

# **Sustaining the AIDS Response in a Time of Economic Crisis**

*How and Why 'AIDS Exceptionalism' Strengthens Health Systems*

DRAFT

## **Meeting Report – DRAFT – NOT FOR WIDE DISTRIBUTION**

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**Contents**

Acronyms and abbreviations ..... i

1. Background and overview ..... 1

    1.1 Key objectives of the meeting ..... 1

    1.2 About meeting participants ..... 2

    1.3 About this report ..... 2

2. Myths and facts about AIDS exceptionalism ..... 3

3. How and why HIV/AIDS is critically underfunded ..... 4

    3.1 The current situation: Slouching away from universal access ..... 4

    3.2 Notable existing and future challenges ..... 5

4. True priorities revealed: Donors renege on commitments ..... 7

5. Identification of key strategies and proposed action points ..... 8

    5.1 Setting a common vision and identifying core principles ..... 8

        5.1.1 Defining the movement ..... 8

        5.1.2 Rules of engagement and principles ..... 9

        5.1.3 Strategies to strengthen the movement ..... 9

    5.2 Evidence ..... 10

    5.3 Watchdog functions ..... 12

        5.3.1 Early warning systems ..... 12

        5.3.2 Long-term monitoring and advocacy projects ..... 13

        5.3.3 'Do your job watch' ..... 13

    5.4 Campaigns ..... 14

        5.4.1 Demand campaign ..... 14

        5.4.2 Financing campaign ..... 15

Annex 1. List of participants

Annex 2. About the Free Space Process

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## Acronyms and abbreviations

ARASA	AIDS and Rights Alliance for Southern Africa
ART	antiretroviral treatment
ARV	antiretroviral drug
CCM	Country Coordinating Mechanism (of the Global Fund)
CHALN	Canadian HIV/AIDS Legal Network
CSAT	Civil Society Action Team
DFID	UK Department for International Development
DR-TB	drug-resistant tuberculosis
FSP	Free Space Process
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GHI	global health initiative
GNP+	Global Network of People living with HIV/AIDS
HSS	health systems strengthening
ICASO	International Coalition of AIDS Service Organizations
ICSS	International Civil Society Support
ICW	International Community of Women living with HIV/AIDS
IDU	injecting drug user
IHP+	International Health Partnership and Related Initiatives
ITPC	International Treatment Preparedness Coalition
MSF	Médecins Sans Frontières
MSM	men who have sex with men
PEPFAR	US President's Emergency Plan for AIDS Relief
ODA	official development assistance
Ops Research	operations research
PIH	Partners in Health
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS

Note on text: All figures marked in \$ are US dollar amounts.

# 1. Background and overview

## 1.1 Key objectives of the meeting

The meeting this report is based on was held in Amsterdam on 12–13 March 2009. Hosted by International Civil Society Support (ICSS) and organized by a working group of civil society advocates, the meeting aimed to develop strategies to improve and expand the global civil society response to HIV/AIDS. This effort was deemed vital at this moment in time for two reasons: i) the global economic downturn, which has prompted many donor nations to place even greater priority on domestic demands, and ii) a rising “backlash” against disease-specific initiatives (especially those focusing on HIV/AIDS) among highly visible and influential donors and commentators.

These complementary developments already threaten to limit if not reduce key funding and support for HIV prevention, treatment and care, especially in resource-constrained nations with the greatest need. Should this happen, hard-won gains in recent years to improve the health and well-being of millions of HIV-affected individuals could conceivably be reversed. Many millions more still without treatment and other key services would find their desperate hopes ignored and quashed. HIV-related deaths and suffering in most countries and communities would increase; a global health and human rights disaster would accelerate.

The primary objectives of the meeting were to consider ways to identify and initiate a coordinated civil society response that could help prevent or at least mitigate such catastrophic outcomes.

Presentations and discussions therefore focused on:

- taking stock of the current situation regarding the global HIV epidemic, HIV/AIDS financing and investment, and financing and investment on other health-related Millennium Development Goals (MDGs) and health systems strengthening (HSS);
- identifying core principles to underpin a common civil society vision; and
- developing an advocacy strategy that determines action steps for the global HIV/AIDS movement. Such a strategy is based on a recognition that targeted HIV/AIDS funding should not only be continued, but significantly expanded.

It was understood that this overall effort is taking place in an era in which requests and demands for more money for all health-related programs and initiatives are facing greater scrutiny and scepticism. While recognizing that reality, meeting participants also agreed that governments and other donors must nonetheless be held accountable for meeting recent pledges to greatly increase support and financing for HIV and other key global health priorities. The urgency is clear: reneging on such pledges would be devastating for many individuals, communities and countries. It would also represent a clear rejection of core principles underpinning Universal Access and the UN’s MDGs, including the right to health, and the ability of most countries to meet health MDGs would be further weakened.

Discussions during the meeting also flowed from the belief that de-prioritizing the needs of the global poor would also be incredibly short-sighted from the richer countries’ perspective. The persistent gap between wealthier and poorer nations would widen, thereby increasing global insecurity and instability linked to poverty and desperation. A healthier world is a safer, richer world—and achieving this goal is not a question of money, but entirely related to lack of political will. The resources needed to move in this direction are dwarfed by what many rich nations are planning to spend domestically in response to the economic downturn.

## **1.2 About meeting participants**

In attendance at the March 2009 meeting were nearly 40 individuals based in 15 countries in Africa, Asia, Europe and North America. (A full list of participants may be found in Annex 1 of this report.) All are affiliated with organizations or initiatives that focus significantly – and in many cases exclusively – on HIV treatment advocacy. All are active to some extent at the global level, with most also leading and participating in treatment and prevention advocacy at national and community levels.

