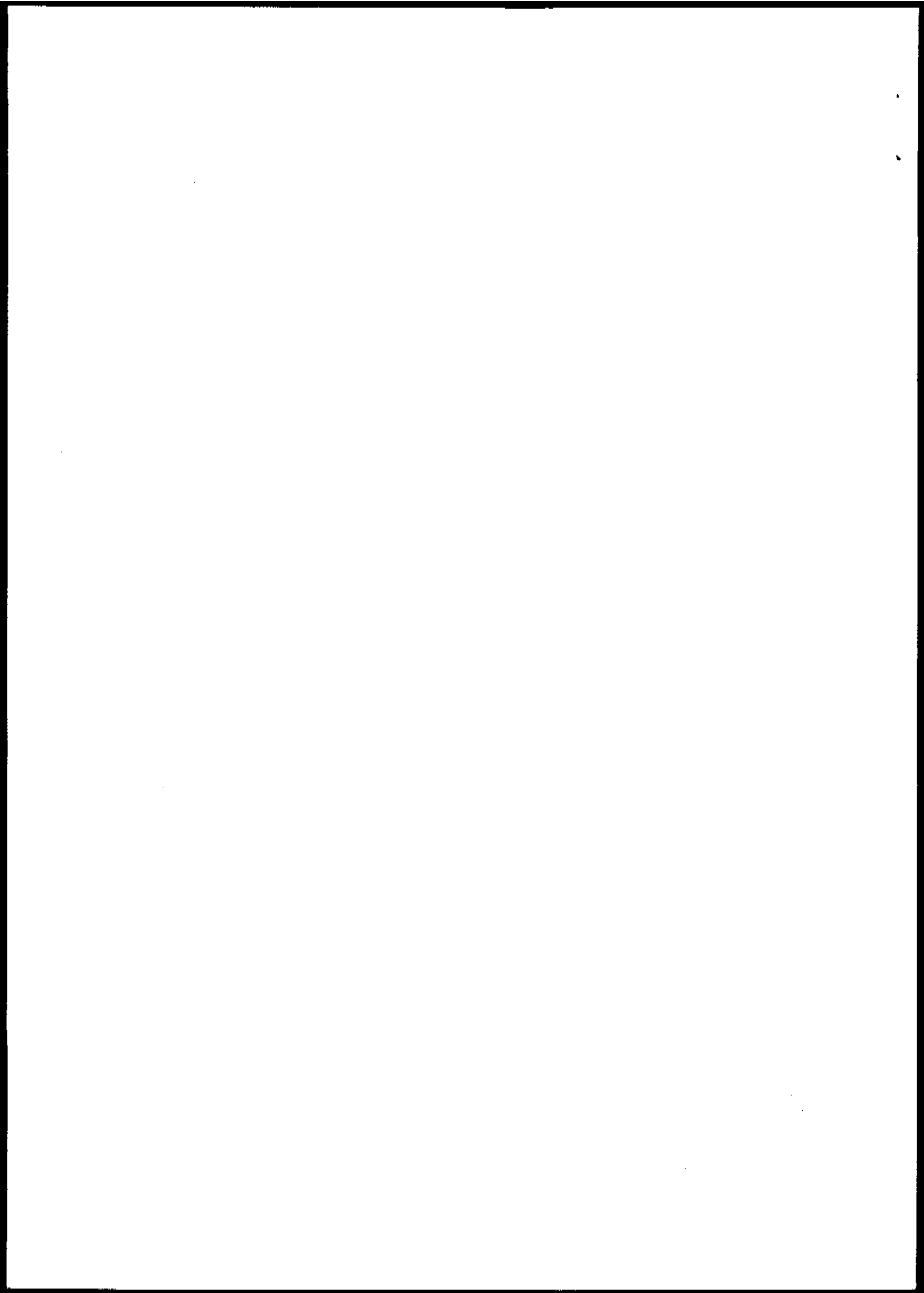
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Introduction

