

**HIV/AIDS and Communication Issues and solutions:
Grounding the debate**

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Good morning ladies and gentlemen. First, I want to reassure you that I have no intention of repeating what has already been said. Second, I would like to thank the organizers of this roundtable, for the opportunity to address this meeting. Thirdly, I hope you can allow me to briefly tell you about the work of the African HIV Policy Network.

It is a unique organization in many ways, but more so as a voice for Sub-Saharan African communities in the UK. One of its most notable achievements to date is the degree to which it has succeeded in mobilizing Africans in the UK in response to the HIV epidemic. Many issues that affect Africans in the UK are the same as those that affect Africans on the continent. Through the organization's innovative structure of bringing together community-based organizations and people working with African communities – under a total of 12 African Forums throughout the UK, African communities are provided with a clear mechanism through which they can be engaged and consulted by the department of health and other government departments on HIV and sexual health issues.

The organization which is now six years old, is beginning to link up with other organizations in different African countries.

On a more personal level, I have written extensively about HIV, an issue that I personally know a great deal about. I have been living with HIV for the last 14 years. Since my diagnosis, I have lived in North America, in Africa (specifically in Uganda) and I currently reside in the United Kingdom. Having the opportunity to live and or travel to the North and South has provided me with experiences that hopefully put me in a good position to talk about some of the communication issues in the area of HIV/AIDS.

I feel a need to express my frustration about the kinds of questions we are still asking ourselves, 20 years into the HIV epidemic! Why are there more people infected with HIV around the world more than ever before? What is going wrong? Why is prejudice and stigma such a big problem? What is wrong with the messages being communicated to people about HIV? How come most people living with HIV do not have access to care and treatment? Why are resources still hard to come by to help solve a problem that the whole world desperately needs answers to? I am sure I'm not the only one who wonders why HIV continues its relentless assault despite the different

efforts made to stop its progress.

I would like to reflect a bit on my experiences. In the few years that I have been writing and talking about living with HIV and on issues related to HIV in general, I have encountered mixed responses. I would like to share a few quotes;

- **‘thanks for writing in a way that we can understand; in simple English’**
- **‘reading about your experiences gave me courage to get through some of the of the issues I was facing. Now I know I am not alone.’**
- **‘I look forward to your article each month’**

We cannot underestimate the importance of information in clear language that directly relates to people’s experiences and lives, and the difficulty we still have in breaking through people’s emotional barriers. Many people are very much intellectually aware that the virus exists and caught through sex, but we haven’t been successful particularly with men, in getting to translate that knowledge into action. That is because we are not addressing the emotional and cultural issues that account for their behaviour. I have to confess I have not fully been involved in the debate that forms the background to this meeting and therefore not familiar with the thinking behind it. My primary concern is not so much how the cake is made but

what it tastes like, and right now it doesn't taste very good.

I have also given many presentations about my experiences of living with HIV. I would like to again share a few more quotes;

- **'listening to somebody living with HIV talk about their experiences made more of a difference than any other HIV message I have ever heard'**
- **'If you are brave enough to stand before us and talk about being HIV positive yet you still look healthy, I think I am strong enough to go and take an HIV test.'**

Some of these responses emphasize the importance of the role of HIV positive people in the fight against AIDS. People living with HIV give a human face to the virus instead of theorizing about it. People do not seem to relate to statistics any longer, but can relate to others. However, HIV positive people need to be empowered with skills and get paid for the work they do.

In Uganda for instance, openly positive people have been helpful and very influential in turning the tide of the HIV epidemic. However, in the last couple of years many have been snapped up by NGOs in the North, leaving the communities where they were much needed. It would make more sense

to encourage and empower these ‘PWAs’ to remain in the communities where they are much needed and more likely to have a significant impact. But because for some, leaving their countries involves a better quality of life including HIV medication, the decision to leave is easy. And that brings me to the treatment issue! The argument in the past has been that there is no infrastructure in the developing countries, not to mention the exorbitant price of antiretrovirals. Though the price of antiretrovirals has been significantly reduced, the drugs are still unaffordable by many. We can no longer wait to have all the infrastructure in place while people are dying. Personally, I live with the guilt of having access to combination therapy while many people I know wither away and die because they just can’t afford the medication. I am aware that the treatment issue is not the primary concern of this meeting, but we have to be mindful of unexpressed messages. One of those messages is that for people in Africa there is virtually no access to treatment. So there is a sense of hopelessness! A sense of why should I care attitude. So while we are theorizing about communication issues here today, it’s quite necessary to think about practical solutions.

Thanks for listening.

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