

Consultation with Large NGOs

International AIDS Conference Future Directions Project

17 March, 2005
Geneva, Switzerland

Summary

Fourteen representatives from large non-governmental organizations involved in the response to AIDS 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 Steps

- ❑ Distribute minutes of the consultations
- ❑ Arrange an opportunity for representatives of various stakeholder groups to be consulted jointly
- ❑ Involve NGOs in nominating people for conference planning committees; have NGOs provide regular input to conference planning
- ❑ Review literature on knowledge transfer

General comments about the International AIDS Conference (IAC)

- The conference should meet the needs of both novices in the field and conference junkies. It is important to be clear ahead of time about the image of the IAC we want to project; this will, to a large degree, determine who comes.
- There needs to be more voices of young people and more representation from international NGOs, not just those organizations working in AIDS.

Promoting greater dialogue and engagement

- Use different methodologies to promote dialogue. The “Open Space” format is one approach.
- Promoting dialogue could be an NGO responsibility with support from IAS.
- The IAC presents opportunities for people to engage on a particular project, for example the *Code of Good Practice for NGOs*. Those of us working on this project came with a draft document and particular issues to explore; we had panel discussions and open forums, and it worked very well.
- The daily conference newsletter is a good place for knowledge transfer. We should do more to summarize key points from the day and make them readily accessible to conference delegates.

- Find more ways to meaningfully link people working on prevention, treatment and research. Make the conference a place to identify synergies between these fields. Consider a mentoring program for new and old delegates to team up.

Involving less developed countries (LDCs)

- It is critical that we hear more voices of people from the South. The cost of satellites is an issue, particularly when we want to encourage more developing country involvement. More scholarships are needed.
- We need to ask people in LDCs what they need in order to participate.
- Have an IT hub in various places in several regions and beam in regional voices during the conference. Hold more conferences in the South.

Facilitating Scale Up

- We need to hear more from people who are on the ground providing services.
- Literature on knowledge transfer should be reviewed to inform conference planning.
- It is important to think about having more translation tools and “whisper translation”.

Expanding the presence and quality of science at the IAC

- Set a higher bar for quality in considering science abstracts. We need more rigor in the scientific presentations, whether or not they are “hard” or “soft” science.
- There should be more discussion of key scientific challenges including choosing diagnostics and development of better, more affordable diagnostics.

Day “themes”

- Having themes for each day will make it easier to digest information and make sense of all the discussions and inputs. This is true for the media as well as for conference delegates. There needs to be an open, transparent way of choosing themes.

Meeting the needs of providers

- Health professionals are organized in many places but lack resources to get their message across. Many are not doing work that fits neatly into an abstract, but they still have important information to share.
- Skills building sessions need to bring real practitioners in to educate others. There should be an attempt to sustain contact between people with skills to share and those who attend skills building sessions.
- There needs to be a place to debate health guidelines.

- IAS has a role in preparing and sustaining the workforce that responds to the epidemic. IAS members can do more sharing of information and helping with capacity development in LDCs.

Promoting accountability

- The IAC is, in effect, a policy intervention. It is a major opportunity to assess the field.
- The conference should make accountability more of a focus. What has happened on all the promises made at Bangkok?
- Present scorecards. We already have accountability measures that are not enforced; should we introduce more at the IAC? There needs to be greater attention to sessions and policy dialogues that examine government responses to existing commitments and mechanisms for accountability, including the Millennium Development Goals and UNGASS.
- NGOs have a major role to play in making accountability more of a theme.
- Do more to link people with policy makers and promote serious policy dialogues.

Conference structure

- There should be shorter presentations at sessions and more debates in general.
- Need for more non-abstract driven sessions. The most successful panels and debates will require advance work and collaboration with a coalition of groups.
- The Global Village was great, partly because it was new. It's important to take risks like that. The opening and closing sessions at Bangkok were problematic, including on the question of who was represented at those sessions.
- Plenaries are a good place to introduce innovations. In choosing plenary speakers ask what kinds of presentations will really make a difference. Plenaries should provide multiple perspectives, including Southern perspectives.
- After plenaries there should be a place to discuss the ideas presented. At past conferences people in prominent positions have been protected from delegates. Speakers should have to spend more time at the conference and have an open dialogue with delegates and the media. This sometimes happened in the Global Village, but it should also happen in a more high profile venue.
- Speakers need exposure, so they should be willing to put up with a requirement to engage in a dialogue.
- Skills building sessions should be more intentionally designed and driven less by who happens to submit abstracts. Skills building is not just about presentations, it's about building the capacity of those attending.
- More reviewers of skills building session proposals should be from the South.
- There should be an audit of skills that are needed at this point in the response. Some skills building sessions are more appropriate for regional conferences.
- Think about training the trainers: making sure skills building presenters have some guidance. NGOs have a big role to play here too.
- Skills building sessions will probably not work on webcasts.

