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SPECIFIC GROUPS AND INDIVIDUALS

**Note verbale dated 5 December 2002 from the Permanent Mission of Brazil
to the United Nations Office at Geneva addressed to the Office of the
High Commissioner for Human Rights**

The Permanent Mission of Brazil to the United Nations Office and other International Organizations in Geneva presents its compliments to the Office of the High Commissioner for Human Rights and has the honour to request that the following text* concerning coordination between the Government and the civil society and among the health system bodies in Brazil concerning human rights and HIV/AIDS be circulated as an official document of the fifty-ninth session of the Commission on Human Rights.

* Reproduced in the annex as received, in the language of submission and English only.

Annex

**COORDINATION BETWEEN THE GOVERNMENT AND CIVIL SOCIETY
AND BETWEEN THE ORGANS OF THE UNIFIED HEALTH SYSTEM
IN BRAZIL ON HUMAN RIGHTS AND HIV/AIDS**

Introduction

In accordance with unified health system guidelines, the National Coordination Office on Sexually Transmitted Diseases/AIDS (CN-EST/SIDA) of the Brazilian Ministry of Health has established under its programme of activities a common agenda with civil society organizations. This decision was taken as a result of the efficient responses and mobilization activities undertaken by these organizations.

Implementation of the agenda is innovative in that it has spawned mechanisms that have broadened participation by civil society in devising responses to the AIDS epidemic. The principal characteristics of these mechanisms are the incorporation of the contribution by representatives of civil society organizations in the formulation of strategies and activities to promote public health policies, and technical and financial support for participation of these representatives in various federal, state and local bodies.

The National Coordination Office on STD/AIDS is focusing on human rights guarantees in HIV/AIDS prevention and treatment, in acknowledgement of the fact that difficulties in gaining access to health services, education and information reflect social inequalities within Brazil. As a result, participation by society is essential in pursuance of policy on AIDS.

There are many challenges in implementation of a human rights-based health policy to prevent HIV/AIDS as it involves controversial issues on which consensus is difficult, such as, for example, gender, sexual orientation, sex workers, intravenous drug users and the prison population, among others.

Interaction with civil society takes place in the three areas indicated below.

Promotion and guarantee of the human rights of HIV/AIDS carriers

In response to recurrent instances of prejudice and discrimination against HIV and AIDS carriers, since 1999 we have conducted surveys of the most frequent human rights demands in the form of complaints and/or requests for information. Data are collected on the basis of reports sent by civil society organizations providing legal assistance to HIV and AIDS carriers. The

most frequent questions relate to guarantees of the right to work, right of access to care and treatment, and social security issues. The National Coordination Office on STD/AIDS also receives complaints and requests for information regarding the rights of the child and teenager, the ethical and professional conduct of health professionals, and the right to health of the prison population.

The National Coordination Office's activities are aimed at ensuring a direct link between public policy on sexually transmitted diseases, HIV and AIDS and human rights by advising and orienting local government and non-governmental bodies with respect to guarantees of rights and by combating socio-political patterns of prejudice and discrimination against HIV/AIDS carriers.

In this regard such activities as training of legal operatives, printing of publications, promotion of public and private initiatives on defence of the human rights of HIV/AIDS carriers, training/empowerment of HIV/AIDS carriers, and dialogue/coordination with executive, legislative and judicial authorities are carried out.

Empowerment of seropositive individuals and civil society organizations

In terms of training/empowerment of HIV/AIDS carriers, the "Activism and leadership" training project, carried out from 1998 to 2002, is of particular note. This project, designed to expand the pool of trained personnel, was aimed at seropositive individuals in every region of the country; a total of 76 individuals were trained.

The principal objective was to help these individuals to politicize seropositivity by bolstering their self-esteem and promoting awareness of the structure of the Brazilian unified health system so as to direct their demands more effectively.

As an outgrowth of the training in activism and leadership, and in response to demands by seropositive women, the "Positive woman" project was designed; the project covered 60 women throughout the country, on three regional courses.

The National Coordination Office on STD/AIDS continues to provide support for the national survey of HIV/AIDS carriers, an annual survey organized by Groups for Life in the cities of Rio de Janeiro and Niterói, and for various regional meetings of the National HIV/AIDS Carriers Network (RNP+), as necessary forums for dialogue not only between peers but also between the social sectors with which seropositive individuals identify.

The presence of HIV/AIDS carriers and the partnerships between organizations working with AIDS and those working in the health sector have created new possibilities in terms of public health programmes.

With regard to the promotion of public and private initiatives to defend the human rights of HIV/AIDS carriers, 31 human rights projects, focusing on legal issues, implemented by civil society organizations in every region of the country, receive technical and financial support.

Dialogue on human rights in the political and legal sphere

In view of the fact that legislation plays a fundamental role in implementation of human rights, and that changes to legislation involve complex processes which, in a democratic society, include wide-ranging popular debate, in October 2000 the Parliamentary Front against AIDS was launched in partnership with UNESCO. The aim of the Front is to review draft legislation on AIDS before the Chamber of Deputies and to propose actions for its enactment.

