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IPU ADVISORY GROUP ON HIV/AIDS

FIELD VISIT TO BRAZIL

4 – 7 JUNE 2007

Participation

The following members of the group took part in the visit: Dr. Elioda Tumwesigye (Uganda, Advisory Group Chairman), Mr. Jesudas Seelam (India), Ms. Ewa Bjorling (Sweden), and Ms. Hendrietta Bogopane (South Africa).

They were accompanied by Ms. Pregaluxmi Govender, Senior Consultant, and Mr. James Jennings, Secretary of the Group.

Purpose of the visit

The Brazilian response to its HIV/AIDS epidemic has been widely acknowledged as a courageous and successful campaign. The national programme stopped the epidemic in its tracks in the mid 1990s and currently provides care, at no charge, to those known to be carriers of the virus. Brazil has also taken pioneering steps in making drugs affordable to the population, this approach being evident in the recent confrontation with the pharmaceuticals manufacturer Merck over the Efavirenz drug. In keeping with its mission statement, the IPU Group was keen to gather practical details about the control of the epidemic in the country and the way parliament had been instrumental in the response. They sought to identify lessons that might be helpful for the parliaments of other counties facing similar challenges.

The HIV/AIDS epidemic in Brazil

Brazil has more than one third of the total number of people living with HIV in Latin America. Brazil's response to AIDS has benefited from consistently strong political support from the highest level of government, which has led to regulatory policies as well as a very clear and permanent allocation of financial resources to national, state and local levels. Brazil's epidemic at first affected mainly men who have sex with men and then injecting drug users. However, the epidemic has grown more heterogeneous and heterosexual transmission is now responsible for a growing share of HIV infections, with the ratio between men and women decreasing from 26.5 infected men for each woman in 1985 to 1.5 in 2006 (Brazilian National STD/AIDS Programme, Epidemiological Bulletin, 2006). Harm reduction programmes in some cities have been associated with steep drops in HIV prevalence among injecting drug users in recent years- notably in Salvador where prevalence fell from 50% in 1996 to 7% in 2001 (Ministry of Health, 2003). Brazil is the first developing country to achieve universal access to HIV treatment via its national healthcare system. Currently more than 180,000 people (Brazilian National STD/AIDS Programme, 2007), have access to free treatment provided through government financing. The strong partnership with civil society has been crucial to the HIV response in this country.

Emerging issues and challenges for 2007 include the following:

The Brazilian Government is now discussing ways of facing the challenge of sustaining its treatment programme since the number of patients receiving antiretroviral drugs through the Public Health System increases every year and the prices of new medicines are rising rapidly. In this context, negotiation of prices with pharmaceutical companies and strengthening the national capacity of producing antiretroviral drugs are key elements for the future. Reinforcing prevention activities and promoting early diagnosis, especially in medium-sized cities and in the interior of the country will be essential elements for the sustainability of the Brazilian response to the epidemic. Links with poverty, race, inequality and gender are emerging issues, which will need intensified focus.

(source UNAIDS, Country situation analysis: Brazil, 2007)

Report on the field visit

1. Sao Paolo

Monday 4 June, morning

Meeting with Dr. Aristodemo Pinotti, Minister for Further Education of the State of Sao Paolo and former member of the Advisory Group

Discussion covered the subjects of the use of the female condom, religious obstacles to treatment, the link between poverty and HIV, and the question of patent law.

Dr. Pinotti said that the female condom had great advantages over the male condom. Though it was more expensive than the male version, it could be re-used, and it had the enormous benefit of allowing women to take the decision to protect themselves. It could be applied before rather than during the sexual encounter. Religious reservations applied equally to both types of condom, but these were not major problems in Brazil, as most people took a fairly relaxed approach to their religion.

The link between poverty and HIV was becoming ever clearer, and some NGOs were becoming less focused on HIV prevention as a result of that relationship and the sheer magnitude of the problem. Nevertheless, Brazil provided free medicine to all, under its Constitution, and the adherence rate was very good – between 75 and 80 per cent.