## **1.3 About this report**

This report is intended to serve more as a summary than a comprehensive, in-depth account of all proceedings. The main focus is not on the process, but on the outcomes. As a result, the bulk of the report (Section 5) discusses the action steps agreed to by meeting participants.

Sections 2 through 4 lead directly to the comprehensive list of action steps proposed in Section 5. Section 2 discusses the “backlash” against AIDS and summarizes arguments that HIV/AIDS financing tends to enhance, not weaken, health systems in general. Section 3 highlights the need for increased HIV/AIDS financing by listing key HIV trends and estimates. Section 4 provides a brief discussion of how donors are using the global economic downturn to scale down and reduce funding for HIV/AIDS. The language and points made in each of these sections are based on meeting discussions and presentations, but with few exceptions participants’ comments are not listed verbatim or necessarily in the order in which they were made.

Supporting materials will be made available on the ICSS website ([www.icssupport.org](http://www.icssupport.org)). These materials include PowerPoint presentations from several participants that provided background information and observations intended to jumpstart discussion and, eventually, the determination of action points. Due to space limitations, it was not possible in this report to refer specifically to all presentations.

## 2. Myths and facts about AIDS exceptionalism

The “backlash” against AIDS has many sources and several different strands. Some stem from plain envy: HIV/AIDS advocates have been extremely successful in raising global awareness and generating a response. The creation of UNAIDS is a prime example of “AIDS exceptionalism” that critics decry and advocates continue to believe is necessary given the disease’s unique social, economic and epidemiological factors. For example, although cancer and malaria may claim more victims globally, neither can be transmitted from one person to another and people living with cancer and malaria experience far less stigma and discrimination than those with HIV.

The most common claim of those leading the “backlash” against AIDS is that it gets “too much” money. In their view, all health-related resources should be distributed more equitably across health systems, primarily to strengthen the very systems themselves. This argument has proved persuasive in some quarters. Staff at some leading donors, notably DFID, have subscribed to this view and sought to restructure how official development assistance (ODA) and other health-related assistance are provided to recipient nations—e.g., the IHP+ initiative.

The “too much” money argument is, however, based on two false assumptions: i) that there is a specific, limited amount of money available for health; and ii) that HIV/AIDS financing has a negative impact on overall health systems. Meeting participants agreed that they need to do a better job at gathering evidence and mounting advocacy campaigns to refute both assumptions. The core premise of HIV/AIDS advocates’ efforts should be on making the case that i) far more money should be made available for health in general (i.e., the pie should be larger, not divided differently); and ii) HIV/AIDS-specific funding actually can actually strengthen health systems and thus plays a vital HSS role on its own.

For every cautionary tale—notably, the oft-cited example of Malawi’s overall health system facing collapse in the wake of donor money moving to HIV programs—there are clear indications of HIV/AIDS financing doing far more good than harm (real or alleged). In Botswana, for example, heavy investment in paediatric care through the HIV/AIDS program has had positive impacts across the health spectrum, including in regard to overall maternal and infant mortality. In Haiti, too, improvements beyond those specifically related to HIV/AIDS can be attributed to targeted investment in HIV. In Lesotho, laboratories established with HIV/AIDS funds are used for needs across the general health system. These examples show that the impact of HIV/AIDS financing depends more on implementation and follow-through than specific objective.

Several meeting participants noted, too, that one of the most prominent HIV/AIDS global health initiatives (the GFATM and the GAVI Alliance) specifically allows countries to request money for longer-term HSS activities, such as increasing the number of health-service workers. To date, though, only a handful of countries have included such specific requests, at least in part because of concerns about sustainability. For example, out of \$2.8 billion approved for the HIV/AIDS component in the Global Fund’s Round 7, just \$363 million was targeted toward HSS. Greater uptake of this GFATM option, which would likely require improved national-level advocacy and awareness, could conceivably blunt complaints about the supposedly limited nature of HIV/AIDS financing.

Moreover, advocates recognized that they should stress more clearly that at the most basic level it is practically impossible to separate HIV/AIDS programs from overall health systems in most countries with high HIV prevalence (including much of sub-Saharan Africa). In those nations, which tend to attract the most HIV-specific external assistance, HIV is a constant, daily reality on some level for nearly every resident. And, as discussed in Section 3, the achievements in the past few years are quite limited given the massive size and scope of the epidemic.

### **3. How and why HIV/AIDS is critically underfunded**

#### **3.1 The current situation: Slouching away from universal access**

Contrary to what some observers have stated, HIV/AIDS remains a serious global health problem: according to UNAIDS, at least 2.7 million people around the world contracted HIV in 2007, and more than 32 million are thought to be living with virus. The epidemic's impact is exacerbated by the fact that it continues to disproportionately affect the less developed world, where resources are scarce. An estimated 1.9 million of new infections in 2007 occurred among people who live in sub-Saharan Africa.

HIV/AIDS does not discriminate based on gender. Yet although about half of all infections worldwide are among women, that share rises to about 60 percent in sub-Saharan Africa. The fact that the epidemic in that part of the world—where HIV prevalence in general is by far the highest—is becoming more feminized is a likely indicator that women's share of global HIV infections will rise ever higher in the future. This trend is particularly worrying because in much of the world, women face greater obstacles than men to adequate health care due to cultural bias and ingrained social and economic discrimination, as well as abuse and violence.

