2003-2004 NGO Report to UNAIDS Programme Coordinating Board on the State of the HIV/AIDS Pandemic

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I. Introduction

It is the responsibility of the non-governmental and PLWHA community-based organizations serving on the UNAIDS Programme Coordinating Board to be absolutely forthright and frank in our observations on the state of the global AIDS pandemic. The pandemic exists for failure of individuals, communities, states, nations, and international bodies to act soon enough, with seriousness of effort and with application of all means available. A solution is to renew our commitment each day, in every sector of every nation, to fight back with the force of true public-private partnerships, about which we hear so much, but of which we see so remarkably little evidence. The contributions of the most heavily-affected communities are essential to the success of efforts to stop HIV/AIDS where it burns the hottest: in poor and vulnerable communities around the world. But the dollars to support these efforts are languishing in treasury accounts of governments in both North and South.

In this report, the five regional NGO/CBO delegates and five alternates of the PCB have put forward the highlights in our regional epidemic issues, progress in coordination of response, and policy recommendations to UNAIDS. It is our intention to provoke debate and to contribute to making this PCB meeting a memorable event, generating renewed vigor, through UNAIDS and member states, in commitment and action to stop AIDS.

II. Coordination of Global Response: Issues and Progress

In 2001, 189 United Nations member states signed the UNGASS Declaration of Commitment against HIV/AIDS. Since 2001, political will within bilateral and multilateral aid agencies has been scaled up to dramatically extend the reach of Global Fund grants and to scale up the number of people on ARV therapy. Unfortunately, the political will of many governments and their ministries to implement effective HIV prevention interventions and introduce generic or imported patented drugs subject to tiered pricing has not been generated as rapidly. The so-called bilateral and regional 'free trade' agreements that certain powerful governments are crafting throughout parts of the world hardest hit by the pandemic stand to undermine the universal right to health.

By refusing to agree to the widely accepted pre-qualification standards of the WHO, these governments are once again going against world opinion on fixed dose combination generic drugs (FDCs). The lives that will be lost due to both its delaying tactics and overspending for brand name pharmaceuticals are unforgivable.

Similarly, the bold-faced public misstatements made by the pharmaceutical regulatory body of a certain powerful Western nation is an international disgrace, that can cripple the ability of Canada to contribute greatly to the UNAIDS/WHO joint initiative goal of '3 by 5' by exporting generics to countries in the developing world.

In unprecedented agreements between the Clinton Foundation, the World Bank, Global Fund, and UNICEF, the price of 3-drug antiretroviral regimens will now drop from US 55 cents to US 38 cents per patient per day. Costs of viral load and CD4 diagnostic tests will also be reduced by as much as 80 percent. Country governments will be responsible for drug purchasing. How can the world watch in conscience as these life-saving medications still dangle beyond the reach of people who will die within months without them, all because of the difference of a few dollars between patient purse and access? How can governments fail to reform health care sector HIV testing and drug delivery systems at a moment when AIDS drugs are so nearly accessible to even the poorest?

UNAIDS and WHO have accepted the mandate to provide technical assistance for a massive scale up in programming to fight AIDS. However, it is proving amply evident that the funding within both agencies to support the human resources needed for large-scale application of technical assistance provision is grossly lacking.

Volume of donor and domestic response

The global level of donor and domestic response to AIDS as of May, 2004 is still less than 50 percent of that called for by this point in time at the UNGASS in June 2001. However, in total, it provides an enormous injection of new funding to fight a pandemic which has run roughshod over tens of millions of people in the world. What remains to be demonstrated is that it will be aid and assistance well invested. The old ways of cycling health aid solely through government agencies will not distribute billions of dollars with the speed and effectiveness that can be effected by public-private sector implementation designs. Some countries are seeing the Global Fund's support as a substitute funding source for their meager spending on HIV/AIDS. In many regions, free trade, economic and human rights situations are placing the sustainability of these newly-funded programs at risk. Intellectual property rights, thanks to these "free trade agreements" become more important and pre eminent over the rights to life and to health care, enshrined in many of countries' constitutions.

