

Consultation with AIDS Activists

International AIDS Conference Future Directions Project

18 March, 2005
Geneva, Switzerland

Summary

Thirteen AIDS activists, most representing activist organizations, and five International AIDS Society (IAS) staff members met for a full day to explore ideas for improving the International AIDS Conference. Both thematic and operational issues were discussed.

Action Items

- ❑ Hold a joint follow-up meeting that involves people from all the Future Directions consultations that addresses the input of all stakeholder groups.
- ❑ Hold another consultation with activists at the Rio conference in July.
- ❑ Make the minutes of all consultations available
- ❑ Review Rapporteur reports from the Bangkok conference to identify ideas for the Toronto conference.
- ❑ Review the Retrovirus Conference and Global Fund models on community representation
- ❑ Report what has been done in response to activist concerns

Detailed comments, organized by theme

New Freedom of Expression policy

- Craig McClure, Executive Director of the IAS, led off the meeting by describing IAS Freedom of Expression and Peaceful Protest Policy that will be in effect at all IAS-organized conferences, including the Pathogenesis and Treatment and the International AIDS Conferences. This policy is founded on the principle that all voices have a right to be heard at the IAC and that peaceful protest is a legitimate and important element of open dialogue on HIV/AIDS issues. Destruction of property and the prevention of speakers from addressing the audience during conference sessions cannot be seen as legitimate means to expressing oneself and will not be tolerated. The IAS policy and procedures for handling situations at conferences where disruptions take place in the exhibition area or during meeting sessions are posted on the IAS website and attached to these minutes.
- *There was a spirited, indeed angry, response from several participants to the policy. Comments on the policy and activism at the conference generally:*
- Sometimes disruption is the best option. There is no right or wrong way to be an activist.

- There needs to be an outcry about the world's response to AIDS. Some of the most effective sessions are when you cannot hear the speakers.
- The IAC must have tolerance and enthusiasm for action and outrage from the audience.
- We need to make sure that a fundamental critique is delivered. Protest cannot be silenced at the conference.
- At Bangkok the police presence was overwhelming; it should not be this way again -- there should be more respect for the attendees.
- There needs to be much more involvement of people living with HIV. What happened with Paisan Suwannawong (of the Thai AIDS Treatment Action Group) at the opening night ceremony in Bangkok should never happen again. (*note*: Paisan was scheduled to speak near the end of the ceremony and the Thai Prime Minister and other dignitaries walked out of the conference hall just before Paisan spoke.)
- A lot of what I hear about GIPA (Greater Involvement of People with AIDS) is just lip service.
- We have a treatment agenda. Now we need to insist on accountability.
- The international conference should be more radical than those at the country and regional levels.
- IAS should support activism at the regional conferences.

What do we want the International AIDS Conference to be? Does it have value?

- There are multiple purposes for the IAC. It brings together stakeholders in a dialogue on key issues, lessons learned, assessments, and finding common ground.
- One challenge is finding ways for different kinds of people to interact more at the conference. Many people in resource-poor settings see the conference as important, but often feel lost and that there are not enough regional forums and not enough language diversity. There should be more opportunities for networking, including dedicated space for this purpose.
- What do we want these conferences to be? Big international circuses? A place to engage policy makers? The Durban conference was successful because it was organized by community and not IAS.
- Yes it's a circus, but this also creates media coverage that has a major impact on global consciousness. We do need to develop a media strategy for the conference, however.
- The cultural programming is disturbing; we need to have a crisis perspective about the epidemic.
- Actually, many people like the cultural programs, including the Global Village. The cultural aspects are relevant to the epidemic and the response to the epidemic.
- OK, but the Global Village is too loud for holding meetings that everyone can attend. The Global Village was not a place for serious dialogue.