More than 3 million people around the world currently have access to antiretroviral treatment (ART). Although undoubtedly a significant improvement from even just five years ago, this number represents at best one third of all individuals who should be on ART now. Moreover, even many of those who have consistent access to ART do not have access to a comprehensive range of HIV treatment services, including adherence support, nutrition support, safer-sex information, and prevention materials such as condoms.

Such a disconnect reinforces the belief among most civil society advocates that progress toward universal treatment access is overstated. Most data are based on UNAIDS' definition of universal access, which starts off well—"global commitment to provide HIV prevention, treatment care and support to all those in need"—but then states that numbers are "based on national targets set by countries." However, experience and other evidence sources indicate that national targets differ greatly from actual need in most cases, with the latter nearly always higher than the former. The consensus among meeting participants was that UNAIDS' definition of universal access should therefore be replaced by a more realistic one that includes all people in need of HIV treatment, not just the numbers provided by governments that often wish to downplay the problem.

UNAIDS' estimates as to the amount of resources and investment needed for HIV/AIDS are also based on national government data. However, such numbers are likely to be more realistic because governments want to secure as much external funding as possible to allocate to HIV and other health problems. According to recent UNAIDS estimates for 132 low- and middle-income countries, a total of \$19.8 billion will be needed for the HIV/AIDS response in 2009, an amount that will rise to \$25.1 billion in 2010. (The total includes HIV-specific health services, HSS and cross-cutting activities, and multisectoral services.)

This is a huge amount of money, but it should be put in perspective. In 2007, health-related ODA comprised just 10 percent of all ODA (which in turn totalled about \$100 billion), according to some calculations. And in late 2008 and early 2009, many Western governments allocated vast sums in the hundreds of billions of dollars for special domestic spending programs designed to mitigate the impact of the economic downturn. Several of those governments had few qualms about those allocations, but claimed at the same time that they were unable to find a fraction of such funds for the GFATM, which faces an unfunded gap of between \$4.3 billion and \$9.8 billion through 2010.

To summarize, key issues of concern for HIV/AIDS advocates vis-à-vis HIV treatment care and support are i) underfunding of current and future needs; ii) the setting of targets that do not truly

represent universal access; and iii) the belief that HIV prevention and treatment are separate issues, with the former greatly underfunded in comparison with the latter. Taken together, such observations and beliefs provide unwarranted support for those who believe that HIV/AIDS does not deserve dedicated funding at all, or that the current amount is too large.

### **3.2 Notable existing and future challenges**

Several presentations at the meeting highlighted other specific issues of growing importance to comprehensive HIV/AIDS treatment. All of the following lend even greater weight to efforts to expand funding initiatives.

- Drug-resistant TB (DR-TB) is increasingly common, and has reached epidemic levels in several countries (such as South Africa). Unfortunately, the full extent of the epidemic is difficult to determine because of poor or nonexistent surveillance in the majority of African countries. It is thought, though, that less than 5 percent of people with DR-TB have been diagnosed, and that at most 3 percent of them are receiving appropriate treatment.

Some new data indicate a trend of DR-TB being transmitted directly from one person to another (i.e., not occurring as a result of inadequate adherence to drug regimens). This trend challenges the notion that prevention is always better than treatment; instead, it is clear that much more investment is needed in treating DR-TB specifically, TB more generally, and TB-HIV coinfection. Treating earlier and more aggressively also makes sense from a cost perspective given the much higher costs of treating DR-TB, which often requires extensive hospitalization and expensive drugs. In South Africa, for example, an estimated 70 percent of the national TB budget goes to treating DR-TB, even though that form of the disease accounts for just 2.6 percent of recorded cases to date. Moreover, the human resource challenges of dealing with TB, especially DR-TB, are huge: staff turnover is extremely high, which creates gaps in programs in regards to health personnel, capacity, knowledge, etc.

- The vulnerability of women and children presents difficult and ongoing challenges. The increasing feminization of the HIV epidemic is placing major strain on many countries' ability to limit vertical transmission. Paediatric ART options are limited and expensive just about everywhere, unfortunately, and many HIV-positive (and negative) children continue to be orphaned when one or both parents die from AIDS. Implementation bottlenecks are as much of a problem as funding constraints in many vertical transmission programs.
- Limited access to viral-load tests makes it difficult in many contexts to determine when a patient should switch to a second-line regimen. A related problem is that even if a first-line regimen is clearly failing, there are often no other options because a second-line alternative does not exist. This occurs almost exclusively due to the fact that a second-line regimen is several times more expensive, depending on patent protection.

A vital goal of all HIV advocates must therefore be to improve access to ARV regimens beyond the first line. Failure to reduce costs will lead to more situations such as that currently faced by South Africa, where a recent WHO report estimated that more than half of the national health budget would eventually be needed to pay for second-line treatment. Calculations such as that one have prompted the government to make a cost-benefit decision to offer only first-line ART through the public sector, a decision that has already condemned thousands of people to death from AIDS.

- The human rights aspect of HIV treatment cannot and should not be underestimated and ignored. For example, in many parts of the world, including the Caribbean and Eastern Europe, HIV rates are several times higher among highly stigmatized vulnerable groups—

such as men who have sex with men (MSM), sex workers and injecting drug users (IDUs)—than the general population. Global treatment advocacy has greatly improved such individuals' access to HIV services and care, a development that would not likely have occurred if only local and national governments were involved. Access to comprehensive services for members of vulnerable populations thus depends heavily on funding and support from global health initiatives (GHIs).

- The size and quality of HIV/AIDS programs may look great on paper, but the situation on the ground often differs. This is especially true in poor countries with ramshackle or non-existent infrastructure, including roads, electricity supplies, and schools. Those countries, such as the Democratic Republic of Congo, attract HIV/AIDS financing because the needs are great—yet the positive impacts are harder to see because of the massive societal constraints. More financing and support, not less, is needed in those environments to ensure that supply chains work properly and consistently; that patients have easier access to clinics; that monitoring systems are in place to address corruption and graft, etc.