Dr. Pinotti added that Brazil faced two major challenges: education and access. Good access to treatment had certainly led to a major decrease in the infection rate in Brazil. The difficulty lay in convincing the major pharmaceutical companies to accept lower profit margins. Recently, Brazil had confronted Merck over access to an antiretroviral, Efavirenz. A decision had been taken to import a cheaper generic version from India at a quarter of the price, and thereby break the Merck patent.

The question was how parliaments could be influential in getting the pharmaceutical giants to change their outlook. After all, the firms drew on research done by others, particularly universities, for which they did not pay. Saving human lives was not merely a question of financial gain, and, moreover, the money spent on antiretrovirals could well be spent on other needs, such as the rising incidence of cervical cancer in Brazil, or indigenous tropical diseases.

He had been a member of parliament when the matter was discussed in the Brazilian Congress. He had wanted recognition of the patent law only for companies manufacturing in Brazil, and their rights should remain valid for only five years after their approval, the necessary time for the industry to gain the strength to compete. The patent law should not apply to State industries producing free drugs for use in the national health service. But his views had not met with broad acceptance.

He wanted to provoke wider discussion of the issues involved. The collective opinion of the Inter-Parliamentary Union could be extremely useful in promoting national changes through parliaments. The role of his own parliament in Brazil, which had a serious credibility problem with much of the population, was not a strong one.

Visit to the AIDS News Agency

The Group visited the AIDS News Agency, led by Roseli Tardelli, a well-known AIDS campaigner and journalist in Sao Paolo. Her agency centralized news on HIV/AIDS in Brazil and sent it to other news agencies and newspapers, as well as running its own news website. The members were able to gain information about the way news on the subject was circulated in the country, and they were informed about levels of stigma and discrimination in Brazil, which, though low in a place like Sao Paolo, was said to be much higher in remoter areas of the country.

Visit to ASF (Family Health Association)

At the Associação Saúde de Família (ASF) headquarters, the group watched a presentation of the HIV/AIDS/STD prevention campaign. There was a total of 320 projects in Brazil focusing on Sao Paulo and Fortalesa, and covering HIV, STDs and reproductive health. The association was receiving sponsorship from Johnson & Johnson. They provided training to health community teams who gave assistance and referral services. Eight hundred professionals were trained every year. In 2006, there had been 400,000 home visits and the potential number of contacts over the previous two years was 6 million people. 1.7 million condoms were distributed annually, which was far from covering all of the needs.

There were various constraints to be grappled with. One was political (Sao Paulo had had three mayors in the space of three years), and another was the deficiency of data collection.

Members of the Group asked questions and requested additional data about the profile of the epidemic in Sao Paulo. They were provided with educational materials and demonstration kits used by health visitors.

The ASF then hosted a lunch at which the discussions continued informally.

Monday 4 June, afternoon

Visit with ASF to Jardim Sapopemba Health Unit

The hospital at Jardim Sapopemba is located in a relatively deprived area of the city. Dr. Celma Buff welcomed the Group and showed the members around the facilities and introduced her staff. The Group then attended a training session for HIV/AIDS family health personnel, noting with interest - and some concern - that all of them were women. A folk group gave a humorous musical performance with a strong didactic message about HIV prevention. The women then engaged in role play activities designed to work through some of the emotions connected with being HIV-positive.

Visit to Juta I

The team then visited a smaller heath facility prior to joining a health visitor on her rounds in a poor district of town. The Group stopped in one house to talk with the large family living there under the charge of the grandmother after the mother, a sex worker, had died of viral meningitis. Elsewhere there was an encounter with a person with HIV, but his mental state did not allow for a useful exchange of views. One of the principal lessons emerging from the visit was that Brazilian policy included HIV/AIDS as one pathology in a broader range of public health concerns, thereby allowing for an element of discretion in the door-to-door health visits and allaying risks of stigma.

(2) Brasilia

Tuesday 5 June, morning

Meeting with Mr. Arlindo Chignalia, Speaker of the House of Representatives

On arrival in Brasilia, the Group went directly to see the Speaker of the House. **Mr. Alexandre Santos**, Chairman of the Brazilian IPU Group, **Mr. Heraclito Fortes**, IPU Executive Committee member, and other parliamentarians were also present.

