



THE SOCIAL IMPLICATIONS OF AIDS

A report from the programme on
Health Policies and Planning



WORLD HEALTH ORGANIZATION
Regional Office for Europe
COPENHAGEN

TARGET 4

Reducing disease and disability

By the year 2000, the average number of years that people live free from major disease and disability should be increased by at least 10%.

TARGET 34

Management of planning and resource allocation

Before 1990, Member States should have managerial processes for health development geared to the attainment of health for all, actively involving communities and all sectors relevant to health and, accordingly, ensuring preferential allocation of resources to health development priorities.

Index:

ACQUIRED IMMUNODEFICIENCY SYNDROME
FORECASTING
SOCIOECONOMIC FACTORS
HIV INFECTIONS
AUSTRIA
GERMANY, FEDERAL REPUBLIC OF
ITALY
NETHERLANDS
SPAIN
SWITZERLAND
EUR

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THE SOCIAL IMPLICATIONS OF AIDS

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Note

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Introduction

The Working Group on the Social Implications of AIDS is one of two groups which support the European scenario project on the social and economic consequences of AIDS. The meeting was organized by the WHO Regional Office for Europe and hosted by the Austrian Ministry of Health. The 26 participants - who included social scientists, epidemiologists, policy-makers and physicians - were welcomed by Dr Rafael Bengoa and Dr B. Gredler on behalf of the WHO Regional Office for Europe, Dr Anthony Ambrose on behalf of WHO headquarters (Global Programme on AIDS) and Dr Helga Halbich on behalf of the Austrian Government.

The objectives of the Working Group were to:

- provide a forum and structure for discussion of the major psychosocial implications of AIDS;
- provide support and guidance for national projects in which AIDS scenarios are being developed.

With these objectives in mind, the Group's five tasks were to:

- monitor and analyse the social implications of the AIDS epidemic and relate them to scenario-building;
- survey the impact of the AIDS epidemic on health and social services;
- indicate the contribution made by the social sciences to AIDS research and AIDS policy development;
- review the methodological and psychosocial aspects of national scenario project proposals;

- assess whether it would be possible to design mechanisms for exchanging information between countries, with special emphasis on the possibility of developing a set of common denominators.

It is intended that the papers presented at the meeting should be published.

Social impact of HIV/AIDS

The consequences of HIV/AIDS are wide-ranging and affect all sectors of society. The complex interactions and relationships of modern social structures intensify the impact of the direct social consequences of the infection, since no effective vaccine or cure exists. The major direct consequences include: fear of infection; illness and death; the reallocation of resources at the macro, micro and individual level; and emotional and psychological problems for people with HIV infection, their families, their friends and those who care for them. These direct consequences are associated with conflicts and tension in society concerning such matters as public health versus individual rights or the stigmatization and isolation of people at risk of AIDS and discrimination against them. In addition, the reallocation and/or redistribution of resources may result in the further polarization and marginalization of poorer social groups.

The direct social consequences of HIV/AIDS are also likely to have an impact on family organization, the roles of family members and individual, family and community perceptions of reality particularly where HIV infection is endemic.

Finally, there is a constant interdependence between the social setting, the development of the disease and its social consequences. Future policy intervention on

AIDS will therefore depend on a better understanding of these multidimensional relationships.

Impact of HIV/AIDS on health and social services

HIV/AIDS has affected the organization of health and social services and the type of service provided, the resources available for providing care, and the professional staff providing the services. A major consequence of HIV/AIDS for health and social workers is emotional and physical stress leading to "burn-out" or "battle fatigue". In addition there may be occupational risks of infection, conflicts between providers of care and the cared-for, and conflicts between prevention strategies for HIV/AIDS and the prevention of other social problems, particularly intravenous drug use.

Social implications of HIV/AIDS

The impact of HIV/AIDS on health and social services and on society, combined with the nature of the disease, has serious social implications. A major implication is that behavioural and attitudinal change is needed to combat the negative consequences of HIV/AIDS, including the reduction or elimination of high-risk activities associated with AIDS transmission on the part of both people belonging to high-risk groups and the general population. In addition, institutional and attitudinal changes are required if discrimination, stigmatization and the isolation of people with HIV/AIDS is to be avoided or reduced.