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#### **4. True priorities revealed: Donors renege on commitments**

Adequate external funding to address the needs identified in Section 3 has never been made available. At one point, though, it appeared that policymakers in donor nations had begun recognizing their shortcomings and were seeking to rectify them. Most notably, Group of 8 (G8) leaders in 2005 vowed to take a major step toward achieving universal access by 2010 as part of an effort to achieve the MDG on HIV/AIDS (to halt and reverse the spread of the epidemic by 2015). In their communiqué at the Gleneagles summit that year, they pledged to provide financing and other support to ensure that some 10 million HIV-positive people were on HIV treatment by the end of that year. Just two years later, however, they cut the goal in half, to just 5 million people. Even that number is wildly improbable given the funding gaps faced by the GFATM, which was to be the vehicle through which much of the assistance flowed.

More recently, the Obama administration signalled in a budget framework released in late February 2009 that it intends to ignore the then-candidate's commitment to double foreign aid by 2012. If that decision stands, US funding for HIV/AIDS abroad will be far less significant than advocates hoped in June 2008, when Congress passed a bill authorizing the spending of \$48 billion over five years for PEPFAR and the GFATM. Since then, though, support in the US government for such vital funding has fallen sharply. About \$5.8 billion was appropriated for the 2009 fiscal year, less than two thirds of the annual amount (more than \$9 billion) needed to reach the June 2008 goal. The new administration, meanwhile, has asked for only slightly more for the fiscal 2010 budget.

Its supporters blame the economic crisis for the decision to backtrack from Obama's commitment, but HIV/AIDS advocates have been quick to point out that the administration has found hundreds of billions of dollars to bail out failing financial institutions and fund stimulus programs. Meeting participants therefore agreed that a campaign to hold Obama accountable to his pledge on HIV/AIDS funding was not only appropriate, but necessary.

According to some US-based advocates, efforts are already under way to figure out how to use the fully committed funds wisely. Among the objectives is to help target countries meet minimum WHO standards for having 2.3 doctors, nurses and midwives per 1,000 people. That number is still far too low, advocates agree, but it would represent a substantial improvement on current levels in many nations. Another focus would be on providing direct support to train and retain 140,000 new health workers, with the emphasis on doctors and nurses. Such objectives have the dual focus of improving both HIV/AIDS responses and health systems in general.

Individual governments are not the only culprits behind the lack of adequate funding for HIV/AIDS and health in general. As pointed out in one presentation, domestic government expenditures on health have actually declined or at best remained stable in many of the world's poorest nations even as the impact of HIV and other health problems accelerate. Many of those countries' leaders have held back health spending as part of efforts to meet fiscal targets set in loan agreements with the International Monetary Fund and World Bank.

Among the many perverse outcomes of such steps is that the benefits of external support for health (from bilateral agencies and the GFATM, for example) potentially are cancelled out, even if such support is increasing. Observers who want to discredit AIDS exceptionalism put the blame for health-sector constraints in such countries on disease-specific GHIs even though in reality the international financial institutions and national governments are responsible.

## **5. Identification of key strategies and proposed action points**

Based on in-depth discussion of the issues, questions and concerns raised in Sections 2 through 4, meeting participants rejected the option of diluting their specific focus on HIV/AIDS and advocating more loosely on health in general. They agreed instead that their overarching goal of social justice is best achieved through an HIV/AIDS movement—but one that is re-energized and more cohesive.

Participants acknowledged that another challenge hindering their effectiveness in recent years is that the movement has been perceived by many in the outside world as more successful than it really has been, a perception that has generated resentment of the sort exhibited by the AIDS “backlash”. This development indicates that the HIV/AIDS movement has failed to consistently and clearly communicate its goals and objectives, including the crucial linkage between health and human rights. There was consensus too that the movement would be strengthened by reenergizing its focus on Universal Access while at the same time building strategic alliances with other health and human rights communities and constituencies, including the women’s movement. Coalitions of this sort would be useful in helping educating people as to the myriad reasons that HIV/AIDS financing should be increased as well as illustrate why reallocation of the current budget for global health will not serve anyone’s goals.

The outcome-oriented process at the meeting consisted of four break-out sessions focusing on the following focus areas: i) setting a common vision and identifying core principles; ii) evidence; iii) watchdogging; and iv) campaigns. Each group was asked to propose specific tasks related to its focus area; identify potential steps to achieve those tasks; consider the type and extent of capacity needed to undertake those steps; propose timelines; and assign responsibility to participants and/or organizations represented at the meeting.

Each group subsequently presented its findings and recommendations for consideration by meeting participants. Summaries of those presentations are provided below in Sections 5.1 through 5.4.

Several activities and action steps were proposed within each of the four focus areas. Where determined by meeting participants, individual action steps are directly linked to individuals or organizations with responsibility (“associated responsibility”) for initiating and/or fully implementing the specific action. Proposed dates (“timeline”) for specific actions are also noted.

### **5.1. Setting a common vision and identifying core principles**

Meeting participants agreed that articulating a common vision would enhance the clarity and cohesiveness of the global civil society response to HIV/AIDS. This vision is intended to improve advocacy effectiveness and impact at all levels, with the ultimate goal being access to key services for all HIV-affected communities and individuals in need.

The vision focus group’s discussions were divided into four parts: defining the movement for universal access; identifying the rules of engagement and principles; proposing strategies to strengthen the movement; and setting a tentative timeline for specific activities.