The National AIDS Prevention and Care Programme Review Consultation was the first in a series of consultations aimed at strengthening collaboration between the Global Programme on AIDS, Regional Office for Europe, and national programmes. The scope and purpose of the meeting was to gain a more detailed understanding of the National AIDS Programmes, and to gain a greater insight into the historical development, the successes, constraints and lessons learned, of selected country programmes. This insight would enhance the role of the Global Programme on AIDS as broker, facilitating the exchange of experiences between programmes as relevant and appropriate. This understanding was important to gain both about programmes with which the Global Programme on AIDS has had little involvement, as well as in programmes with a high level of contact with the GPA, in order to monitor and adjust the technical input from WHO. The aim was to provide elements of a successful programme which may be transferable from more mature European programmes to newer ones in central and eastern Europe.

In opening the meeting and welcoming participants the Director, Lifestyles and Health, outlined the major challenges facing the Regional Office for Europe and stressed the need to appropriately serve the rapidly growing number of new Member States in central and eastern Europe, which are at present undergoing critical social, political and economic changes:

- How can disease prevention and health promotion, and especially HIV/AIDS prevention, be implemented in these low prevalence countries?
- In what way can we assist these newly independent states?
- How can we use the experiences made in other countries and enlist the help of existing programmes?
- What is the specific role of WHO?

The organizational structure of the Global Programme on AIDS was then presented, and an overview of the epidemiological situation in countries of central and eastern Europe. It was stressed that prevalence is still low in CCEE relative to other countries in Europe, and that there are widely varying reasons for and patterns of the epidemic in this part of the European Region.

The goals of the consultation were; to gain a more detailed understanding of selected National AIDS Programmes; to gain insight into the historical development of programmes, including the successes, constraints and lessons learned. The review process was outlined: based on programme evaluations conducted, participants would present critical assessments of programmes as a retrospective analysis; how would programmes have been developed with the benefit of hindsight. These would be made in the light of specific national frameworks of culture, legislation and epidemiology. The expected outcome of the consultation was:

- to monitor and adjust the technical advisory function of the Global Programme on AIDS in order to more appropriately meet the needs of Member States;
- to facilitate the exchange of experiences between National AIDS Programmes; and
- to document, as case studies, selected National AIDS Programmes, to identify transferable programme elements, based on more mature programmes in the European Region, to programmes in countries of central and eastern Europe.

Dr Wallin was elected Chairperson, followed by brief introductions by all participants.

Overview of evaluations of selected National AIDS Programmes

1. Finland

This programme was created relatively late in the history of the pandemic and Finland still experiences low incidence of HIV infection. A cumulative total of 125 AIDS cases have been reported, with a growing number of heterosexual cases, of which a majority has been acquired from endemic areas abroad. The Finnish programme is marked by a highly centralized health care system in which 70 per cent of patient care is provided by public service and 30 per cent by the private sector. It has a long standing and well trusted public health system, and the AIDS programme is centralized for the nation as a whole, with a separate programme for the city of Helsinki. A network of nongovernmental organizations (NGOs) includes a coalition of sexual minorities, the Finnish Red Cross, the Diakonissen Institute, and others.

Testing for HIV is conducted in primary health care centres free of charge and anonymously, if desired, as well as through NGOs. Seroprevalence figures seem to be stable, based on several sources.

Reference was made to the All-Baltic Union against AIDS which has met regularly for the past four years, and includes representatives from Estonia, Finland, Latvia, Lithuania and Russia (St. Petersburg) and most recently Denmark, Poland, Sweden. Newly independent Estonia, Latvia and Lithuania are in need of practical contacts with colleagues in other parts of Europe, especially for opportunities to carry out brief training and study visits abroad and help to gain political influence on matters related to HIV/AIDS prevention and care in their respective countries.

2. Germany

The German programme was introduced with a short epidemiological overview. On the basis of the voluntary, anonymous AIDS case register and the mandatory laboratory reports the following numbers were reported to the Federal AIDS Centre by August 1992: a total of 8763 AIDS cases, predominantly in men who have sex with men. The epidemic is most predominant in big cities of the western part of Germany. In the new Bundesländer there are only 51 AIDS cases reported, with a significant rise in incidence since the fall of the Berlin Wall, but not as high as expected. The number of STD cases is declining.