- The opening and closing ceremonies at Bangkok were insulting. They were just entertainment. We are there to work on HIV, and the entertainment should not control the program.
- The opening ceremony sets the tone. We should not have acrobats.
- The closing ceremony should be a “Call to Action,” an event that responds to what has happened over the week.
- The Rapporteur track is very good, but it was not prominent enough at the closing ceremony.
- The conference is simply too large and there are too many people.
- There should be no exhibit stands, no free coffee from the pharmaceutical booths.
- But these things are popular with participants.
- Commercial booths don’t fit at the conference – the Retrovirus Conference does not have them.

Promoting interaction with policy makers

- The decision makers who came to Bangkok seemed to be hermetically sealed away from delegates. The Thai Prime Minister came to last year’s conference and lied about his efforts on harm reduction.
- My favorite conference was Durban because of the activism. I felt Bangkok was about people who are working in the AIDS field.
- There should be a requirement that speakers respond to questions from others on the stage or at microphones. There is not enough interaction between plenary speakers and delegates. The *Hard Talk* interview model is good; speakers should be asked tough questions.
- Somehow we need to promote a more critical critique in the media.
- There should be more debates and more civil society representation in debates. Politicians and industry representatives will come even if they have to answer tough questions. And if they don’t it’s a statement too.
- It should be a Conference Organizing Committee (COC) policy that decision makers who speak at the conference must agree to participate in a dialogue with delegates.
- Community members should be on more panels and be able to engage in questions and answers with others on the panels. When drug companies get a spot on a panel, community providers should get one too.
- Community people should be asked to speak earlier in the programs.
- The Media Center and press conferences should be more open to conference delegates. Press conferences should be linked to a dialogue between speakers or dignitaries and delegates.
- There could be meetings where pharmaceutical representatives and activists are invited to talk with each other. We would need to find a balance between preparing and managing the dialogue, and allowing full and free exchange of ideas. Perhaps smaller meetings with activists and industry, convened by the IAS in advance of conferences, would make sense.
- There also needs to be a discussion venue for activist meetings with politicians.

- But remember that creating these forums for discussion and more inclusion of activists in conference sessions does *not* mean anyone has (or could) promise that booths won't be trashed.
- There should be space for engaging in productive dialogue, but not too big a space so as to make these sessions feel deserted.
- Too often there is cherry picking of community representatives who are invited to meetings with political and industry leaders. We need more open meetings where everyone can go.
- We want to have dialogues with senior level pharmaceutical people – people at the CEO level. We should encourage the Hank McKinnell (CEO of Pfizer) level of participation.
- Activists also need to be talking with the generics industry and companies that produce monitoring tools and other health care supplies. Issues for discussion include open licenses on drugs, access to drug registration data, and use of flexibilities in trade agreements.
- Activists should interview company representatives and they should interview us. Questions could be provided in advance then an open forum would be held. IAC would provide the space, but the meeting would belong to activists and they would shape it. Is the IAC the right forum for all this, though?

Holding policy makers accountable

- There should be “accountability for all” – everyone needs to be under a lens. Accountability should be a major theme and should be structured into all levels of the conference. Community forums can help provide critical assessments of major government and multilateral agency efforts. Report cards should be presented at the conference as they can be critical to framing the debate.
- Assessments need to happen before the conference. Sessions to discuss various topics or agencies should be announced in advance so advocates can prepare critiques and bring them to the session.
- We need to critique institutions, targets, and issues.
- It seems like no one talks about failures at the conference. The point is not to crucify agencies but to engage them.
- To critique PEPFAR: invite people from several countries to talk about implementation of the program. PEPFAR staff needs to be there as well. Have a dialogue where people can learn from each other.
- We have to discuss how the 3 by 5 treatment numbers were determined.
- The turf wars between agencies should be exposed.
- Reports should come out of sessions, small documents that suggest how we go forward.
- At Toronto look at pledges made at the Bangkok conference. Announce at Toronto that promises made there will be reviewed at the 2008 conference.
- There should be a roundtable on donor restrictions on aid, addressing issues such as interventions for IDUs, sex workers, sexual and reproductive health rights for women, gay men and men who have sex with men.

