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CONSENSUS STATEMENT FROM
THE FIRST INTERNATIONAL MEETING OF
AIDS SERVICE ORGANIZATIONS

VIENNA
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WORLD
HEALTH
ORGANIZATION

Consensus statement from the first international meeting of AIDS service organizations

The first international meeting of AIDS service organizations (ASOs) was convened in Vienna by the World Health Organization (WHO) Global Programme on AIDS (GPA) from 28 February to 3 March 1989. The meeting was jointly organized by GPA, the WHO Regional Office for Europe and the members of participating AIDS service organizations (ASOs). Fifty-three representatives of 49 AIDS service organizations in 25 countries attended the meeting. The participants are listed in the Annex.

A working group drawn from ASOs and WHO established the objectives of the meeting:

- to identify and define problems faced by ASOs in the areas of strategic planning, organizational structure, communications and networking;
- to exchange experiences in these areas;
- to provide technical information in these areas;
- to identify steps for improving coordination between WHO and AIDS service organizations.

The meeting developed the following consensus statement.

AIDS service organizations (ASOs)

ASOs provide support to individuals and communities in response to needs created by the AIDS pandemic. Those needs arise particularly in relation to prevention, care, and resources. ASOs are usually community-based and nongovernmental. Among ASOs, those formed by and for persons living with HIV infection or AIDS by definition best represent the interests and needs of people affected by the pandemic. Other ASOs reflect a wide diversity of origin groups such as sex workers, gay and lesbian movements, health care providers, ethnic minorities, and communities with specific national or cultural interests. The objectives of ASOs are solely or predominantly AIDS-related. Many other nongovernmental organizations have added AIDS components to existing programmes.

The fact that the majority of ASOs originated from within the communities they serve is the basis for three of their main attributes:

- their identity and credibility with the individuals and groups they were set up to serve;
- their ability to act as reference points or mediators between those individuals and groups and providers of public services; and
- their legitimacy as advocates for those individuals and groups.

Inherent in and integral to ASOs are the personal knowledge and experience unique to persons living with HIV or AIDS and to their partners and families.

ASOs have been formed mainly in the industrialized countries that have been most affected by AIDS in the 1980s: in North America, Australia, Western Europe, and New Zealand. They are increasingly being formed in those developing countries which also have large numbers of cases, as well as in areas where the pandemic is less widespread.

Areas of common interest and objectives

As ASOs continue to be formed and develop their programmes, their community-based response simultaneously strengthens and can be strengthened by national and international authorities. The degree to which nongovernmental, governmental, and intergovernmental responses to AIDS are complementary is reflected in the existence of areas of common interest and in common objectives.

The definition of health in the constitution of the World Health Organization as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity", and the related constitutional principle that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" are inseparable from the development of priorities and activities for the care and support of people affected by HIV. Nongovernmental, intergovernmental, and governmental organizations working on AIDS, while maintaining their autonomy and specific interests and constituencies, share as common aims the objectives of the Global AIDS Strategy which are:

- to prevent HIV infection;
- to reduce the personal and social impact of HIV/AIDS; and
- to unify national and international efforts against AIDS.

To prevent HIV infection, ASOs have created and distributed well-designed community-specific information and education material and in particular have developed ways to support individuals in reducing their risk behaviours. In this they have achieved important successes in bridging the gap between knowledge and practice. By creating a supportive social environment, they have strengthened a basic element in the quest for successful HIV prevention.

In providing care through hospices, home care, "buddying", counselling, and AIDS-specific clinics, ASOs do essential work in mitigating the physical and psychological impact of HIV infection on individuals and communities. They exert national and international influence in promoting improvements in the public sector's services for persons affected by HIV or AIDS and in reducing discrimination against them.

As ASO networks evolve and expand, the local experience of small organizations has been shown to provide vital lessons for others in different towns, cities, countries, continents, and cultures. The sense of national, international, and intercultural unity developed through ASO networks enables such lessons to be heard and is therefore vital to the success of the worldwide struggle against AIDS.