The National AIDS Programme was established in 1987 as a central AIDS Unit within the Ministry of Health, supported by the National AIDS Working Group at the federal level, interministerial Working Group, Aids Coordination Group, the Federal Office of Health Promotion (BZGA; for prevention on population and target group level) and the Institute for Information and Documentation. Major NGOs are the Deutsche AIDSHILFE, with branches in the different Länder, and the AIDS Foundation.

The Federal Government can only institute start-up or model programmes, which thereafter are delegated to the different Länder. In former East Germany, the "new Länder", the development of AIDS programmes had to take an abbreviated course after the fall of the Berlin Wall; since new Länder lacked funds and structures similar to those in the "old" Länder, local project groups were set up with the aim of utilizing the experiences of their western counterparts. The surveillance system in the eastern part of the country is reliable, and the present low number of cases is considered to be an accurate reflection of the epidemiological situation.

The National AIDS Programme has conducted a wide range of targetted prevention campaigns, including the general population, health care providers, prostitutes and their clients, sex-tourists, youth, men who have sex with men and injecting drug users. Problems encountered in the efficacy of these campaigns has included resistance to condom use, lack of safer sex practiced among drug users and declining interest in the general population.

3. Romania

The Romanian National AIDS Programme started in 1990, with intensive support from WHO. The main route of transmission found in Romania has been through contaminated blood supplies and the use of unsterile equipment in the treatment of hospitalized or institutionalized infants and children. By March 1992, 1 846 cases of pediatric AIDS were reported; of these 118 were in children born after 1 January 1990. Since October 1990, blood safety is reported to have been achieved and findings showing a marked decline in pediatric cases of HIV/AIDS were presented. The aim of the National AIDS Programme is to keep the pediatric situation under control while focusing on adult HIV transmission, which seem to be on the increase. Conclusions of a recent study conducted in Romania found that the risk of HIV transmission in children through blood transfusions, multiple injections and multiple hospitalizations has decreased, and the mother-to-child transmission has increased, according to the global pattern.

In the discussion it was pointed out that the Romanian experience illustrates dramatically that traditional measures of infection control work well where appropriate (blood safety in the case of pediatric AIDS) but that adult HIV/AIDS requires quite different ways of thinking and an approach different from the traditional public health measures in order to be effective.

4. United Kingdom

With a cumulative figure of 6 140 reported AIDS cases in the UNK, it is a low prevalence country within the European Community; heterosexual incidence, however, seems to be on the rise.

The main elements of the Government strategy in HIV prevention has focused on:

- limiting the spread of HIV transmission by public education and by public health measures;
- monitoring, surveillance and research;
- the provision of appropriate treatment, care and support services;
- social, legal and ethical issues; and
- international cooperation.

In a first period of denial up to 1985, self-deferral leaflets for blood donors were the main Government initiated activity; NGOs especially within the gay community were increasingly active.

In 1985 a major change in policy gave HIV/AIDS high attention in Government and the public with quite abundant funds that allowed for measures and campaigns that made AIDS a major societal issue. The 1988 World Ministerial Summit on AIDS which was held in London marked a peak.

Since 1988 a second period of denial has been described, marked by increasing doubts voiced about the real importance of HIV/AIDS and the effectiveness of the vast prevention efforts, given the still low prevalence rates in the UNK. Among the general population the prevailing attitude would seem to be that HIV/AIDS is a problem only within minority groups; sexual minorities, ethnic minorities, immigrants, if at all.

