

Rapporteur report

Track G – Advocacy and Policy

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.

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.

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...

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

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.

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.

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.

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.

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.

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

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

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

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

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.

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

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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 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.

For example, the mantra of 3 million people in the South receiving ARVs within 3 years has 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.”

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 that debate is, in many ways, just beginning in terms of implementation.

We have repeated said at this conference that the key issue is one of scaling up, and I certainly share in that 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.

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.

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 it 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 the same when it could mean loss of government funding, loss of access to decision makers, unemployment, social isolation, personal experience of discrimination and stigma?

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 perseverance 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,