Most European countries have implemented strategies aimed at modifying risk behaviour in order to prevent HIV infection. The strategies may be coercive, based on responsibility and cooperation, or - as is usually the case - some combination of the two. Prevention strategies include information/education campaigns for target groups, individuals and the general public; screening; counselling; and needle/syringe exchange

schemes. There is some evidence that behavioural change has occurred in some risk groups (particularly among homosexual/bisexual men and also intravenous drug users) in response to supportive measures. However, little is still known about why these changes occurred, their extent, and the effectiveness of various prevention strategies, for example self-help, counselling, information, education and so on.

Contribution of the social sciences to AIDS research and AIDS policy development

Only a limited amount is known about the nature of the social consequences of AIDS, their extent and who is affected. Moreover, the interdependence between various sectors of society, and the circular causality between society and HIV/AIDS, means that the future consequences and implications of the infection are uncertain. Social scientists have an important contribution to make, including the development and implementation of methodological frameworks with which to describe the current situation and model the future; evaluation of the impact of a range of policies for dealing with HIV/AIDS; and research studies to provide the necessary baseline data about the nature and extent of the social consequences. Social science research needs to be multidisciplinary: only in this way can it gain greater influence over AIDS policies and interventions.

Scenario-building

Scenarios are a way of thinking in terms of more than one future. Scenario research is one of many approaches to mapping the future, without predicting it or indicating specific norms. Scenarios provide a framework for combining quantitative and qualitative data about a range of variables, and can incorporate uncertainty about parameters, effects of policies and current and future trends. They can be used to assess possible future states (exploratory scenarios) or to

assess the likely impact of particular policies or strategies and whether they would achieve their objectives (target-setting scenarios). The process of scenario-building may be as important as the outcome: it helps decision- and policy-makers to formulate targets and to make their value judgements and approaches explicit. It can also stimulate discussion between several disciplines and professions and increase the amount of information and the possibilities available to policy-makers.

Review of national scenario projects

Papers were presented concerning six countries which are developing national scenario projects as part of the European project. These countries are Austria, the Federal Republic of Germany, Italy, the Netherlands, Spain and Switzerland, all of which have reached different stages in the development of their scenarios. Three other countries - Canada, France and Poland - are also considering becoming involved in the project.

There are differences between the participating countries in the epidemiological and demographic characteristics of HIV/AIDS, for example differences in incidence rates and trends in HIV infection and AIDS cases, or in the distribution of infection between risk groups. For this reason the priority issues, the focus of national policies and programmes and therefore the corresponding parts of the scenarios also vary, as do the quantity and quality of epidemiological, demographic, social and psychosocial data available. There are also differences in how far research studies have developed to provide the data necessary for the scenarios and in the infrastructure and human resources available.

Some of the participating countries had been able to identify the priority areas or policy issues to be included in their national scenarios, among which were

current HIV/AIDS policy and programmes and their impact; health and social services for HIV/AIDS; the consequences of HIV/AIDS for different sectors of society; the interrelationship and interdependencies between sectors of society; and epidemiological and demographic variables. It was recognized that the priority areas would vary between countries, mainly due to cultural peculiarities, but that the methodological approaches would in some cases coincide. In addition, some of the countries have developed conceptual frameworks with which to analyse the baseline data.

At present, therefore, although they are at different stages of development, six countries are using long-term planning approaches such as scenarios. These approaches include the creation of structures with which to describe and model quantitative and qualitative information. One structure (Federal Republic of Germany) is based on a systems approach, identifying at the individual and system level the direct and indirect impacts of HIV/AIDS, and the individual and social subsystems directly or indirectly affected by HIV/AIDS. An alternative structuring system (Netherlands) is to categorize the impact of HIV/AIDS into its epidemiological, economic and sociocultural aspects (Netherlands). These aspects are divided into issues according to groups at risk, which are further divided into general and relevant target groups. The policies and services needed to tackle these issues can then be identified and sorted according to type, nature and location. Mathematical and heuristic modelling techniques can be applied to analyse and interpret the data, and to build scenarios.

Conclusions

The development of effective policies for HIV/AIDS and the use of scenarios are priority issues for all countries. There are large differences between countries

in the epidemiology of HIV/AIDS, the level of research and the quantity and quality of data available. This means that national scenarios and priority issues will vary between countries and will be defined by national AIDS policies and programmes, the obstacles to implementation, and the means of overcoming those obstacles.