Retrospective analyses

The National AIDS Coordinator for Denmark from 1986 to 1988, summarized the experiences of the programme in its early stage of development. The underlying principles of the Danish information campaign had been reliant upon a non-moralizing, humourous approach. Among the successful aspects of the campaign were:

- Collaboration with voluntary organizations, especially with gay and lesbian groups, was very important because of the tendency towards discrimination. Collaboration gave support and visibility to the nongovernmental groups and was well received.
- Using local and regional networks as often as possible, e.g. at the workplace, in sports, communities.
- Behavior changes can be seen, for example in the willingness and ability of individuals to talk about sex, condoms, HIV; another indicator might be the decline in gonorrhoea and syphilis, which are now at lowest recorded incidence.
- Consistency in the content of the messages was paramount to the credibility and acceptance of HIV prevention activities.
- Similarly important was the credibility of the people involved in the HIV prevention campaign, resulting in support by the media and by the public.

With the benefit of hindsight the following areas where difficulties were experienced and which could have been improved were cited:

- Information and education for health care personnel began too late; their knowledge, communication skills and psychosocial understanding were overestimated, their level of fear underestimated. In addition, health care professionals, especially physicians, were experienced as feeling superior to the need for further training. Remedial measures are not easily definable, but they may include seminars, hotlines, etc.
- While the press was in general quite positive and supportive it was felt that continuous high quality briefing for the media would have been important, especially in explaining policy and strategy issues, and rationales for policy decisions.
- Evaluation of the campaign on an ongoing basis is very important and should have been integrated into the programme from the beginning, providing useful feedback for policy-makers, planners and implementers of the programme. Evaluation should be both internal and external.
- Timely and effective distribution of produced materials is important but not always easy; this point should be given close attention.
- The evaluation of newly emerging potential or perceived risks should be given attention so that these can be compared and put into perspective with the known risks; much confusion and anxiety in the public and among specific groups at risk could be spared.
- The ultimate goal is behaviour change, but it seems that there are hardly any specialists who can provide a recipe on how to translate the relatively easily achievable changes in awareness, knowledge and attitudes into sustained behaviour change. Direct involvement of the community in ongoing dialogue is essential.

"A retrospective analysis of evolving structures and functions 1981-1992", based on a recent survey of National AIDS Programmes conducted by the Global AIDS Policy Coalition was introduced. With a special focus on the structural aspects of National AIDS Programmes the following issues were addressed:

- The emergence and starting dates of National AIDS Programmes globally; the Ministerial Summit, London 1988, clearly boosted the creation of National AIDS Programmes.
- Programme evaluation findings include rapid achievement of operationalization, success in raising public awareness on HIV/AIDS including human rights issues, exchange of information internationally, and growing mobilization of resources. Critical evaluations found lack of focus and priority setting, weak management, and insufficient involvement of other government sectors and nongovernmental organizations.
- The evolution of programme structures sees an increasing trend towards decentralization and more horizontal integration (e.g. with programmes for sexually transmitted diseases.) In recent years there has been mounting pressure on National AIDS Programmes to share resources with other programmes, and to make changes in structures, strategies and staffing.
- Staffing patterns have changed; while young and committed programme staff have often been overworked and have been at risk of losing their jobs. The observed high turnover of staff in national programmes seems parallel to "burn-out" experienced by staff, due to excessive or unusual responsibilities in the face of insufficient professional preparation and available training, high psychosocial levels of stress, due to experiences of identification and bereavement.
- Nongovernmental organizations and AIDS service organizations have been very active and in spite of certain problems and weaknesses, it is crucial to build coalitions between these bodies and National AIDS Programmes. NGOs can have different formats: charities, development groups in communities, advocacy and activist groups, and/or public service contractors.
- National commitment to HIV/AIDS can be measured by certain indicators, such as the time and frequency of statements by heads of states, or the creation of national advisory bodies. Over time, however, the latter seem to be losing their role and sense of purpose, caught between the different, partly conflicting requirements for a technical versus political advisory role. It seems that in order to fulfill the still important roles of a "think tank" and of a coordinating body, new terms of reference are needed.
- Regarding the cost of HIV/AIDS prevention and care, there are great differences in spending and available resources, between industrialized and developing countries; worrisome trends were presented, e.g. the plateauing of research spending, a proportional decline of research spending in developing countries, and a decline of finances awarded to the Global Programme on AIDS.
- A conceptual framework was presented which allows to assess individual National AIDS Programme impact upon reducing individual, societal and programme related vulnerability to HIV/AIDS and to make comparisons between different national programmes.