With regard to the training of legal operatives, national events have been organized in partnership with the Public Health Studies Centre at the University of Brasilia, the Ministry of Labour, the National Council on the Rights of Women (CNDM - Ministry of Justice) and the Department of Human Rights (Ministry of Justice). An estimated 250 people took part.

With the aim of promoting and broadening debate on human rights and HIV/AIDS, periodic publications - network notes and human rights bulletins - and leaflets on various topics are prepared and circulated as a means of ensuring the flow of information on the epidemic and human rights. This information constitutes a means whereby HIV/AIDS carriers can fight for their human rights. In addition to these periodic publications, the Legislators' Compendium on HIV/AIDS, Human Rights and Legislation has also been launched.

Coordination with civil society organizations

Promotion of civil society action in the AIDS programme

Since 1992 the National Coordination Office on STD/AIDS has conducted a policy of cooperation with civil society through various channels: participation in committees, the National Coordination Office itself, and implementation of projects supported by the Ministry of Health.

At the federal level there are two mechanisms for the promotion of cooperation with civil society. The first relates to the promotion of community participation and social oversight of

policies to prevent and control STDs and AIDS, at the planning, implementation, follow-up and evaluation stages, including effective participation in policy- and decision-making bodies, such as committees, councils and commissions. The second offers technical and financial support for the development of health-promotion and STD- and AIDS-prevention activities, care for HIV/AIDS carriers, and institutional strengthening and development.

These activities have been developed on the basis of a commitment with two principal thrusts: decentralization and sustainability. Priority has been accorded the strategies detailed below.

DIAGNOSIS, TREATMENT AND CARE OF STD, HIV AND AIDS CARRIERS

Care for STD/HIV/AIDS patients

The Brazilian Ministry of Health, through the National Coordination Office on STD/AIDS, has intervened with the public health system on a broad front, with the establishment of a network of conventional and alternative services in the states of the federation for the care of individuals with STD/HIV/AIDS. To this end almost 900 HIV/AIDS treatment services have been identified, accredited and registered at the Ministry of Health (conventional hospitals, clinics, specialized outpatient services and home-care services) as well as 1,142 units offering STD outpatient health care.

In view of the change in the profile of the epidemic, the need to improve access by patients to referral services for STD/HIV/AIDS and the limited resources (human and infrastructure) in some cities, we have prioritized the establishment of services that offer outpatient care, use of clinics and home care within a single structure.

HIV/AIDS care projects in partnership with civil society

Another care modality promoted by the National Coordination Office on STD/AIDS is a partnership with non-governmental organizations and other civil society bodies in the form of projects to establish support homes for HIV/AIDS carriers.

These institutions, which seek to provide a substitute home, offer a welcome to HIV/AIDS carriers, and do much to avoid long-term hospitalization. The homes encourage activities directly or indirectly involving loved ones, family and friends. By bringing together people sharing the same experiences and requirements (such as issues relating to prejudice,

relationship with the family, physical and emotional capacity for work, new needs brought on by AIDS, etc.), they contribute to discussion of the social integration of AIDS carriers. At present there are 48 proposals for support homes funded by the programme.

From the government point of view these support homes are important since, in addition to the services they provide, they come closer to the everyday lives of HIV/AIDS carriers. Other projects in partnership with non-governmental organizations involving care for HIV/AIDS carriers (short-stay homes, community-life groups, social reintegration, income generation, home care, psychological and social help for children and seropositive pregnant women, mental health and access to medication and dental treatment) are also being developed, making a total, with the support homes, of almost 200 projects.

Access to medication for treatment of HIV infection and related opportunist infections and for the treatment of STDs

At present almost 121,000 patients receive anti-retrovirals from public health services (95 per cent adults and teenagers, 5 per cent children). The greatest increase in the number of patients undergoing treatment occurred in 1997, when inhibitors first became available, with an increase of approximately 26,000 patients. In 1998 there was an increase of almost 14,000 patients; in 1999, of 19,500 patients; in 2000, of 12,600 patients; and in 2001, of 19,800 patients.

Federal government expenditure on AIDS medication totalled US\$ 34 million in 1996, US\$ 224 million in 1997, US\$ 305 million in 1998, US\$ 336 million in 1999, US\$ 303 million in 2000 and US\$ 232 million in 2001.

The increase in expenditure between 1996 and 1999 was principally due to the greater increase in the number of patients undergoing treatment, an increase in the percentage of patients receiving more complex therapy, and updated treatment protocols. Nevertheless, since 2000 there has been a reduction in overall expenditure on acquisition of medication owing to the significant reduction in the cost of anti-retrovirals; in the period 1996-2001 there was a 54 per cent reduction in the average weighted cost of treatment per patient/year.

The cost of anti-retroviral medications acquired by the Ministry of Health has fallen progressively over recent years owing, to a great extent, to investments by the Ministry in local production by state laboratories and the policy of negotiating price differentials with exclusive transnational suppliers. The most significant reductions have been in the costs of medications

produced in the country (around 80 per cent), either by private national companies or by state laboratories, and in the prices negotiated with multinational corporations (45-65 per cent) adopting the system of price differentials.

