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XIV Conferencia Internacional sobre el SIDA. Barcelona, 7-12 de Julio 2002

Advocacy and Policy

Terje Anderson[1]
Ralf Jurgens[2]
Marie Medene[3]
Oswaldo Rada[4]
Richard Stern[5]
Helen Watchirs[6]
Loretta Wong[7]

[1]Executive Director. National Association of People with AIDS. EE.UU.
[2]Canadá
[3]Cameroon
[4]Colombia
[5]Costa Rica
[6]Australia
[7]Hong Kong

Correspondencia:
Terje Anderson
E-mail:
tanderson@napwa.org

Good morning. It is my honor today to report to you on the discussions and activities of Track G, Advocacy and Policy, at the XIV International AIDS Conference 2002.

Before I proceed, I would like to thank the hardworking members of the Track rapporteur team, whose names you see on the screen, the track co-chairs, and the staff and Board members of the National Association of People with AIDS and the Global Network of People living with HIV/AIDS, who made it possible for me to take on this task by graciously filling in and releasing me from other responsibilities.

I would also like to extend sincere thanks to the participants and presenters and those whose work and lives were studied and researched and shared at this conference. And I apologise that no ten minute presentation can do justice to the knowledge and ideas they shared with us.

If the theme of this conference is the turning knowledge and commitment into action, it is within the advocacy and policy track that many of the most critical issues of how we will do that were made clear.

Advocacy and policy has been front and centre at this conference… From Dr. Piot´s opening speech which set the tone by voicing the fierce impatience shared by so many conference participants… to the many direct acts by conference participants challenging those with political or economic power… the conference has been an advocacy conference, a political conference.

Indeed it is difficult to restrict any discussion of what we have learned about policy and advocacy at this conference to what happened in the Track G conference sessions, when in fact so much of this conference was, in and of itself, an example of advocacy and policy work in action.

I stand before you as a person living with HIV, as a former injection drug user, as a former sex worker, and as a gay man.

I also stand before you fully aware that I am alive today largely because I had the good fortune to have been born a white man in North America.

While I share much with my infected comrades, my fellow HIV+ friends around the world, I do not, and neither can this conference, pretend to speak for those who cannot be here.

> *"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

> *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

Millions of people who will never be able to join us at an International conference, yet whose lives depend on the success of our discussions being turned into reality.

While sessions throughout this conference highlighted that disparity, it is vital that we remember that those voices have largely been unheard at this conference, that those of us with travel budgets, with education, with access, have presumed to speak for them. We must find a way in future conference to bring those voices into more meaningful presence.

Advocacy for effective HIV/AIDS policies

- Strategies and themes for successful advocacy efforts presented in Track G

This conference has seen a clear consensus develop across all disciplines and backgrounds, from all parts of the world-a sense of urgency for effective action and a clear frustration between knowledge of what is possible and what is happening now…

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

We learned much in track G about the critical issues of the role of advocacy and policy making in addressing that issues.

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

We consistently saw that, in order successfully pursue policy aims, advocacy must be multi-pronged and flexible, that a variety of approaches are essential for success.

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.

This was illustrated, for example, in series discussion of approaches to overcoming drug prices, where negotiated price reductions, company donations, patent law, international trade agreements, and generic production were all explored and viewed as relevant in different situations.

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).

We saw that, around the world, advocates are successfully using law and establishing a legal framework to response effectively to HIV/AIDS. Perhaps no where was this more visible than in the widely discussed recent South African court decision on drug access.

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.

Yet, it also became clear that bad laws can be a barrier to effective HIV policies, including the detrimental effect on prevention efforts presented by punitive laws.

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.

The AIDS movement has become adept operating within a human rights framework, and using that framework to advance access to treatment, prevention, and ethical research standards. Yet that framework is far from universal.

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)

And the human rights approach continues to be codified in international and professional standards in areas such as the ILO workplace code - but example consistently showed that adoption of these standards is not a guarantee of real implementation.

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.

We heard more at this conference than ever before about the critical role that those of us living with HIV play in the fight. We saw clear examples of PWA leadership in creation of policy and legislation.

Yet we also saw valuable work that demonstrated that involvement raises challenges and opportunities both for PWAs and the institutions with which we are involved.

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.

We also learned that in order to be real, the meaningful involvement of people living with HIV/AIDS requires real action and commitment, not just ideological lip service.

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

Much of this conference focused on the important question of mobilizing sufficient resources for mounting an effective response, and we learned much about which countries were shouldering their fair share of the burden.

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.

Yet many questions remain unanswered about the degree of investment and the complex question of cost-benefit analysis, questions that will need to be answered if we are to be successful in marshalling resources.

Policy viewpoints

Key policy issues emerging from Track G.

We also saw the increasing emergence of specific advocacy assessment and measuring tools that help advocates and policy makers make good policy choices.

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.

Here in Barcelona, we would argue that some positions became defined as some kind of "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.

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For example, the mantra of 3 million people in the South receiving ARVs within 3 yearshas been so widely repeated that it has become viewed as a goal for many. Yet there are many questions - 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? 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).

We heard repeatedly that the debate over prevention vs. care is over-yet we all know, and heard continuing in various sessions about resource allocation decisions, that debate is, in many ways, just beginning in terms of implementation.

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.

We have repeated said at this conference that the key issue is one of scaling up, and I certainly share in that consensus. Yet it ignores the reality that, in many parts of the developing and developed world, we are still trying to learn the best way to deliver care and prevention services.

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).

And without question, we found here in the sessions and speeches a stronger awareness than ever before that marginalization and stigma continue to shape and define this epidemic. Yet for all the increased discussion of issues such as the human right to travel freely, it is unclear that any of us will have the means to change the most egregious policies that we protest.

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?

Finally, this conference clearly showed that, more than ever before, this fight is being fought, and must be fought, on a political plane. That it requires engaged political leadership and that it is our responsibility to engage that leadership when they don't seem to be paying attention the way they must. 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

What we do while here in the safe "bubble" of an AIDS conference may bear little resemblance to what happens when we leave. We will have the courage and perserverance to really "turn knowledge and commitment into action", it will it become business as usual for another two years? Can those whose voices are not here really count on us to make good on our promises, or will millions die because of our inability to take action?

I want to end by recalling a quotation that Helen Gayle used in one of her plenary presentations earlier in the week: Justice will come when those who are not injured are as indignant as those who are. As we leave Barcelona, we must leave more indignant, more angry, more impatient and more ready to act than when we arrived. Only if we do that can this conference meet the test that Judge Cameron laid out at the beginning of the week.