- Community and activists need spaces to revisit where we are with targets like 3 by 5; a place to assess our own failures and successes and engage in a critical dialogue.
- Daily themes could be built around key challenges in the response. These would be announced ahead of time so advocates and others would have time to prepare.
- There need to be regional discussions on the daily themes/challenges.
- There should be a more visible countdown to the conference to help people get their critiques and other materials ready.
- Perhaps there should be a daily time slot for presentations and discussions on hot topics and breaking news.
- Where are “leaders” pressured to make promises, where are they held accountable? This needs to be part of the Leadership Track (LT). Leaders are not always officials or movie stars.

Representation on IAC decision making bodies

- There needs to be more transparency about the IAS. And there needs to be more transparency about where the money from the conferences goes, and what funding community organizations receive.
- We need new leadership on the COC. Now it is like conference planning is done by an institutionalized mafia, a closed group, with no reporting back to the wider community. Only a few organizations are representing the community and they are being used.
- There should be an open application and selection process for the COC membership. The community co-chairs should rotate, but should not change all at once. See the Retrovirus Conference model on representation. The Global Fund model is that NGOs and the Global Fund call for nominations. The Committee is set up by ICW, GNP+ and ICASO. There should be a job description and criteria for co-organizers.
- Track and abstract review committee selection also should be opened up, and there should be an open nomination and selection process for all these bodies. There should be a plan or guidelines for how community representatives communicate with the broader community. These representatives should be accountable in some way.
- It is also important to ensure gender diversity on the COC. There needs to be a women’s group represented on the COC. Gender is the missing link.
- There needs to be more representation of drug users in the conference planning structure.
- Community Co-Organizers have much higher expenses than the support received from the IAS to do this work. There is no support for people on IAC committees.
- A larger stakeholder group should replace the Big Five “co-cosponsors”. There should be a multi-stakeholder advisory board to the conference including representation from government, the private sector, pharmaceutical industry, community, etc. There needs to be an open and transparent process for selecting

these stakeholders. The responsibility should be on the current co-organizers to propose a new system of representation. The stakeholders should rotate, but should serve for more than one conference in order to develop expertise.

Conference accessibility

- Craig McClure discussed the efforts of the Toronto Host Committee and the IAS to seek changes in Canadian regulations so that people living with HIV will not experience difficulties attending the conference. Craig said the Host Committee is optimistic that needed regulatory changes can be confirmed in the coming months, and that this victory can leverage change in other countries.
- IAS should be more public about the travel ban debate. Many people coming to the conference will need access to methadone and other services. The conference must be prepared to meet the needs of IDUs.
- All self-identified members of the community should have access to the conference, not just the Global Village. The global community should be more in the center of the conference.
- The registration fee is too high. It's very important to get Southern doctors and researchers to attend, and the fee is a problem for many of them.
- Groups need more access to free space to meet. There needs to be access for activism. It is a real problem if people are removed for disrupting sessions.
- Latin Americans are largely left out of the IAC because of inadequate access Spanish translation and sessions in Spanish.
- Not all the scholarship applications got a response. People who get housing scholarships should not be assigned to a hotel one hour away from the conference venue. I am concerned that the number of scholarships for the Pathogenesis conference have been cut.

Linking regional and international conferences

- There should be more collaboration with regional conferences. At the closing sessions of the regional conferences the critical issues should be summarized and sent to the IAC and visa versa. Regional conferences could help set the agenda for IACs.
- The IAS can review the big issues at the regional conferences and provide a global overview on what follow through has been achieved. There could be a roundtable presentation on key issues from the regional conferences. Program chairs from the regional conferences could be invited to join a Toronto planning committee.
- There needs to be some coordination among those reviewing abstract submissions; sometimes just keywords are changed and essentially the same abstracts are submitted to the international and regional conferences.

