

Speech

How to reduce the stigma of AIDS

Keynote address

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I am very pleased to be invited to this meeting and to see so many people concerned about stigma, discrimination and gender inequality in the HIV epidemic. UNAIDS considers these issues of the highest priority in the response to HIV.

Since the beginning of the epidemic, stigma, discrimination and gender inequality have been identified as major causes of personal suffering, and as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them. All these efforts have been relegated to the bottom of AIDS programmes, together with human rights, and often with no funding attached to them. I am talking about stigma and discrimination broadly: that aimed against people living with HIV, women, poor people, drug users, sex workers, men having sex with men, prisoners, migrants and refugees.

In fact, there seems to be denial, and even stigma, against stigma and gender inequality! And just as it has been difficult to overcome denial of HIV, so it is difficult to overcome denial of stigma, discrimination and gender inequality. But in the last five year, there have been important developments that show progress in this regard, and if we do not capitalize on these now, we may not get further opportunities.

First, we now have frameworks of political commitment and accountability – the 2001 Declaration of Commitment on HIV/AIDS and the 2006 Political Declaration on HIV/AIDS. In both of these documents, governments commit themselves to take action to address stigma, discrimination and gender inequality. In the Political Declaration of this year, governments “recognized that addressing stigma and discrimination is...a critical element in combating the global HIV/AIDS pandemic”. They agreed to “increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection”; and they “pledged to eliminate gender inequalities, gender-based abuse and violence” and “develop strategies to combat stigma and social exclusion connected with the epidemic.” They did this largely because stigma, discrimination and gender inequality were overwhelmingly cited as major barriers to universal access in the country and regional consultations leading up to the High Level Meeting. But let me point out that despite this progress, the grip of stigma and discrimination is still so powerful that some communities could not be named in the Political Declaration, namely injecting drug users, men having sex with men, and sex workers.

Secondly, we now have the results from important research that confirms the prevalence of stigma, discrimination and its impact, particularly on women. Much of this work has been done by people in this room. However, the findings of this research have not been widely disseminated, and funding for further research is hard to come by. But I feel strongly that we need to do better in terms of down to earth, very practical actions that counter stigma, discrimination and gender inequalities. Much of what is proposed is still general or academic.

Thirdly, we now have important tools both to measure stigma and to overcome it. We have the excellent toolkit of the International Centre for Research on Women (ICRW), the work of networks of people living with HIV, and the work of the Policy Project, Synergy and the Futures Group – to name but a few.

And finally, we have indications of increased interest from various important players. One major donor is conducting a study of how their assistance does or does not sufficiently support anti-stigma interventions. I see here that the Elton John AIDS Foundation has provided significant support to this symposium. In June, the Programme Coordinating Board which is the governing board of UNAIDS called for gender assessments of 3-5 national AIDS programmes and development of guidance for gender action at national level. The Secretary-General and myself recently met with pharma companies to discuss how they can

continue to increase their involvement in the response, and I welcome the support and interest of GlaxoSmithKline here today. We are also working closely with the Office of the High Commissioner for Human Rights to help integrate the issue of HIV stigma and discrimination into the work of national human rights institutions, the UN human rights treaty bodies and special procedures, and this work benefits from the personal interest of the High Commissioner herself.

In the drive toward universal access and because it is a good in itself, UNAIDS is advocating that governments and donors:

- Make the reduction of stigma, discrimination and gender inequalities explicit programmatic priorities.
- Devote political and programmatic efforts and resources to significantly scale up the reduction of stigma, discrimination and gender inequality.
- Rapidly conduct operational research on stigma and discrimination and how to reduce it and feed the findings without delay into national programmes.

In particular, UNAIDS supports:

- Concerted national and community campaigns against stigma and discrimination and harmful gender norms.
- Inclusion of indicators in monitoring and evaluation efforts that will capture stigma, discrimination and gender inequality as well as efforts to overcome them, and
- Creation of legal support services for those who have experienced stigma and discrimination, and law reform, where necessary.

In my speech at the opening ceremony tomorrow I will stress that we must invest far more in tackling the drivers of this epidemic, and that includes stigma, discrimination, and gender inequalities. Without such action for social change, a long-term sustainable response is just a pipe dream.

But major barriers remain. In spite of the existence of tools to measure and overcome HIV stigma and discrimination, they are not widely known, implementers are not always comfortable with them or do not have faith in them, and they have not been widely taken up in national AIDS responses or in national AIDS monitoring and evaluation systems.

And though efforts toward universal access represent a great opportunity, they also represent risks. For many, universal access means “medicalising” the response, that is, provide more HIV prevention, treatment and care services and ‘voilà’ mission accomplished. And we have not done a good job in proposing practical and realistic interventions on stigma, discrimination and gender inequalities. So we need more evidence on crucial questions, such as:

- Does increased knowledge of HIV status through expansion of HIV testing *really* “normalize” HIV and what does that mean?
- Does increased access to treatment automatically decrease stigma and discrimination as many assume?
- *Exactly* how does stigma, discrimination and gender inequality block people from taking up prevention, care and treatment?
- Do interventions to reduce stigma, discrimination and gender inequality improve both quality of life for individuals and the effectiveness of AIDS responses?
- How best to overcome the *multilayered* nature of stigma and discrimination?

Furthermore, we need more concrete examples of what works. Recently the UNAIDS *Protocol for the Identification of Discrimination against People Living with HIV* was adapted and used in Spain to measure stigma and discrimination there. The work brought together a range of academics, experts, activists, people living with HIV, and government officials; and documented HIV discrimination in health, employment, prisons, reproductive

and family life. Its purpose was to help the National AIDS Programme expand its work to eliminate discrimination. Such an effort is a good example of political will and empirical study coming together for expanded action on stigma and discrimination. This model -- research for action, with broad participation at every step, and very importantly, government participation -- is something we think can be useful in other countries.

In the next few months, global and national networks of people living with HIV, supported by the International Planned Parenthood Federation and UNAIDS, will be field testing an index on stigma and discrimination developed by and for people living with HIV. It is intended to fit into the ongoing work of many of you here, and we plan to use this exercise to educate our own Monitoring and Evaluation officers on this important issue. We feel such an effort is very important because ultimately it has been the demands and activism of those affected by HIV, in fact their human rights demands, which have resulted in major gains in the response - for access to treatment, for greater participation, and more lately, for real access to prevention. If those affected by stigma and discrimination become empowered to demand for their end, then change will really begin to happen.

For these reasons, we at UNAIDS are very excited by this satellite and its part in pushing the agenda, empowering people, and building on the momentum to finally do something real about stigma, discrimination and gender inequality. I wish you all the best in your work and look forward to hearing how UNAIDS can do more to support it.

Thank you.