#### **5.1.1 Defining the movement**

Civil society advocates and their communities must work toward ensuring widespread understanding and acceptance of their own definition of “universal access”—a definition that is pointedly more expansive than that used by UNAIDS. Therefore, comprehensive universal access consists not only of prevention, treatment, care and support for all HIV-affected individuals. More broadly:

- The movement toward universal access should be considered part of the global health movement in general.
- The movement prioritizes a rights-based approach to the AIDS response, an emphasis that places it at the forefront of a much bigger movement: the right to health for all and full funding.

### **5.1.2 Rules of engagement and principles**

The following are among the key underlying principles of the movement:

- GIPA is the primary catalyst of all actions and responses.
- Civil society engagement should be initiated and sustained at all levels.
- Members of the movement “do no harm” to each other.
- Mutual reinforcement is expected.
- A human rights approach must be prioritized and upheld.
- The concept of global solidarity, which translates into global responsibility for global health rights, must be emphasized.

#### Associated responsibility:

- A statement of goals, shared values and rules of engagement will be drafted by a working group comprising Kieran Daly, Mayowa Joel, Gorik Ooms, Peter van Rooijen and Marcel van Soest.
- A separate group, comprising Linda Hartke and Peter van Rooijen, will simultaneously develop a strategy for using the statement internally and externally.

Timeline: April 2009

### **5.1.3 Strategies to strengthen the movement**

The group proposed a variety of different strategies related to i) overcoming competition both within the HIV/AIDS movement and the broader global health movement, ii) raising awareness of the movement’s shared vision, and iii) putting the vision into action. Among those strategies are the following:

- Hold a global health summit that will bring advocates together. This summit ideally should take place before the 2010 International AIDS Conference in Vienna. Planning for the meeting requires strategic dialogue and face-to-face meetings, and needs estimates for different MDGs and different sectors should be conducted prior to the summit.
- A PIH summit is scheduled for May 2009. This meeting represents a key opportunity for identifying shared goals and strategies for the global health movement.
- Civil society should comment on the report released on March 13 by the Taskforce on Innovative International Financing for Health Systems.
- Uniform messaging is needed within civil society forums at GHIs (UNAIDS, PCB, IHP+, GFATM, UNITAID).
- There’s a real need to strengthen the movement at the national level. The Free Space Process would be useful in this effort, as would other initiatives designed to support civil society movements on health and rights.

Mapping the support available for strengthening policy and advocacy capacity at the national level is an important activity in this regard. The mapping process should include resource estimates and consideration as to whether current and proposed future resources

can realistically achieve the goal of universal access.

- Concerted and coordinated efforts should be made to influence national health planning strategies at country level. IHP+ could be used as an entry point.
- ActionAid is coordinating a global meeting on universal access, to be held in Nairobi. This meeting represents an excellent opportunity to coordinate future activities and identify new partners.
- The global civil society movement should play a more direct role in influencing the agenda of the 2010 International AIDS Conference.
- Similarly, the movement should seek to wield greater influence in the development of the agenda for the UN's Millennium Summit planned for September 2010 in New York. Civil society must also advocate forcefully for more extensive participation in the meeting itself.
- A communications strategy should be developed to guide both internal and external communications of the global HIV/AIDS movement.

## 5.2 Evidence

The overarching assumption among all meeting participants, not just those in the evidence focus area group, was that they and their allies must do a much better job of showing how and why HIV-specific funding initiatives support and enhance health systems in general. Their ability to make this case would be greatly increased by identifying and highlighting evidence that supports their claim.

The specific tasks mooted for achieving this overall objective are grouped within six categories, as listed below. Proposed responsibility and timeline information accompanies each discrete task.

1) Gather, review and synthesize already-existing data and observations regarding how GHIs, particularly those that focus all or in part on HIV, influence HSS efforts.

Sources include:

- Positive Synergies initiative launched in mid-2008.
- An ongoing IAS scan of research showing that HIV-focused GHIs have improved health systems. It is assumed that evidence of this impact will more likely be available at local levels than at national ones.
- Article in the *Lancet*, tentatively scheduled for June 2009 publication, which focuses on the positive impact of GHIs on HSS. As currently structured, the article relies on existing data and previously published reports only. The draft nearing completion replaces an earlier version that was rejected by the magazine on the basis that it was "too political". In addition to requesting a new draft, *Lancet* editors reportedly have commissioned commentary and articles from opponents that will appear in the same issue.

At least two of the Amsterdam meeting participants are directly involved in this process. As part of an effort to ensure accuracy and comprehensiveness, they agreed to ask the other primary authors for permission to circulate a draft among all meeting participants for review prior to finalization. IAS will coordinate the review process among Amsterdam meeting participants.

2) Stimulate more debate and discussion about what needs to change in health systems' definition.

Key issues and areas to consider:

- What are the bottlenecks in health systems? What are the negative implications of these bottlenecks?
- Should more attention be paid to how health systems work at local and regional levels, in addition to the national level?

Some useful sources already exist and should be thoroughly explored first. For example, Health Systems 20/20 reportedly has a database with information on health systems research conducted to date.

3) Advocate for and initiate more extensive research and evidence-gathering, both short and long term.