Dr Tarantola concluded by stating that without major societal changes there will be no success in HIV/AIDS control, referring to a cause-effect analysis which had been conducted in a community in New York City where urban degeneration was seen as a direct link to contributing to the high incidence of HIV in the area.

Discussion

While acknowledging that the focus of prevention is on risk behaviours not on risk groups, it was agreed that it is useful to distinguish between population groups (traditionally defined for epidemiological purposes) considered to be at risk, because many members of this group practice risky behaviours and individuals outside these groups occasionally engage in risk behaviours. Therefore interventions and education messages must be targeted to both groups considered at risk, and to the overall population.

Men having sex with men should be considered a behaviour practiced by a diversity of the general population, rather than as a static group. Reference was made to a recent Swedish study in which four definitions of men who have sex with men were identified:

1. men who openly identify themselves as gay, are activists for gay rights, belong to NGOs and other gay support groups, reside in urban areas;
2. men who live in smaller towns, who practice sex with other men clandestinely, often on travel abroad;
3. bisexual men, who do not identify with the gay community and therefore do not consider themselves to be at risk;
4. young boys at the age of sexual debut who experiment with their new sexuality.

Because of such a diversity among the overall population, it is important to gear prevention messages to the general public and to young people which are relevant to the behaviour practiced. A mix of general public information, and NGO- and advocacy-group work is necessary with messages worded accordingly.

NGOs originating from the gay community have taken a leading role in activating and mobilizing governments and the public toward awareness of HIV/AIDS in the early 1980s; their drive and commitment have been regarded as both too aggressive in style or explicit in language for some politicians and public, and as essential to ensuring continued momentum to HIV/AIDS awareness. HIV/AIDS is not only solely their responsibility; all efforts must be coordinated with statutory agencies and policies. The special situation in countries of central and eastern Europe, where NGOs are few or nonexistent, needs the support of well established programmes, in which collaboration between statutory and non-statutory groups exists. It is crucial that decriminalization and destigmatization of men who have sex with men is ensured as a first step.

Political support is paramount as decision-makers are influential on matters of funding as well as being leaders of opinion-making. Firm support in government was reported by participants to be an essential asset in National AIDS Programmes. When convinced that HIV/AIDS prevention has critical social benefits, political support can be forthcoming.

The role of the media is also critical; it both influences political opinion, and reflects political opinion to the public. Careful and consistent briefing on HIV/AIDS to the media are tasks of utmost importance. Misinformation can lead to setbacks in programmes, as fear and misconception are easily promoted.

HIV/AIDS is no longer only a health problem; the broader social context must be taken into account, including inequities such as poverty, unemployment, discrimination.

Another often overlooked problem is the lack of knowledge and understanding and often acceptance among health care providers towards men who have sex with men and other HIV-affected people. There is a need for improved training for health care professionals to reduce discriminatory tendencies and to enhance solidarity.

Injecting drug users pose a major challenge to both prevention and care intervention programmes as they are most often socially marginalized without advocacy through support groups or networks; they may have a poor economic base and an unstable social network. Furthermore, prevention campaigns must address both drug addiction, drug taking behaviour (harm reduction) as well as sexual behaviour. Needle exchange programmes were regarded with varying acceptability, with national differences, but it was agreed that these programmes are not sufficient on their own, and should be accompanied by additional medical and psychosocial support.

The present economic imbalance across borders in Europe today is a source of potential tension for example through cross border sex trade. This has included men from the western part of Europe travelling to the CCEE for sex tourism where costs are lower, or sex workers travelling to western Europe to increase earnings. It was felt that the responsibility to curb and avoid cross-border exploitation should be shared by all Member States.

The importance of good STD surveillance was repeatedly stressed as an early warning system for sexual risk behaviour. It also was stated that epidemiological data should only be collected insofar as they were actually useful for a defined purpose; scarce resources should not be used on surveillance in favour of more essential interventions.