Additionally, we have seen a poor response in private sector investment in the fight against HIV/AIDS from businesses in the South.

Prevention, care, treatment and support coordination

- Prevention cannot be forgotten or ignored in low prevalence countries. This is the only way these countries to remain low prevalence.
- Prevention in low prevalence countries must be provided first to the most affected and vulnerable groups, such as commercial sex workers, men who have sex with men (MSM), intravenous drug users (IDU), people of color, immigrants, and the incarcerated.
- Prevention must focus on peer education, voluntary counseling and testing, treatment of sexually transmitted infections and condom distribution to the most vulnerable and affected, including PLWHA, evidence-based strategies that have proven their efficacy.
- Treatment and prevention must be integrated, regardless of the scale of the treatment availability.
- HIV/HCV co-infection represents a potential new manifestation of the epidemic in all countries. Little information is available about this; UNAIDS should include this in its data collection.
- Expansion of access to treatment must be accompanied by training for physicians, proper equipment for viral load and CD4 monitoring and strong adherence programs. In the absence of this, an epidemic of drug- resistant HIV is inevitable.
- Access to treatment depends on drug cost, which is inequitable across regions; with the countries with the least resources challenged with some of the highest prices. Management of TB (through DOTS) has been an abysmal failure in many countries. The prevalence of TB is rising and sadly there is increasing incidence of multi-drug resistant TB (MDTB). We strongly recommend that any country that intends to provide ARVs must also evaluate its DOTS programme. Support for population-based provision of ARVs must be provided to help countries succeed with both DOTS & ARVs.
- For the 3 X 5 initiative to be successful, adequate attention must also be paid to availability and access to diagnostic services and facilities for treatment monitoring, such as viral load and CD4 counts. Availability of facilities for CD4 and viral load should be assessed and built immediately. UNAIDS and WHO should include this as a policy and assist countries to take advantage of initiatives such as that offered by the Clinton Foundation.
- Access to treatment and care services (e.g. WHO 3x5 initiative, GFATM, MAP, etc.) must address stigma and discrimination issues faced by people living with HIV/AIDS and the most vulnerable and affected populations.

Special attention is required to ensure that children orphaned by AIDS receive care, support, education, and are protected from abuse, exploitation and discrimination. Regional youth co-operation should be strengthened for the prevention of the spread of HIV/AIDS across borders. International agencies can facilitate such bilateral and regional co-operation.

Harmonization and partnership

Without the full engagement and participation of civil society in the staging of the Three Ones, internal harmonization of efforts in HIV prevention, care, treatment and support

will not fully unfold. In all stakeholder meetings which seek to lay out the framework for the Three Ones, civil society organizations must be invited to the table, in each country, and in each region, from the outset. The Three Ones construct, which calls for one national AIDS coordinating authority, one national AIDS action framework, and one agreed country-level monitoring and evaluation strategy, will falter if civil society groups, ever increasing in importance as key players in the landscape of the fight against AIDS in highly-impacted countries, are absent. For now, members of national AIDS coordinating authorities are appointed by either Heads of States or Ministers of Health, and the selected members, depending on politics in their countries, recruit others. In light of the effort to stage a uniform monitoring and evaluation strategy at each country level, it should be noted that the Monitoring and Evaluation Toolkit developed by WHO, the World Bank, UNICEF, UNAIDS, US Department of State, HRSA, CDC and the Global Fund must be widely released for public comment and put into action as soon as all stakeholders have opportunity for review and input.

III. **Policy recommendations to UNAIDS**

By region UNAIDS has few programs and little impact on AIDS issues in. North America. Conversely, however, certain North American governments' policies and the self-serving tactics of North American based pharmaceutical companies have a major negative impact on the epidemic in the developing world, where UNAIDS is doing the bulk of its important work.