Key issues and areas to consider:

- More targeted advocacy should be initiated and sustained around the 2007 Sydney Declaration, which called for 10 percent of all resources dedicated to HIV programming to be used for research towards optimizing interventions utilized and health outcomes achieved.
- Effective Operations Research can strengthen HIV prevention, care and treatment scale up in resource-limited settings. Funding for such endeavours is available through the Global Fund; uptake of this opportunity should be increased in as many countries and contexts as possible. It is necessary to mobilize groups at the community level to i) advocate for the inclusion of funding for this initiative in Global Fund grants, an effort that should focus on CCMs, and ii) have the capacity and expertise to eventually undertake the work themselves. IAS 2009, to be held in July in Cape Town, includes a session in the Professional Development Programme (titled "Learning by Doing") that focuses specifically on Operations Research in this area.

4) Create more shared spaces among civil society for data dissemination and evidence-gathering.

This effort would, for example, promote community models such as that used by ITPC for its biannual *Missing the Target* reports. Such models are considered extremely useful for advocacy purposes in all environments.

5) Focus on gathering data that support and reinforce the need to achieve universal access to HIV treatment and care.

Key issues and areas to consider:

- Who is getting HIV treatment, and what does their treatment actually comprise? Such information should be disaggregated by gender, age, income, etc. to the fullest extent possible. Preliminary sources might include government data, PEPFAR and UNAIDS.
- Recalculate costing of what countries need to what people need. A higher standard of "need" should be developed so that more people are covered; this would ideally flow from the results of papers commissioned to identify real and persistent needs at the community level.

IAS is currently developing its own costing analysis mechanism that is intended to be more precise and inclusive than the existing standard (from UNAIDS).

- Build data-gathering on treatment as prevention. Such efforts will help clarify and improve participating organizations' advocacy on prevention issues. They should also prompt the creation of new treatment and funding models based on revised treatment guidelines that more comprehensively take prevention into account.
- Promote Ops Research at the community/clinic level to determine what does and does not work in terms of HIV care support. Funding for such endeavours is available through the Global Fund; uptake of this opportunity should be increased in as many countries and contexts as possible.

#### 6) Other relevant evidence-gathering options and sources.

- An article "telling the truth" about SWAPs (sector-wide approaches), with particular focus on their negative impact on HIV/AIDS funding.
- Advocates need to do a better job learning about, understanding, and highlighting the negative effects of IMF policies on health indicators. For example, evidence has shown that IMF policies have contributed to a worsening of the TB situation in Ukraine.

### 5.3 Watchdog functions

A key role of civil society organizations in any context is to monitor the implementation and impact of programs and initiatives directly related to their work. The focus group identified three different kinds of watchdog functions of relevance to civil society advocates working on HIV and health issues: early warning systems; long-term policy and programme monitoring; and accountability ("do your job watch"). For all three functions, discussion centered on how to improve existing watchdog efforts and what kind of (if any) additional strategies and efforts should be developed.

#### 5.3.1 Early warning systems

Various list-serves (e.g., ITPC and Health GAP) essentially serve as early warning systems. The most efficient option would be to strengthen these existing structures, not create new ones. Effective follow-up is one persistent challenge, which means that efforts are often ad hoc and prone to lose momentum quickly. This points to a need to devise ways to reach a broader audience both to send warnings and information and to support follow-up action.

The group differentiated between two different kinds of early warning systems, rapid response and long-term pre-emptive action. It was agreed that early warning should trigger both kinds of action, depending on the nature of the problem.

- Rapid response refers to short-term, urgent action in response to reports of (for example) ARV stock-outs and human rights violations. Although ITPC was singled out as having a good track record in this area, more attention should be paid to:
  - flagging actions requiring rapid response so as to ensure that those requiring immediate responses stand out;
  - bridging the time lag between email action and developments on the ground; and
  - tracking and recording the outcomes of urgent action interventions.

Associated responsibility: ITPC will take the lead in proposing strategies regarding rapid response priorities; it will then circulate among meeting participants for consideration.

- Pre-emptive response refers to more long-term action in response to future problems and concerns. One notable example is the fact that Global Fund grants all last for a pre-determined period of time (almost always five years). This means that efforts should be made as far in advance as possible to develop strategies for the sustainability of programs

and projects initiated and funded through the Global Fund. Pre-emptive responses require extensive moderation and coordination; both could be improved by:

- identifying specific focal people to follow upon issues. It is important to determine in advance how many people might be needed, which organizations (such as ITPC and Health GAP) should take the lead, and how many issue-specific areas should be prioritized; and
- more thorough discussion of how burdens are shared so that not just one person or organization has disproportionate responsibility.

Associated responsibility: ITPC and Health GAP will propose strategies to improve coordination on early warning long-term responses.

### **5.3.2 Long-term monitoring and advocacy projects**

Group participants acknowledged being stymied in their efforts to name existing initiatives of this sort. They therefore concluded that a key priority should be to identify those that do focus on such work (in addition to T-MAP) and seek to harmonise and strengthen their efforts. One useful step would be to create a website to serve as a clearinghouse for all initiatives—such a site would provide a comprehensive overview of all civil society monitoring efforts. Other priority efforts in terms of strengthening existing structures might consist of:

- creating stronger links to advocacy;
- building the monitoring and research capacity of activists;
- improving continuity by establishing indicators that can be used to gauge the quality and effectiveness of monitoring efforts; and
- broadening focus to include non treatment-specific issues such as resource allocation and CCMs.

Group participants also agreed that more consistent and coordinated monitoring is needed in regards to HIV and human rights issues. Such issues might include HIV criminalisation (which groups such as GNP+, ARASA and CHALN are working on) and travel restrictions on HIV-positive individuals (a priority area of GNP+, most notably).

Associated responsibility (re HIV criminalisation): Consultation with ARASA and CHALN; report from GNP+. Timeline: July 2009 and December 2009, respectively.

Associated responsibility (re travel restrictions): GNP+. Timeline: Next steps to be determined after UNAIDS meeting in April 2009.