There was a useful dialogue that centred on different aspects of the AIDS epidemic in Brazil. Mr. Chignalia said that the uniform health care program in Brazil, the SUS, had not been achieved without a struggle. The Brazilian Constitution enshrined the right of all citizens to free medical care. Everyone had the right to the same level of treatment in State hospitals, regardless of whether or not they were employed. Constitutionally, no other country was comparable on such a scale. If there was flaw, it was that millions still did not have sufficient access to medicines. In Brazil, as elsewhere, that was an issue related to patent law, and he believed that the IPU could help to encourage informed debate and bring useful pressure to bear on the different parties involved.

Brazil had to contend with lack of knowledge and poor access to information. Many people believed that the disease affected drug users and homosexuals, and were unaware of the increasing feminization of the epidemic.

After covering other technical questions about AIDS in Brazil, the talks broached questions relating to the government's approach to the crisis in South Africa and the evolution of democracy in Venezuela.

The discussions continued at a lunch hosted by the Chairman of the Brazilian IPU Group.

Tuesday 5 June, afternoon

Panel discussion in the Committee on Social Welfare and the Family

The panel was chaired by Germano Bonow, MP, former Secretary of State for Health for Rio Grande do Sul. Mr. Bonow began by sketching out some of the social benefits provided to HIV/AIDS carriers since the emergence of the disease in the mid 1990s. They were granted exemptions from certain taxes, food allowances, welfare payments, and the right to draw their pension more quickly when they knew their life expectancy was diminished. There were exemptions from social payments both for the employee and the firm that hired HIV/AIDS carriers. They also received priority in judicial procedures.

The parliament had legislated in a number of those areas. One area of concern had been issues relating to disclosure of status prior to marriage or for job applications. In total there had been 187 bills tabled before the Brazilian Parliament relating to HIV/AIDS, not all of which had been passed.

Turning to the question of condom use and religious pressures, he pointed out that although the Catholic Church publicly disapproved of condom use, no medical institution had ever bowed to pressure to restrict such usage.

The members of the Group asked questions concerning treatment for pregnant mothers (why only 57% of pregnant mothers seem to receive treatment), the reasons behind the successful acceptance of condoms among young people, the level of participation of disabled people in prevention programmes, the care provided to healthcare workers, and progress made in research towards a vaccine. They were told about the intensive health and prevention education provided in schools and the moves to ensure that disabled persons had complete access to treatment. As for the vaccine, that was a matter for the future.

Asked about the role of parliamentarians in combating the epidemic, Mr. Bonow referred to the Parliamentary Front for Health, a cross-party group of 50 MPs which had been instrumental in exerting pressure for more public resources to be channelled into HIV/AIDS control. It had to be understood that AIDS was only one of the many public health problems in Brazil, some of which - such as dengue fever or malaria - affected a far larger number of people. Moreover, reaching every patient in a country the size of Brazil presented an enormous geographical challenge.

The Chairman of the IPU Advisory Group emphasized the importance of political leadership. When the politicians had become involved in his country, Uganda, the prevalence rate had dropped from 18 to 6 per cent. The Group needed more information on how parliamentary oversight was performed, what the relations were between parliaments and the national AIDS body, how parliament had been involved in WTO/TRIPS negotiations and whether it encouraged South-South cooperation in research.

The Group was told that in addition to debating bills going through the House, the parliament had staged a number of events, in particular to commemorate World AIDS Day. It should, however, be understood that the primary task of parliament was to legislate, and if the Congress of Brazil had managed to establish the necessary enabling legislation for others to do their work then it had done well. With respect to the question of trade in pharmaceuticals, he believed that Brazilians needed to wake up to the idea of a far stronger indigenous manufacturing capacity. The health industry should be conceived of as generating rather than spending resources. The Deputy Director of the National AIDS Programme added that the IPU should exert pressure for the achievement of universal access. The right to life had to supersede the right of the research companies to receive payment of their royalties.