Protection of the human rights and dignity of persons affected by HIV or AIDS and the avoidance of discrimination and stigmatization in the provision of services, employment, and travel are central to the attainment of the common objectives of prevention of the disease, reduction of its personal and social impact, and unity in international efforts.

Major problems facing AIDS service organizations

ASOs encounter major impediments to their successful operation which vary from country to country and are often interlinked. They can be summarized as follows:

ASOs often lack official acknowledgement of their legitimacy. This includes under-recognition of their competence and the value of their contribution to prevention, care, and the development of public policy. In addition, even among ASOs there is sometimes a lack of acknowledgement of the particular knowledge, experience, and roles of persons living with HIV or AIDS.

The expertise of ASOs is underutilized. They are, for example, under-represented in official bodies working on AIDS within countries and regions and internationally. In particular, indigenous peoples and ethnic minorities are under-represented.

Adequate sustained funding is a problem for many ASOs, and is often related to the legitimacy accorded to them by governments and other major providers of funds. The development of relations with institutional funders, however, implies a need for accommodation on objectives and operations which may threaten the autonomy of the ASOs.

Attitudes, regulations, and laws form a set of structural impediments to the operations and, in some circumstances, the very existence of ASOs. These impediments include attitudes, laws, or regulations against sex workers, homosexuality, availability and possession of needles and syringes, and publication of clear educational material on the prevention of sexual transmission of HIV.

The terminology used in connection with AIDS often reinforces negative attitudes, blocks understanding, and offends persons living with HIV infection or AIDS. While persons living with HIV or AIDS strive to develop supportive social environments, including the use of words that provide strength and encouragement rather than passivity and resignation, much public rhetoric includes terms such as "victim" and "sufferer" that undermine this effort and contribute to discrimination.

ASOs have accumulated much experience in many areas and countries. The lessons learned from this experience need to be shared among ASOs and with the authorities nationally and internationally. The mechanisms for achieving this are not sufficient at present, and support is necessary for their development.

Having grown exceptionally rapidly in the face of the pandemic, many ASOs find that they now need to develop management skills specific to their particular circumstances. These skills include strategic planning, communication, networking, fund-raising, and the development of effective management structures to deal with rapid growth, innovations in service delivery, concerns related to volunteers, and unpredictability of future needs.

Future cooperation between ASOs and WHO

A diversity of ASOs representing many interest groups, particularly persons with HIV infection or AIDS, have objectives in common with each other and with WHO: the prevention of HIV infection, minimization of its personal and social impact, including the care and support of persons affected by it, and national and international unity in confronting the pandemic and its effects. Participants at the first international meeting of ASOs stressed the importance of those objectives and urgently recommended that ASOs and WHO continue to increase cooperative efforts to attain them.

Participants appreciated WHO's support for the Vienna meeting, itself an example of cooperation among organizations. As a part of future collaboration, the meeting strongly recommended that WHO continue to work with ASOs to seek ways to overcome constraints on their operations, particularly in relation to official acknowledgement of the legitimacy and competence of ASOs, representation on AIDS-related bodies, and such structural impediments as attitudes, laws, and regulations that hinder the prevention of HIV infection and the care and support of persons affected by the disease. The meeting also recommended that WHO continue to work with ASOs on building national and international networks and strengthening organizational capabilities in strategic planning, identification of sources of finance, and the development of appropriate management structures. Participants emphasized that the recommendations concern the overcoming of constraints in both developed and developing countries.

The meeting recognized that the autonomy, independence, and varying interests of organizations, whether nongovernmental, governmental, or intergovernmental, often lead to difficulties in cooperating successfully. Participants emphasized that autonomy can be maintained at the same time as organizations collaborate in areas of common concern to attain common objectives, and they recommended a continued positive effort to create and sustain local, national, and international alliances to confront AIDS.

ANNEX

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