However, it is possible to construct a common framework to guide the national scenario projects. All the national scenarios should at least include baseline analysis and context analysis of how AIDS policy is affected by adjoining social "compartments", and of the consequences of AIDS programmes for policies developed for other diseases. The baseline analysis should: identify research programmes and highlight gaps in information; assemble data from health and social services (governmental and nongovernmental) and from affected individuals; and evaluate preventive programmes, social and epidemiological research, and research into the social environment. The baseline analysis should also identify successful intervention programmes and the human and psychosocial consequences of HIV/AIDS at several interrelated levels; and it should reconstruct national AIDS policy and analyse the data collected.

The baseline analysis is feasible in all the countries participating in the scenario project. All of them have the epidemiological data which is fundamental to scenarios and provides a starting point. However, there are gaps in other necessary baseline data. A major information gap in all countries concerns the causes of high-risk behaviour, and the means of bringing about and sustaining long-term behavioural change.

Recommendations

1. Since education, information and fear of HIV/AIDS are not sufficient to modify behaviour, the appropriate supportive measures (HIV-specific and non-specific) should be introduced to change the social environment.
2. As social science research should be multidisciplinary, structures need to be developed to ensure that it is multisectoral and that there is interaction between research projects.
3. Social science research should be undertaken on the influence of peer groups, and on personality factors, such as life-concepts, risk-perception and self-esteem, to improve prevention policy with regard to individuals, groups and society as a whole.
4. Scenario projects should define the users of the scenario, its products and the way in which the results will be communicated, which should permit interaction between the parties concerned.
5. There should be close links between social science researchers and policy-makers, and between researchers and members of high-risk groups.
6. Most Member States now developing AIDS scenarios are learning simultaneously to deal with a new content (AIDS) and a new approach (the scenario). There should therefore be a system of regular information exchange and a series of international meetings for national researchers and policy-makers.

Annex 1

WORKING PAPERS AND BACKGROUND DOCUMENTS^a

Working papers

- ICP/GPA 013/5 The sociocultural impact of AIDS on society, social sciences, scenario-research and long-term planning: methodology and recommendations, by Frans M. van den Boom
- ICP/GPA 013/6 Social epidemiology of HIV infection and AIDS in industrialized countries, by Norbert Gilmore
- ICP/GPA 013/7 Describing the consequences of the HIV/AIDS epidemic, by Maarten Lagergren
- ICP/GPA 013/8 Effective prevention and education, by Bengt Brorsson
- ICP/GPA 013/9 Control strategies for the AIDS/HIV epidemic, by Rolf Rosenbrock
- ICP/GPA 013/10 Three partnerships in AIDS - management: health and welfare, public and private, research and policy, by Bernd Marin

^a Copies are available from the Regional Programme on AIDS, WHO Regional Office for Europe, 8 Scherfigsvej, DK-2100, Copenhagen O.

- ICP/GPA 013/11 The basis of prevention of AIDS and HIV, by Bertino Somaini
- ICP/GPA 013/12 Social aspects of AIDS: research activities in Switzerland, by Rainer Hornung
- ICP/GPA 013/13 AIDS in Austria: epidemiology and social implications, by Gerald Haidinger
- ICP/GPA 013/14 Psychosocial aspects of AIDS, by Xenia Scheil-Adlung
- ICP/GPA 013/15 Social dimensions of AIDS in Italy, by Massimo Giuliani
- ICP/GPA 013/16 Psychosocial issues in the Netherlands in the AIDS era, by Dick P. Reinking
- ICP/GPA 013/17 AIDS: psychosocial and cultural factors and social impact, by Gerardo Clavero

Background documents

- EUR/ICP/GPA 013 Multinational study on scenarios on social and economic impacts of AIDS. Report of a consultation of national coordinators, Bilthoven, 25-26 May 1989. Copenhagen, WHO Regional Office for Europe, 1989 (unpublished document).
- EUR/RC39/15 AIDS - progress report. Copenhagen, WHO Regional Office for Europe, 1989 (unpublished document).

EUR/ICP/GPA 040 AIDS policies and programmes in the European Region. Copenhagen, Regional Programme on AIDS, WHO Regional Office for Europe, 1989 (unpublished document).

Selected bibliography - Global Programme and European Programme on AIDS. Copenhagen, WHO Regional Office for Europe, 1989 (unpublished document).

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^a Participation expenses not paid by WHO.

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