Wednesday 6 June, morning

Ministry of Health

Meeting with the directorate of the AIDS Programme, discussion with representatives of civil society including representatives of persons living with HIV/AIDS, discussions with representatives of UNAIDS and UNFPA.
Chair: **Eduardo Barbosa**, Deputy Director, National AIDS Programme

Carlos Passarelli, Coordinator of the National STD/AIDS Programme International Centre for Technical Cooperation on HIV/AIDS, said that through the link with the IPU, new solutions might be found, not just for Brazil, but for the world. He said that globally available funds for HIV/AIDS had increased along with the global commitment to universal access to prevention, treatment, care and support by 2010, but new trends such as a focus on abstinence and being faithful had emerged. Presenting the national programme, he said that in Brazil there had been a reduction in mortality over the past ten years, an increase in the proportion of heterosexual HIV/AIDS transmission and an increase in infections among the 40-59 age bracket.

The backbone of their success was:
- An early response in the form of a State programme on HIV/AIDS
- Civil society participation
- A balanced approach (prevention and treatment)
- An integrated plan and a consolidated national institution
- One system for monitoring and evaluation
- Among poor populations, government's role in prevention and treatment.

The National Health System works on the basis of universal access. It is decentralized, with a single management unit at each level of government. Civil society plays a strong role. The main challenges are to improve the quality of care, strengthen the promotion of human rights for vulnerable groups, tackle the feminization of the epidemic, and ensure decentralization of resources and the sustainability of the treatment programme.

Sustainability of the treatment programme was the real challenge for developing countries. Their objective was the continuous provision of medicines and laboratory supplies at affordable prices. Brazil had developed production capability through its 17 State laboratories, had passed intellectual property legislation and entered into diverse ARV price negotiations. At the same time, attention was being paid to increasing rationality in ARV use. On the international stage, TRIPS flexibilities were being used to the full, and Brazil was a leader in striving to bring the DOHA Agreements to bear on the global agenda.

Strengthening South-South cooperation: that had been based on a horizontal approach since the 1980s. The aim was to exchange experiences, share technology focusing on the needs of the partner country, draw on lessons learned, and tackle common problems. The International Centre for Technical Cooperation on HIV/AIDS was a joint Brazil- UNAIDS initiative. Brazil had set up a technology network to address issues such as costs and condom supplies with a range of countries including Thailand, Russia, Nigeria, China and others.

Civil society

The history of Brazil, as a country which had emerged from a dictatorship into a democracy, with a strong civil society, was explained. The context of social transformation was central to how it dealt with HIV/AIDS. The role of civil servants was also seen as different – more as 'activists', as explained by the civil servants themselves. The groups present were generally positive about the role of parliamentarians vis-à-vis civil society. Power came from the people through representatives who were there to tend to the needs of people, and MPs created instruments that allowed them to live positively with AIDS. Resources through social benefits helped people living with HIV/AIDS.

Legislation had enabled them to challenge stigma through the courts in, for example, cases of discrimination by schools against children who had HIV/AIDS. Problems arose with those MPs who were members of fundamentalist churches and who opposed condoms, for example.

UNAIDS

Luiz Loures, Associate Director, Global Initiatives Division, UNAIDS, provided the delegation with additional clarification about the programme in Brazil and the work of UNAIDS, which played a key role in co-coordinating the joint United Nations team. Different United Nations agencies were working with various ministries to ensure quality of response. UNAIDS also played an important role in facilitating South-South co-operation and sharing the experiences of Brazil with other countries.

UNFPA

Alanna Armitage, United Nations Population Fund (UNFPA), said that her organization worked with young people and women in a number of areas that included condom programming and South-South initiatives. Brazil had a comprehensive sexuality programme at schools. They were not promoting promiscuousness and there was evidence of decreasing HIV infections. UNFPA had worked with Brazil on helping it develop a plan to halt the feminization of HIV/AIDS, which linked sexual reproductive health to sexual and gender violence.

Meeting with José Gomes Temporao, Minister of Health

The group was received by the Minister of Health and held a brief dialogue with him on universal access to health and the health/trade dichotomy. The group raised questions about the key challenge of trade repercussions, the role of TRIPS flexibilities, and the need for pharmaceutical companies to be able to invest in research. Questions were also asked about relations between the Executive and the Legislature and the role of parliamentary oversight.