### **5.3.3 'Do your job watch'**

Governments, UN agencies, bilateral agencies and the Global Fund are among the primary targets of the third watchdog function. Some efforts are being made in this regard, but they are ad hoc and fragmented. More sustained and coordinated pressure is needed, particularly in regards to UN agencies and many Southern governments, in order to prompt effective and significant change.

Proposed strategies:

- A “name and shame” publication put out by a global civil society coalition on a regular basis, perhaps monthly or quarterly. The publication would highlight particularly egregious actions, statements or decisions directly related to HIV made by individuals, organizations and governments. Each issue should be tied to a specific concrete action, such as letter-writing and political-pressuring campaigns. Efforts should be made to disseminate each publication widely, in both Web and print mediums, in tandem with press releases and press conferences.

An editorial committee comprising civil society advocates would solicit nominations for the target individual, government or agency. To attract attention, articles and reports should be not only evidence-based and concise, but humorous in tone.

More effort should be made to link the HIV and women's rights movements, which increasingly share similar goals and concerns. A priority in this regard should be to convene a meeting with all women's health and women's rights groups to discuss creating a common agenda.

## 5.4 Campaigns

The group focused on two broad campaigns to be initiated this year: one on demand, the other on financing. The campaigns are based to a significant extent on the common principles discussed and summarized in Section 5.1.

### 5.4.1 Demand campaign

The main proposal was to initiate a "close the gap" campaign over the next 18 months. This campaign would be specifically linked to the goal of universal access by the end of 2010.

The campaign could be structured around an overall framework at the global level that country-level advocates could use for specific in-country campaigns. This template should be devised with significant input from country-level advocates.

Associated responsibility: Vuyiseka Dubula and Bactrin Killingo will take the lead in designing the template. They will be supported by Rajiv Kafle, Othman Mellouk. Mellouk will also provide links to CSAT.

Subsequent steps in this campaign would include the following:

- Step 1: In-country work ideally would seek to identify gaps in universal access by reviewing existing sources, such as figures and projections from UNAIDS and Aidsplan, and comparing with universal access targets.

Such work is likely to be daunting and complicated in most countries. Therefore, support from the global level is likely to be necessary, ideally by connecting and coordinating with organizations and initiatives already engaged in work of this sort (such as ICASO and ITPC). The full cooperation of UNAIDS is required as well, particularly in regard to obtaining information on the agency's reviews of national strategies.

Associated responsibility: Daniel Berman, Kieran Daly, Sharonann Lynch, Asia Russell and Paul Zeitz will arrange meetings with key UNAIDS personnel, including Michel Sidibé, in order to discuss needs. They will also propose that UNAIDS build a network for real-time information-sharing that civil society can not only access, but provide input into directly as well.

- Step 2: Civil society advocates would prioritize the closing of gaps by ensuring adequate resources in funding proposals submitted to donors such as the Global Fund and PEPFAR. Particular efforts should be made to mobilize representatives of bilateral and multilateral organizations on CCMs.

The success of such efforts is likely to be increased in many countries when results indicate the true extent and size of gaps, which would highlight inadequate progress toward

meeting targets. The situation in Zambia was presented as an example. Closing the gap would mean treating 300,000 people, a number that should be highlighted to show the massive needs and staggering impact on individual and public health in the country. The country-level campaign in Zambia would focus on ensuring that policymakers recognize the importance of responding fully and adequately.

- Step 3: Shine a spotlight on—"name and shame"—countries with particularly massive gaps. This effort should also focus on countries in which identified gaps are not sufficiently addressed in funding proposals, notably for the Global Fund's Round 10.

The group proposed that the "close the gap" campaign be pilot-tested in a few countries initially before being rolled out globally.

Associated responsibility: Jacqueline Wittebrood will set up an email group to facilitate communications and process for the overall campaign. Khalil Elouardighi will take the lead in proposing a media strategy for the campaign, a process to be initiated via e-mail.

#### **5.4.2 Financing campaign**

The group devoted far less attention to the financing issue, mainly because relevant campaigns (e.g., "Fund the Fund") already exist. It was agreed that focus should be placed on strengthening and supporting such campaigns. Among the priority areas identified would be to encourage the Global Fund to talk more about the significant gaps in universal access and to develop talking points about why it is important to invest in health during this period of economic downturn.

## Quotes from participants

*"I think that if we settle for minimum rights, we go backwards. Rights should be progressive. I want not just second line, but also third and fourth line. The South African Constitution doesn't say you have a right to life only if you have money....My concern is that rights-based approach will be hijacked, that people will think rights have no part of health."*

— Quote from meeting participant

*"Yes, there is a huge economic downfall. But somehow [governments] can justify expenditures and find money when they want to. See, for example, the huge economic stimulus plans that were easily rustled up in the US and elsewhere...surely there are resources available. The juxtapositions can be so vivid as to compel a response. We're asking for such miniscule resources....We can and should fight this."*

— Quote from meeting participant

*"I think this crisis gives us an opportunity to think carefully about how we define and present ourselves. For a long time we focused only on number of people on treatment...and we haven't communicated well how as to how we've changed other things, such as community care, addressing stigma, and helping those who are vulnerable."*

— Quote from meeting participant

*"Let's take the global financial crisis out of the current backlash debate for awhile. There was resource gap in the past even before the financial crisis. Now, though, for some reason we're being told that because the rich have less money we should also ask for less or in fact stop asking for help....[or] otherwise the Lancet, BMJ or the New York Times will keep coming up with arguments such as ARVs are a luxury. It is like saying oxygen is a luxury."*

— Quote from meeting participant

## Annex 1. List of participants

Individuals who attended all or part of the 12–13 March 2009 meeting are listed below in alphabetical order by last name. The country listed refers to current base for work, not citizenship or national affiliation.