It was generally felt that youth is a vital target group; appropriate prevention interventions in youth have long term effects and constitute a sound investment. It was agreed that it was most beneficial to integrate HIV/AIDS education in sex education in school health education so that a general programme of school health education would be a prerequisite for HIV education. Ensuring HIV education in schools would therefore achieve the goal of ensuring school health education where it does not exist.

Programmes should be ongoing on a yearly basis, as new cohorts reached sexual maturity. Messages and interventions need to be tailored and timed according to varying stages of awareness, knowledge, attitudes and behaviour, both on the different individual, and different national levels.

Adequate time and planning was regarded as the key element of programme development; thorough planning, involvement of key people in government, NGOs, and the media, as well as adequate preparation of agencies and health care systems for the consequences of the pandemic, can reduce the need for "crisis intervention" at a later stage.

Conclusions

1. In the new, open, Europe, responsibility for ensuring human rights and for controlling the epidemic must be shared by all Member States to counteract discrimination and complacency especially at a time of increased population mobility between countries.

2. The causes and effects of HIV infection must be considered within a broad social and economic context. As national AIDS programmes include health and social care and research components and as they are intended to address ethical, legal, policy and resource issues, an intersectoral approach is needed. As medical aspects deal only with part of the phenomena of HIV/AIDS programmes should not be limited to the responsibility solely of health departments but should be developed to include all concerned government departments.
3. Emphasis should be placed on the appropriate use of resources. For example, adequate HIV and AIDS care, support and prevention services can often be provided by existing health care and health promotion services.

Recommendations

To WHO:

1. WHO should intensify efforts to educate and inform the media, by for example, exploring the feasibility of linking an intercountry meeting on the media with the planned Ministerial Meeting to be held in Riga, Latvia, April 1993.
2. WHO should maximize the use of existing mechanisms or establish new ones where appropriate to facilitate bilateral cooperation between established National AIDS Programmes and newly developed ones in the European Region.
3. WHO should explore the possibility of arranging an inter-agency meeting with other intergovernmental organizations in Europe such as the EEC and the Council of Europe, with a view to establishing an interagency coordinating committee on HIV/AIDS.
4. Recognizing the diversity of interest and expertise of nongovernmental organizations, particularly in countries of central and eastern Europe, WHO should prepare a consultation to explore the natural evolution, development and role of NGOs as well as collaboration between them and governments to gain a clear understanding of their role in the fight against AIDS.
5. WHO should further develop effective mechanisms for twinning and establishing partnerships among NGOs in the European Region.
6. WHO should explore with the Council of Europe further follow-up to the Working Party on Early Intervention in HIV Infection specifically to develop appropriate infrastructure for care, counselling and support, including training of professionals.
7. In order to strengthen evaluation of national AIDS programmes, the Global Programme on AIDS, Regional Office for Europe, should formulate indicators, quality of service measures, and other assessment tools as appropriate for European national programmes.

To Member States/National AIDS Programmes:

1. HIV intervention must be sensitive to the social and cultural climate of each Member State. This strengthens the public and political commitment to combat the pandemic and provide care and support to those affected by it.
2. Epidemiologically it is helpful to differentiate between population groups considered to be at risk and individuals outside these groups who occasionally engage in risk behaviours. Therefore, targeted interventions should be introduced on both a group level and an individual level.

3. Nongovernmental organizations have played an important role in established programmes in the European region. Their development should be fostered in countries with newly established programmes.
4. Discrimination against vulnerable people such as men who have sex with men, injecting drug users, people with STDs, and others, is counter-productive to both the individual and society.
5. Addressing sensitive social issues, for example sexuality, drug use and discrimination, must be timely within a given culture, and must be sustainable.
6. It is well accepted that it is easier to reinforce healthy lifestyles in the young than to attempt to alter well established patterns of behaviour later in life; it is, therefore, crucial to give priority to health education about HIV and AIDS for young people.

Annex 1

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