It is incumbent upon the governments of G8 countries to contribute their fair share to the global fight against AIDS by meeting their OECD commitment of ODA of 0.7%, honoring debt relief agreements through the Enhanced HIPC Initiative and other mechanisms, taking a progressive position on procurement of health commodities, by honoring the DOHA Ministerial Declaration on the TRIPS Agreement and Public Health, supporting evidence-based HIV prevention interventions such as promotion of condoms and needle exchange, at home and abroad, and accelerating a broad national AIDS research agenda, on treatment, vaccines, and microbicides.

In Russia, the Advisory Council on HIV/AIDS has been highlighted in the 2003 UNAIDS Report on the Epidemic as an example, fulfilling one of the UNGASS indicators on civil society partnership. Though a new phenomenon, involvement of networks and communities of PLWHA's in all HIV planning and decision-making bodies is expanding throughout Eastern Europe.

By interventions: Legislation and enforcement of human rights protection is central to the response to AIDS. Confidentiality protection and enforcement of anti-discrimination laws are paramount in all nations. UNAIDS should lead processes that will increase sustainability of these protections and restore the basic human rights to life and health care to the pre- eminent position they have always held, upholding the UNGASS Declaration of Commitment, Article 58.

Fewer than 5% of those who require ARV treatment have access to it. UNAIDS must engage in the fundraising for and in the implementation of infrastructure and program which will be necessary to engage those for whom ARV treatment is indicated.

UNAIDS and its cosponsoring organizations need to support the governments of these developing countries to resist and publicly denounce the efforts by powerful countries to

defeat the rights won in the DOHA Ministerial Declaration on the TRIPS Agreement and Public Health, by enforcing stricter intellectual property rights, jeopardizing the public health. Even if the WHO or UNAIDS is unable to make a counter-attack for political reasons, it needs to consistently counter the unfounded claims made by some countries with public statements of the proven facts regarding pre-qualified generics.

Needle exchange and harm reduction programs must be legalized and supported. As the UNGASS Declaration of Commitment stated, vulnerable populations such as drug users, men who have sex with men and sex workers must have access to prevention tools and to anti-discriminatory legislation to protect both themselves and the people with whom they engage in environments where HIV can easily spread. In the spirit of harm reduction, the use of prevention tools can and does ameliorate the challenges of drug-using and sexual risk behavior. Inconsistencies between UN policies and government adherence to treaties have led to denial of methadone maintenance, police abuse and harassment of drug users, sex workers and men who have sex with men, and inconsistent access to harm reduction.

A significant increase in the UNAIDS unified budget must be sought in order to provide for the increase in human resources available within UNAIDS for technical assistance provision.

By vulnerable population: 50% of people living with HIV in the world today are women and girls. As put forth by the International Community of Women Living with HIV/AIDS, networks of women living with HIV/AIDS are making a unique and valuable contribution in tackling the spread of HIV and fighting AIDS, and their involvement needs to be promote and supported at all levels. HIV positive women, girls and their networks are key agents of change and central assets in the fight against AIDS. Their participation must be supported.

The relationship between violence against women and their vulnerability to HIV/AIDS is well established, but most countries are not addressing the real dimensions of this hidden and destructive epidemic which put women at higher risk of contracting HIV.

Abstinence-until-marriage and other prevention strategies that have failed miserably in some donor countries are now being exported in unilateral AIDS relief plans. Furthermore, recipient countries are often required to comply with unscientific restrictions even in programs that are funded by other bilateral or multinational funding mechanisms, including the Global Fund. PCB cosponsors and member States must bring public, international, political pressure to bear on these countries, by championing the use of evidence-based interventions.