<b>Name</b>	<b>Affiliation</b>	<b>Country</b>
Paula Akugizibwe	ARASA	South Africa
Donna Barry	Partners in Health	USA
Daniel Berman	Médecins Sans Frontières	Switzerland
Marine Buissonniere	Open Society Institute	USA
Robert Carr	Vulnerable Communities Coalition	Jamaica
Kieran Daly	ICASO	Canada
Lola Dare	ACOSHED	Nigeria
Paula Donovan	AIDS Free World	Canada
Vuyiseka Dubula	Treatment Action Campaign	South Africa
Khalil Elouardighi	PLUS	France
Eric Fleutelot	Sidaction	France
Raoul Fransen-dos Santos	ICSS	The Netherlands
Rolf Goldstein	Action Against AIDS Germany	Germany
Gregg Gonsalves	Yale	USA
Linda Hartke	Ecumenical Advocacy Alliance	Switzerland
Lyndon Haviland	World AIDS Campaign	USA
Jeff Hoover	Rapporteur	USA
Elaine Ireland	Action for Global Health	UK
Mayowa Joel	CFDC	Nigeria
Rajiv Kafle	National Association of PLHIV	Nepal
Anton Kerr	International HIV/AIDS Alliance	UK
Bactrin Killingo	HIV Collaborative Fund	Kenya
Christoforos Mallouris	GNP+	The Netherlands
Othman Mellouk	Association de lutte contra le sida (ALCS)	Morocco
Stephen Lewis	AIDS Free World	Canada
Sharonann Lynch	Médecins Sans Frontières	South Africa
Ron MacInnis	International AIDS Society	Switzerland
Royston Martin	World AIDS Campaign	UK
Nicoli Natrass	University of Cape Town	South Africa
Carol Nyirenda	CITEM+	Zambia
Gorik Ooms	Institute of Tropical Medicine	Belgium
Sue Perez	Treatment Action Group	USA
Fiona Pettitt	ICW	UK
Mit Philips	Médecins Sans Frontières	Belgium
Asia Russell	HealthGAP	USA
Surendra Shah	Nava Kiran Plus	Nepal
Aditi Sharma	ITPC	India
Peter van Rooijen	ICSS	The Netherlands
Marcel van Soest	World AIDS Campaign	The Netherlands
Jacqueline Wittebrood	ICSS	The Netherlands
Paul Zeitz	Global AIDS Alliance	USA

## Annex 2. About the Free Space Process

The meeting was part of a new initiative, the Free Space Process (FSP), which was formally unveiled in October 2007 during a meeting in Amsterdam of some 20 civil society advocates. (Some of those advocates also attended the March 2009 gathering.)

The FSP aims to provide a dedicated space for in-depth and creative thinking and sharing for the civil society architecture, both in terms of how it operates at the global level and how national-level work and priorities are connected to regional and global ones. It does so primarily by facilitating improved coordination among existing HIV/AIDS networks, and more broadly among civil society representation in the boards of the various international health initiatives. The overall goal is to strengthen civil society's response to HIV/AIDS and health in general through enhanced collaboration at the global, regional and national/local level.

Activities within the FSP focus on the following activity areas:

1. Establishment of an HIV/AIDS strategy caucus. This is a space for strategic thinking and systematic linking and learning among leaders of the networks<sup>1</sup> and other sectors of civil society (HIV/AIDS, key populations, health) from the international, regional and national level, in order to develop a proactive response based on a common vision on HIV/AIDS and health in general.
2. Supporting civil society delegations. This consists of increased capacity support for civil society representatives in the international institutions<sup>2</sup> as well as facilitating a process for strategic collaboration among these representatives and with a wider group of civil society stakeholders.
3. Strengthening the civil society architecture at the country level. This includes enhancing collaboration at the country level to improve civil society's ability and inclination to i) strategize and work together on the national agenda vis-à-vis HIV/AIDS and health, and ii) develop a shared advocacy agenda and appropriate actions.
4. Creating a better communications environment. Efforts are being made to collectively i) address the urgent need for alignment and support of an efficient civil society communications environment, processes and tools, and ii) develop accountability mechanisms at the international, regional and national level.
5. Leadership development. A main priority is on creating an environment and appropriate curricula for development and support of new (and young) leadership.
5. Funding needs and resource mobilization. Funding needs are considered in regards to essential capacity gaps—in communication, policy advocacy, and management—that hamper scale up and quality improvement of the response.

The FSP's overall goal is to support these networks and civil society representatives to identify and review current gaps in civil society infrastructures and capacities and propose various strategies to overcome them. Equally important, the FSP creates a space for the networks and delegations to discuss and build on current strengths and share resources more consistently. Taken together, these steps increase the ability of civil society actors at all levels—national/local, regional and global—to provide extensive, appropriate, and sustainable services to their core constituents.

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<sup>1</sup> Including the Global Network of People living with HIV/AIDS (GNP+), the International Community of Women living with HIV/AIDS (ICW), the International Treatment Preparedness Coalition (ITPC), the International Council of AIDS Service Organisations (ICASO), the International HIV/AIDS Alliance, the World AIDS Campaign, and the Ecumenical Advocacy Alliance.

<sup>2</sup> Including representatives to the UNAIDS Programme Coordinating Board, Global Fund to Fight AIDS, Tuberculosis and Malaria, UNITAID, GAVI Alliance and IHP+ .