Anticipated topics of discussion in mid-2006

- Health care systems challenges
- Human resources development and the role of PLWHIV

- US prevention policy: abstinence only, restrictions on appropriate interventions for vulnerable groups. There will be abstinence advocates at the conference.
- Reproductive health and safe contraception methods, and US policy on these.
- Harm reduction
- Ideology vs. science
- Restrictions on funding and gag rules
- Co-infection with TB, Hepatitis C (especially in Eastern Europe)
- Traditional medicine and the need for more research and discussion on this topic
- “Denialist doctors” – we need international condemnation of their activities.
- The role of nutrition in AIDS care.

(The three bullets above are TAC priorities.)

- Scale up of prevention alongside treatment
- Clinical trials in LDCs
- Macroeconomic factors in brain drain
- Community research priorities, including research on women, liver disease
- Migrant populations in the Western world
- Doctor-patient dialogue: fostering this dialogue with doctors in a wide range of specialties, not just infectious disease specialties
- ARV access in the US (44% of people who need ARVs are not on them)
- Canadian drug policy (e.g. model harm reduction policy)
- Regulatory issues: FDA and EMEA; questioning the need for FDA approval of drugs for use in LDCs; re-importation; pharmaco-vigilance; in-country regulatory issues
- Pediatric treatment formulations
- Treatment literacy
- WHO Essential Medicines List; why is it a two year review process?; need to list tenofovir
- Drug registration: patent issues and data exclusivity
- GIPA
- Free vs. free ARV provision
- HIV testing policy (routine, opt-out policy)
- Human rights for women and violence against women
- Virginty testing (a growing movement)
- Medical marijuana
- Denial of ARVs to IDUs
- Financial support for uncompensated care providers
- IMF and World Bank policies
- Negative effects of US pressure on UNAIDS and WHO

Communications & other issues

- There should be a communications advisory group that includes advocates. There needs to be follow up on communications suggestions.
- There should be more debates, more question and answer sessions. Controversy is good.

- Don't put community speakers at the end of the program. There need to be more speakers from the community. Every session should have community representation.
- There should be activist representation on the IAS Governing Council. One can become an IAS member and be eligible for election to the Governing Council. IAS membership services need to improve. There should be a community-oriented caucus for the IAS.
- Abstract review: should be more mentoring for new people on the program committee. The reviewing system for abstracts needs to change. Oral sessions are often not well described in the catalogue – for example, do sessions provide cutting edge information or old news? The abstract review system needs to notify people of results more quickly. We need to hear more from PLWHIV.
- There should be a place to – optionally – mark if you are a PLWHIV.
- How do we bring neglected issues and recommendations forward? Rapporteur reviews could identify these. There could be discussions on the website.
- [Note: Gracia Violeta Ross was invited to the consultation but was not able to attend. She sent an email outlining a variety of suggestions, including: translate the minutes and more IAS documents into Spanish; make the Conferences much more accessible to Spanish speakers; broaden Latino participation in the Conference; increase the number of people who are working at the grassroots levels who are able to attend the Conference; promote more contact between abstract reviewers and submitters; set regional agendas for action at regional conferences; address immigration issues, including the difficulty of getting visas to travel to Canada; make accountability (including for the Global Fund) a major Conference theme; on anticipated topics for 2006, include AIDS financing, the effectiveness of Global Fund projects, and inclusion of youth in the prevention response; ask what the collective agenda of conferees is; lower registration fees; hold the next conference in South America; demand Spanish translation; under hot topics include sexual and reproductive rights for HIV positive people, specifically women; and, create more spaces for community inputs.]

The Future Directions project

- There should be a way to report what has been done in response to activist issues with the conference. Highlight what has been built into the conference to encourage activist involvement.
- Hold a meeting that involves people from all the Future Directions consultations, at which the combined input of all the consultations is discussed. Hold another consultation with activists at the Rio conference in July. IAC Community Co-Organizers should hold more consultations for the Future Directions project.
- We would like to see the minutes of all the consultations.
- The Rapporteur sessions at Bangkok should be used to inform conference planning for Toronto.