UNAIDS, at country-level, has a responsibility to fight for gender rights-sensitive programming, addressing specific vulnerabilities of women and girls in all regions, in budgeting, monitoring and evaluation. There must be special focus on bridging populations, particularly men who have sex with men, also addressing their specific vulnerabilities (including gender and masculinity issues) in all regions, in budgeting, monitoring and evaluation.

Marginalized populations, including intravenous drug users (IDU), men who have sex with men (MSM), people of color, immigrants, commercial sex workers, socially

disadvantaged women and youth and the incarcerated all suffer from criminalization and neglect of appropriate and significantly scaled-up interventions.

By sector/cross-sector relationships: One of the five stated pillars of the Joint United Nations Programme on AIDS is **civil society engagement and partnership development**, guiding UNAIDS actions at country, regional, and global levels. Truly successful operation of partnerships with civil society could nourish the other crosscutting functions of UNAIDS. NGO partners, including the PCB NGO delegates/alternates themselves, must be included in all UNAIDS consultations, which has not hitherto been the case, and which impedes the ability of the PCB NGOs to be maximally useful in their advisory role to UNAIDS. **Leadership and advocacy** are foremost among these functions. UNAIDS and its cosponsoring organizations should encourage input from the seasoned AIDS activist and advocacy NGOs in all regions.

To wit, activists in one African country turned the world's attention to ARV treatment access in one of the most stubbornly anti-treatment national platforms anywhere. Through a succession of court challenges, these members of civil society forced the public health system to address one of the most devastating AIDS crises in the world today, through the use of available resources to provide ARV treatment for those in need. In Asia, injecting drug user networks in a particular country struggled for a place at the table and succeeded in securing a Global Fund grant prior to coming to terms of agreement with government. These examples of civil society movement and struggle to act urgently are examples for UNAIDS of the immediacy with which communities feel pressed to act.

These groups have a track record of high effectiveness in working with and pressuring the policy- and decision-making players in their respective countries. For example, the only substantial progress made against the unilateral policies of the government of a powerful donor country has been brought about through pressure from civil society. Furthermore, Canadian citizens can hold their government to their courageous promises and not succumb to economic pressure from pharmaceutical companies and political pressure from other countries.

While there are notable examples of UNAIDS Country Coordinators (UCC) who are committed to supporting NGOs and PLWHA's work in the LAC region, there are still a number of these UCCs who prefer to relate with other UN agencies or with government officials.

Furthermore, UNAIDS Theme Groups do not use their comparative advantage in tackling difficult issues such as human rights related to homosexuality, drug use, sex work, gender and HIV/AIDS, central to reducing the impact of HIV/AIDS in all regions. Many of the Cosponsoring Organizations have conflicting agendas in-country; frequently they do not respect the established national priorities concerning HIV/AIDS; often they implement programs that are inconsistent with or ignore the epidemiological data, helping to fuel the epidemic.

With regard to the proposed adoption of the Three Ones principles, in agreement with the position of ICASO, the NGO members of the PCB propose:

One Agreed AIDS Action Framework: UNAIDS needs to be more prescriptive at both global and national levels, in light of previous strategy agreements. These include, for

example, the UNGASS Declaration of Commitment on HIV/AIDS, the Millennium Development Goals, and other regional and global manifestos and declarations. We know that each of these talks specifically about targets, about getting treatment into people, about raising resources, etc. Many commitments have been made by governments and it is time that these are fully implemented.

One AIDS Action Framework that provides the basis for coordinating the work of all partners: plans need to reflect stakeholders historically excluded from such processes. This includes, for example, issues related to men who have sex with men, intravenous drug users, prisoners, displaced people or non-documented migrants, and sex workers. Many national AIDS committees are predominately composed of government employees. Some examples of the Global Fund's Country Coordinating Mechanisms (CCM) have shown that creating plans to address these marginalized groups has been difficult and painful in many countries. Thus, there needs to be a real effort to include them, if we are to have comprehensive plans developed. Otherwise, it is difficult to accept one plan, if key issues and key stakeholders are excluded from the process or find themselves dominated by governmental interests that could be at odds with community issues.