- The Leadership Program (LP) needs to be restructured. It could be a venue for ongoing dialogue.
- Revisit the LP statements from Bangkok and report on what the follow up has been. How can we make it about doing things rather than just promising things?
- The LP is a place to test new ideas. Activists should have a major role in framing the program.
- Have interviews like those on the TV show *Hard Talk* where policy makers get asked tough questions.
- Do a better job of directing journalists and helping them identify what the story is.
- Make press conferences more public and encourage more informed, and tough, questions. Simulcast the press conferences.
- The IAC is a chance for internal networking within international organizations, but our NGO found it challenging to locate a room where we could have a discussion. There should be more availability of small spaces that people could sign up for in advance.
- Hold the conference every three years rather than two; the conferences are better when there is something new to report.

Conference attendance, planning, and organization

- One criterion for considering scholarship awards should be willingness to be part of the reporting team or do something else at the conference.
- Make it optional on the registration form to contribute \$50 to a scholarship fund. Add a question on the form about the delegate's professional affiliation.
- There needs to be a multi-stakeholder advisory committee to plan the conference.
- Encourage conference planners to communicate with a variety of stakeholders.
- Revisit membership of permanent co-organizers on the Conference Organizing Committee (COC). Rotate membership of community groups on the COC. It seems like the same people are at the table year in and year out.
- Have a multi-stakeholder discussion with a few people from each of the Future Directions consultations to discuss areas of disagreement.
- NGOs need to think carefully about who from their organizations should go to the conference; who can get the most out of it.

Expected major topics of discussion during the Toronto conference

- UNGASS evaluation results
- Testing, both testing capacity and routine vs. voluntary testing
- Prevention integration into treatment scale up
- Disappointment over the outcome of the 3 by 5 goal.
- Pediatric treatments
- Health systems. We should define areas of discussion now. Survival will be a theme. Global donors should be at IAC to discuss health systems. Health care

workers should be a major target for ARV delivery. Front line health care workers should be more visible. There is an IAS role in looking at health systems issues.

- Local reporting on successes and challenges in service delivery. There should be country level reports on health systems and HIV services. Someone needs to compile and present this information. (ICASO has done this in the context of the implementation of the UNGASS targets).
- Donor fatigue
- AIDS exceptionalism
- Increased scrutiny of the Global Fund
- Financing issues
- US government policy: needle exchange, abstinence-only, and reproductive health
- Community care systems
- Vulnerability reduction: expanded prevention messages, legal reforms, stigma, human rights, and the impact of the social climate
- Human Rights: PLWHIV, women, prisoners
- Funding for advocacy capacity
- Home based care: imminent health systems collapse and resulting increase of pressure on home based care; need for more resources; strategies to support women home care providers
- Orphans: care needs, the burden on families
- Geopolitical impact of the epidemic: security, science, economics
- Integration of HIV and sexual and reproductive health
- Generics policy: India's new trade law, Canada's generics policy, WHO report on intellectual property due in May 2006
- Immigration
- Building a social movement for prevention. Linking prevention and care, and avoiding the polarization of these two
- PEPFAR: have representatives from the US and another national program debate each other. Also include a recipient country point of view (like Mozambique). Feature clients of different care and prevention approaches. Report evidence from PEPFAR countries.
- New prevention technologies: new research results may be available on microbicides, vaccines, tenofovir as Pre-Exposure Prophylaxis, circumcision. We will also be discussing the ethics of clinical research; financing for research; involvement of the private sector; global access to new technologies; and community preparedness.
- Prevention for positives
- Millennium Development Goals: tie together HIV and development, poverty, and food security.
- More Western Europe and North America issues: increasing HIV incidence, migration, homelessness, ART cutbacks, African-Americans, lessons of ART expansion in rich countries. Connection of immigration issues and human rights.
- Less interest in discussing the Three Ones

Faith based organizations (FBOs)

- FBO representatives strongly suggested that the term “NGO” does not apply to some FBOs.
- FBOs need space at the conference, representation among plenary speakers.
- We should hear from people who are working for change within the FBO movement (and within other movements).
- Need to see more HIV positive religious leaders.
- Many evangelicals are planning to come to the Toronto conference.

Major hopes for Toronto

- A conference where the community grapples with the key challenges in prevention and treatment scale up.
- Greater participation of developing countries.
- Donors increase investment in the scholarship program
- Reduced fees, more scholarships
- A place where people from the South can confront politicians
- Drug companies must assist 10 NGOs in having fabulous booths
- Focus on poor women and on home based care
- Prevention is given the same priority as access to care. The links between treatment and prevention are highlighted.
- There are fewer didactic presentations
- There are safe spaces for “managed confrontation”.
- More open and transparent conference planning
- More support for young people, including youth living with HIV, to participate
- More community engagement with policy makers
- More women as chairs and co-chairs of sessions
- Greater focus on women’s rights
- No pharmaceutical booths.
- Discussions on making generics available.