The minister emphasized that the HIV programme was not separate from the overall national health programme. On the question of research and intellectual property, many had thought that the compulsory licensing would threaten the emergence of new drugs, but with a range of new partnerships involving a variety of new molecules, in most cases there were no major conflicts.

After a strong political movement in the 1970s and 1980s, the right to health had been written into the Constitution. It was the task of the Executive to ensure the fullest enjoyment possible of that right and both Congress and civil society were playing their respective roles. He added that the Parliamentary Front was working in complete harmony with the Executive in that area.

Wednesday 6 June, afternoon

Visit to Arco Iris Project: Projecto Espaco de Arte e Saude PositHIVa

President**: Dilce Silva Lima**

The Arco Iris Project offers specialized care for HIV-positive people, provides orientation and advice, and runs an arts and crafts center in which HIV-positive people manufacture objects for sale to the public. The Group visited the Center and met some of the artisans at work. Some of them gave emotional testimony about the discrimination they had suffered when their positive status had been disclosed to their family members.

Thursday 7 June, morning

Concluding meeting of the Advisory Group.

The findings of the Group were as follows:

The national AIDS programme in Brazil is an example of a broadly successful response to the epidemic. The results are rooted in a number of positive factors and circumstances:

The right of all Brazilians to free medical care is enshrined in the Constitution. A policy of amalgamating HIV/AIDS care and treatment into overall heath support activities has made it possible to cover the needs of a high number of infected persons. It has also helped to curb stigma by taking the focus off that specific disease.

Government and civil society are working in a mutually supportive way, which made a noticeable difference to service delivery. The three stakeholders: persons living with AIDS, government and civil society appeared to be working in unison.

Parliament has played its basic role by putting in place the necessary legislative framework, but it is necessary to look at how the institution of parliament is responding to the epidemic more closely. Legislation needs a critical review. Some believe that it is the role of parliamentarians to "go beyond the call of duty" by participating in special activities and events, thereby giving them a stronger advocacy role. There was no immediate evidence to suggest that members of the Brazilian parliament were doing that.

Brazil responded promptly to the epidemic when it began to emerge in the mid-1980s. Unlike many countries that went through different periods of hesitation, confusion and even denial, Brazil tackled the problem squarely. It is also a relatively liberated country, in the sense that public discussion of sexuality occurs without major constraints. Although Christianity is widely practised, the churches do not seem to have a strong hold over the behaviour of the individual. The 50 per cent rate of condom use among young people is encouraging.

Brazil has been prepared to take a strong stand on issues affecting the affordability of medicines and has not shunned confrontation with large pharmaceutical firms in the interests of availability. Compulsory licensing has been used to good effect. Second- and

third-line drugs might pose a challenge for Brazil, and it will be necessary to monitor developments.

Personal attention has been provided to large numbers of people through a programme of door-to-door visits that are well funded and for which the personnel are well-trained. It was not immediately clear why the overwhelming majority of the heath visitors were women, but the Group was told that it was not a well paying job, and that it was easier for women than for men to talk about sex and share their own experiences. It also heard. that elsewhere in the country (e.g. Fortaleza) the majority of such personnel were male.

The Advisory Group also found that some issues would have benefited from further investigation if more time had been available. For example:

- The fact that the health programme appeared to contain no provision for nutrition;
- The question of care for those who were terminally ill; and
- Questions about care of orphans.

It had also not been possible to gain a good understanding of the Brazilian stigma mitigation strategy. Finally, no answers had been given about the prospects for long-term drugs research in Brazil and elsewhere. Would all countries shoulder responsibilities or would the US lead the field?

Challenges: The epidemic in Brazil was initially associated with the male homosexual community, and subsequently with injecting drug users. The current trend is towards an increasing feminization of the epidemic. It is too early to forecast whether the authorities will be successful in their attempts to cope with this new development. Additionally, more people in the 50-60 age bracket are becoming infected. The same reservations apply thereto.