Human resources have been cited as a critical component of any work towards achieving the "Three Ones." There is a human resources crisis in both the governmental and nongovernmental sectors, and if we are to scale up responses through better coordination and participation, then more money is urgently required to hire, train and retain leaders, managers, outreach workers, and medical staff. There is need to hire over 100,000 people to deal with the "3 x 5" initiative alone, and that additional hiring would meet other goals related to creating employment and reducing poverty.

National AIDS Coordinating Authorities. The idea of a single coordinating authority is valid but this does not necessarily mean that the authority is exclusively owned and operated by governments. The Global Fund experience to date has illustrated the painful realization that to some governments, this means a country response coordinated and managed by governments, with funding directed to governments. This has resulted in far too little support directed to the civil society sector; and NGO issues and needs are sometimes not taken into consideration when establishing priorities and activities. While coordination and policy/program coherence at country level is necessary, NGOs also require human and financial resources to fully participate in the process - from planning, implementation and evaluation of programs and policies - including coordinating their inputs and activities with those of donors and governments.

Presently, many civil society groups (especially in the South) lack sufficient training in monitoring and evaluation. As a result, many promising interventions remain unevaluated. Some cannot source funding for very good projects because they do not know how to write a convincing proposal. It is recommended that country programmes of UNAIDS should focus intensively on capacity-building (proposal development, monitoring and evaluation, program implementation and report-writing) for local NGOs, particularly those which are community-based.

One agreed Monitoring and Evaluation System: Civil society can fully support the idea of one Monitoring and Evaluation (M&E) framework for each country irrespective of various donor needs. This will mean that many donors will need to review their policies

on M&E and may need to adjust their separate systems to coalesce with one global framework, agreed to by all parties, including NGOs.

Cascading HIV/AIDS work into development: The UNAIDS PCB NGOs support the adding of a 4th "one" related to coordinating donor policies across donor agencies. We support the moving beyond various narrow silo approaches that currently drive donor policies. For example, HIV/AIDS needs to cut across discussions related to agriculture subsidies, trade negotiations, other development issues, etc. HIV/AIDS needs to be raised at all policy levels and in tandem with a range of other issues. We have learned that HIV/AIDS must be a cross-cutting issue for all governments. Perhaps all countries should have HIV/AIDS Ambassadors (currently only France, Sweden and USA have AIDS Ambassadors) to help ensure that all policies have an AIDS-response component across all government policy development.

UNAIDS Reporting

Finally, a general recommendation is the publishing by UNAIDS of frank annual reports on each country with high HIV/AIDS prevalence. Each report would address all four areas of concern above, describing, for example, the status of all partnership agreements reached in the course of the year between government and civil society in developing sustainable AIDS policies, how the human rights of people living with HIV/AIDS are ensured, what legal and ethical steps are taken by a country's leadership to protect and serve AIDS patients, and whether laws, regulations, trade agreements, and patents facilitate or impede access to AIDS treatment. A country's willingness to support research and development into new HIV prevention technologies such as vaccine and microbicides, should also be among the indicators reviewed. Such annual reports could serve as reference tools for UNAIDS, local civil society groups, corporations, and donors in evaluating a country's efforts and readiness to deal with local HIV/AIDS crises. They could also serve as a Hall of Shame for countries, agencies, and corporations which make it unnecessarily difficult to address local or global AIDS issues.

UNAIDS should encourage the setting up of an independent, peer-review mechanism for recognising countries that have made outstanding responses in all areas of the epidemic. Such Country Awards for Best Practices should be considered on regional levels. It should be independent of the UN system, although it is highly recommended that UNAIDS play an important role in setting up the framework for the awards.

United, UNAIDS, working in partnership with civil society, in all regions, can succeed in our mutual goals. Divided, we will surely fail in our urgent mission.