In 2002, when lopinavir/ritonavir distribution began, the Ministry of Health was distributing 15 anti-retrovirals in 30 pharmaceutical prescriptions. Of the 15 anti-retrovirals, 8 are produced by national laboratories.

In 2001, 63 per cent of anti-retroviral drugs, accounting for 43 per cent of expenditure, were acquired from national companies; the remaining 37 per cent of anti-retrovirals, accounting for 57 per cent of expenditure, were acquired from pharmaceutical multinationals.

At present there are some 480 units dispensing anti-retroviral medication in Brazil. The computerized medication logistical control system (SICLOM) has already been installed at 145 of these units. In 2002 it is scheduled to be installed at a further 252 units, which treat 80 per cent of the total number of patients in the country.

A cost-effectiveness study of anti-retroviral therapy is being conducted in Brazil in partnership with the National AIDS Research Agency (ANRS) and the University of São Paulo to evaluate the cost-effectiveness of the national anti-retroviral distribution programme.

Treatment of other sexually-transmitted diseases is carried out in accordance with a standardized national protocol (STD-syndrome focus strategy); medications are acquired by municipal or state coordination offices under the terms of a 1998 tripartite agreement (federal, state and local levels).

Community and basic health-care network STD/HIV/AIDS prevention and control activities

Community health agent programmes and family health programmes are complementary strategies used in Brazil to shape the care model on the basis of locally organized basic care. In May 2002, of the 5,561 Brazilian municipalities, 4,914 (88.37 per cent) had joined the community health agent programme and 3,948 (70.99 per cent) the family health programme.

The strategy seeks to promote primary and secondary prevention through the work of community health agents; these offer the advantage of transmitting information and providing education in STD/HIV/AIDS in the language used by their community, while respecting social and cultural norms. With regard to care for HIV/AIDS carriers, the family health programmes contribute to improved prognosis by encouraging early diagnosis through counselling on the

HIV test for pregnant women, STD or tuberculosis carriers and persons with symptoms and indications suggesting infection with HIV or related opportunist illnesses. Another important activity performed by these agents is assisting in promoting treatment with anti-retrovirals and prophylactic regimens for the prevention of opportunist infections, where indicated, in addition to developing combined complementary activities for patients receiving home therapy and care (ADT). Activities in the community and the basic health network for the prevention and control of STD/HIV/AIDS have been under way since November 1996, with the integration of activities of STD/AIDS coordinators with basic health-care services provided by various levels of Government (federal, state and local); training and follow-up activities are decentralized at the state and municipal levels. With the aim of supporting training for health professionals involved in these programmes, the following training materials have been produced: a manual for community health agents entitled "Prevention and control of STD/AIDS in the community"; a family book entitled "Learning about AIDS and sexually transmitted diseases"; a video and leaflet No. 18 in the series "Agents in action"; an illustrated serial comic book, "What we need to know about STDs"; a serial comic book on STDs; and a notebook on basic treatment of STDs and infection with HIV/AIDS.

By June 2002, 4,159 instructors/supervisors and 308,616 community health agents had been trained.

Palliative and mental health care for HIV/AIDS patients

In May 2000 the National Coordination Office on STD/AIDS introduced palliative care. Three referral services were identified: the Emilio Ribas Institute of Infectious Diseases, in the State of São Paulo; the Nossa Senhora Conceição Hospital, in the State of Rio Grande do Sul; and the State Officials Hospital, in the State of Rio de Janeiro. The National Coordination Office then formulated a project on quality of life for HIV/AIDS carriers - palliative care, aimed at: (a) providing comprehensive therapeutic, psychological and social care for HIV/AIDS patients treated at referral centres (HC, HD, ADT and SAE); (b) producing a methodology for the training of professionals in the specialized SAE, HD and ADT services; (c) producing teaching materials on palliative care; (d) promoting the convening of an annual seminar or conference on the subject; and (e) developing research to assess the effectiveness of these activities. In August 2000 an advisory group on palliative care comprising representatives from the three referral services was established with the aim of drafting the "Handbook on AIDS

palliative care” and preparing material for the palliative care module in SAE, HD and ADT training. In 2000 the National Coordination Office on STD/AIDS financed the establishment of two centres for training in palliative care and HIV/AIDS, the aim being to train teams in alternative care to permit inclusion of such care in the services they provide.

Starting in 1997, on a proposal of the National AIDS Commission (CNAIDS), the link between AIDS and mental health was incorporated in programme activities in accordance with WHO statements on respect for human rights in psychiatric therapy. In 2000 the National Coordination Office on STD/AIDS established the Centre for Training in Mental Health and AIDS, with the aim of training teams of psychiatrists in the development of preventive, counselling and care services for STD/HIV/AIDS patients with psychiatric problems. On the basis of the training, small-scale projects on mental health and AIDS are being funded, with a view to developing such activities on the basis of strategies of decentralization and sustainability for incorporation in the unified health system. At present there are 13 such projects, with a target of 30 by the end of 2002.
