Track G: Advocacy and Policy

Description, analysis and lessons learned in
HIV/AIDS-related advocacy and policy

XIVth International AIDS Conference
Barcelona
7-12 July 2002

Track G Rapporteur team

- Ralf Jurgens (Canada)
- Marie Medene (Cameroon)
- Oswaldo Rada (Colombia)
- Richard Stern (Costa Rica)
- Helen Watchirs (Australia)
- Loretta Wong (Hong Kong)

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Knowledge and
Commitment
for Action
AIDS 2002
Barcelona
XIV INTERNATIONAL AIDS CONFERENCE
JULY 7-12 2002

"We have to ask ourselves, what are we going to achieve in the next seven days? Are the resources required to bring us here worth it? This is a brutal question to ask, but one that we have to ask ourselves constantly.

"Do we have sufficient outrage, anger, will to plan strategies, campaigns? We stand on the brink of hope, but careful thinking, strategic alliances are required. We are responsible. There is a great deal to be done…"

-- Justice Edwin Cameron
5 July 2002 at¨"Putting Third First" satellite


8,500
AIDS
DEATHS
DAILY

"I am here to speak to you today because of this treatment… I have no watch, but I haven´t missed one dose. Somebody with AIDS who is very sick makes everybody afraid because you see death in his eyes…. Today, I am back in my field, back in my church. I can feed my family. I feel I have a future. My neighbours started coming to see me again. I myself have changed…

…Treatment is the best tool against stigma. I used to think that there was no hope for those of us living with HIV, but treatment has changed this."

-Fred Minandi,
Malawian farmer on ARVs imported from India by MSF
"Time to Treat" Satellite, 7 July 2002

Advocacy for effective HIV/AIDS policies

Strategies and themes for successful advocacy efforts presented in Track G

To achieve policy aims, advocates must utilize multi-pronged approaches

Throughout conference sessions, multiple successful advocacy approaches were highlighted, including:

parliamentary, community organizing, use of courts, policy research and analysis, media, capacity-building, protests, leadership training

These strategies were often most successful when utilized in combination

To achieve policy aims, advocates must utilize multi-pronged approaches

- As just one example, sessions at the conference dealing with expanding drug access analysed approaches of negotiated price reductions, company donations, patent law, international trade agreements, and generic production

- Each of these approaches was deemed relevant in different situations

Use of law and legal framework

- In examples ranging from South Africa´s treatment access court victory to efforts to use the law to combat stigma in Nigeria, studies and case examples from around the world showed the extensive ways in which law and a legal framework is used as a tool for achieving important policy ends.

Law and legal framework

- In other studies, rather than being a positive factor, the law became a barrier to effective HIV/AIDS policies, including examples such as impact of drug laws on HIV spread among IDUs (Argentina, Russia, USA), and sex workers (India, South Africa)

Human rights approach

- In examples from around the world (Ethiopia, Ukraine, Brasil, Australia, Canada, and numerous others) the use of a human rights framework provides an effective advocacy approach for advancing successful care, treatment, prevention, and research programs

Human rights approach

- International standards agreements such as ILO Code, UNGASS provide new examples of widely adopted standards for protecting human rights
- Case studies from every region of world showed that formal adoption does not guarantee real implementation

Meaningful involvement of people living with HIV/AIDS

- Impacts creation of public policy and national legislation.
- Seen in sessions and posters highlighting this impact from Chile, Ukraine, Thailand, Indonesia, United States, Honduras, and Kenya (among numerous other sites in developed and developing countries)

Meaningful involvement of people living with HIV/AIDS

- In four country study (Burkina Faso, Ecuador, India and Zambia), important documentation of "the positive and negative effects of PLHA involvement in community-based programs", including:

Positive & negative effects on:

- the quality of life of individual PLHA involved
- the services, policies & functioning of NGOs

Meaningful involvement of people living with HIV/AIDS

- Requires commitment to building human and community capacity
- Recognises and rewards the value of work done by PLWH
- Is a on-going commitment and process, not merely checking a box
- Must move beyond "easy" involvement to include the most marginalized and hardest to reach

Resource mobilisation

- Studies demonstrated wide variations in national commitment to spending for domestic and global AIDS epidemic (in developed world) and for health spending in developing and middle income countries

Resource mobilisation

- Challenges of conducting studies of cost/benefit analysis and reliably estimating the costs of needed activities, create a major barrier to effective policy advocacy for enhanced resources
- Investment in NGO and service provider capacity must be made as part of any scale-up model
- Ethical and human rights perspective must be considered when making economic calculations

Development and use of standardized policy tools and measurements can be effective advocacy tools

- Practical tools such as an HIV human rights audit (NSW, Australia), rapid assessment of drug and harm reduction policies (eastern Europe and former Soviet Union) provide essential information for policy analysis and advocacy

- Such tools must be flexible to be adapted to local needs

Policy viewpoints

Key policy issues emerging from Track G

In Barcelona, some things became defined as "consensus"

- Repeated often enough in oral sessions, plenaries, policy speeches, hallway gossip and and media coverage, they become accepted as our internal "party line," the shared view of the entire AIDS community – whether we all agree with them or not

The Bacelona "Consensus"

- Goal of 3,000,000 people in developing countries receiving ARVs within 3 years

Which 3 million? Where? Who will decide? Who will be left behind? If 3 million is possible, why not 6, 9, 12, 24 million? How does 3 million relate to the number of people who NEED ARVs.

While stated by AIDS "senior statemen" as an ambitious and measurable goal, it is unclear why 3 million is the magical number, or who decided that it is a sufficient, adequate, or achievable goal. Did anyone ask those who will not receive treatment if they if they accepted this goal as "consensus."

Barcelona "consensus" (cont´d)

- Declaration that the "prevention vs. care" debate is over

(Yet while the "debate" may be over in the minds of the opinion leaders present at this conference, the perceived choice between them will continue to fought out in funding decisions from the GFATM, donor countries and institutions, and national and local health decisions makers.)

Barcelona "consensus" (cont´d)

- That is key issue is no longer what to do, but rather about securing the resources and mustering the will to scale up models which we already know work

- While scaling up is an urgent and central requirement, there is still much to learn about the best ways to deliver prevention and care, in both the developed and developing worlds

Barcelona "consensus" (continued)

- Heightened recognition that marginalisation and stigma continue to define and shape epidemic

(including increased focus on human rights approach, including renewed priority placed on travel and immigration issues)

Barcelona "consensus" (cont´d)

- The fight against HIV/AIDS is, more than ever before, being fought on a ***political*** plane .

We have collectively realised that the best science in the world is of marginal relevance without the political will to fund and implement.

Yet is remains unclear if scientists, doctors, PLWHAs, NGOs, service providers, and other relevant players are truly willing to take the risks associated with entering the political arena.

It may be safe to give advocacy speeches and blow whistles among like-minded people at an AIDS conference, but how many are willing to do they same when it could mean loss of government funding, loss of access to decision makers, unemployment, social isolation, personal experience of discrimination and stigma?

Justice will come when those who are not injured are as indignant as those who are.

- Thucydides