

**2007 HIV/AIDS Implementers' Meeting:
People Living with HIV/AIDS as Expert Implementers
PEPFAR, Global Fund to Fight AIDS, Tuberculosis and Malaria,
UNAIDS, UNICEF, The World Bank, WHO, GNP+
June 16, 2007**

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[START RECORDING]

JALI [misspelled?]: Everybody, I have much pleasure in introducing the first speaker, who is Alex Margery.

Alex, currently a treatment literacy trainer for PLHIV and the chairperson of the Tanzania National Network for people with HIV/AIDS, and he has a very compelling description of the importance of literacy programs accompanying treatment for the effectiveness of treatment and of the critical role of POWA's play in that. And I'm pleased to say on a personal note, as the deputy executive director of the Global Fund, that the Tanzanian National Network for people with AIDS is funded from Global Fund money. That's just a little note from me. So without more ado, I'll introduce Alex. Thank you very much.

ALEX MARGERY: Good morning, ladies and gentlemen.
Good morning, ladies and gentlemen.

AUDIENCE: Good morning.

ALEX MARGERY: So you're quiet. Maybe it's going to get it. As I've been introduced, my name is Alex Margery, a person living with HIV/AIDS for more than 20 years, and the chairperson for Tanzania National Network of people with HIV/AIDS. That's all I do.

We should voice up when the opportunity arrives.
That's our motto on our nature of care of HIV in Tanzania.

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My presentation basically plays on the background, the objective or the approach of the outcomes and the challenges and then last, recommendations.

In Tanzania, the pandemic of HIV is second to malaria, with an estimate of people living with HIV/AIDS in Tanzania expected to be 70-percent of the total population, and the HIV/AIDS [inaudible] crisis that affects all sectors.

Although ARVs do not provide a cure and pose additional challenges due to the potential side effect and emergence of drugs resistant to HIV, we have done much proved life of mortality and morbidity and improve the quality of life. Vitalize areas and transform the perception of AIDS from that of pliety [misspelled?] to a manageable chronic illness.

The ART rollout in Tanzanian began on October 2004. The project objective, which I'm glad to share with you today, our projects' objective were to provide information to people living with HIV/AIDS in [inaudible], to provide training treatment adherence for people living with HIV/AIDS in Tanzania, to put in treatment more people living with HIV/AIDS who are eligible.

The approach that was put in place, with regard to a partnership, the Tanzania National Network of People with HIV/AIDS in collaboration with NAPWA-US in a training project

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in 2004, was funded by the Many Source Health in United States.

This was a project whereby we collaborated with the National Succession of People with HIV/AIDS United States to transfer knowledge to people living with HIV/AIDS on adherence and treatment literacy.

So in 2004, we conducted a study on effect of treatment before due to side effects and how it could be addressed. Seven private and public dispensing sites Darasalam and Muinza [misspelled?], where the study was conducted.

The study was purposely to identify the issue as base line for continue of the partner project, whereby the treatment literalist training was to follow.

Data was collected by using questionnaire to 200 respondents who are in majority. Majority who were defaulted on ARV did so because of high prevalence of side effects during the first two weeks of the initiation of the ART.

Also, they did not know what they were considering. The one main program identified was lack basic indication related to taking drugs. Neither the government, non-governmental organization, nor succession of people living with HIV/AIDS has been able to organize key for providing such information.

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In response to adherence, training is now being provided by Tanzania National Network of People with HIV/AIDS to cure HIV-eligible for antiretroviral treatment. And we had depend on fund from the foundation, specifically the type foundations and NAPWA-US through collaborative fund and through collaborating funding.

The facilitator on this project was People Living with HIV/AIDS, who have been trained by the Network of African People living with HIV/AIDS and treatment option compared in Johannesburg. At the end of 2005, people living with HIV/AIDS would be identified from the femark [misspelled?]. The femark [misspelled?] is a conceptual AIDS committee, whereby there are two representatives of people living with HIV/AIDS within the particular district, who are there for representing other people living with HIV/AIDS from their respective association within their particular district.

So we identified the two, [inaudible] in each region from the Lexon [misspelled?]. Lexon [misspelled?] comprises five regions, which was Mara [misspelled?], Mouza [misspelled?], Bokup [misspelled?], West Lake region and Shedonga [misspelled?] region.

More than 400 people living with HIV from Lexon have a still now on treatment literacy and more than 300 on at

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ONART. So people living with HIV/AIDS are effective as activist. Also, people living with HIV/AIDS provide the testimony that the major HIV site are considering.

Right now, the treatment for literacy training is ongoing in the country, whereby people living with HIV enrolled. Our 145,547 audit and 15,335 are achievement and 70,536 people are addicts and 7,416 are treatment, are in ARV treatment. This data was collected on 30th of April this year.

Our recommendation through collaborative programs and training, give an example of this we are sharing today. HIV can be key partners and service providers in the sources for treatment and care programs.

Peer-to-peer publication and provisional mature support by peer HIV improves both parties and groups for the over for preventing HIV infection.

And due to disclosure of the preservative [misspelled?] status in adherence to treatment option participants who are participated on the first training, which was done by a Tanzania National Network with collaboration with NAPWA-US.

The workshop took place at Kubaha [misspelled?] District, whereby we chose the place because we want the full participation with participants, the training was based on treatment TOT. I think that's the end of my presentation.

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DR. DAVID WILSON: You can present me, I was going to stand up quietly and -

JALI: Thank you very much, Alex, for that really interesting presentation. Just to remind you that if you want to talk further about, with any of the speakers but about this programs, that you can do that, meet the professor session following this plenary session.

It's now a great pleasure in introducing Dr. David Wilson. David's worked in the field of HIV prevention for over 20 years as a researcher and a practitioner, and he's currently the senior monitoring and evaluation specialist at the World Bank.

And I had the pleasure of hearing a very interesting presentation of his in New Delhi. And his key message is that you really need to know your particular epidemic to be able to respond to it.

There are two parts to this presentation. David will be presenting and then Dr. Apuuli from Uganda will presenting and David will introduce him. So there are two parts to this session. Thank you, David.

DR. DAVID WILSON: Thank you. Knowing our epidemics enables the money to follow the epidemics. It also helps us to transcend the ABC wars, which has largely grown from a

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failure to know our epidemics, because both are right in the right context and conversely.

This map, which sizes countries by their HIV count, underscores the diversity of the global epidemic and also the dominance of Africa and, within Africa, Southern Africa.

And this comparison of ante-natal and population-based HIV surveys shows that we have underestimated HIV. Overestimated HIV particularly in West Africa and Asia. And it also throws Africa and the global epidemic into shock or contrast.

As we see here in this map of Africa which depicts four clear epidemic sub-types from the hyper epidemics of Southern Africa to the intermediate East African, lower West African and highly concentrated North African epidemics.

In short, HIV in Africa is far more diverse than we recently believed. And we can underscore the point further by this comparison of three cities.

But I'd like to just show the human face of HIV in Southern Africa. And nothing strikes me more than this representative household door-to-door sample in Francistown, Botswana's second largest city, in which 70 percent of women aged 30-34 and 60-percent of men a decade older have HIV. These figures beg of believe [misspelled?].

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Why? Why is it so diverse and so severe in Southern Africa? I think these arguments are familiar, so I'll rehearse them briefly.

I think that acute infection in which we are far more infectious shortly after we sera-convert plays an important role. With this familiar graph showing how infectious we are after we sera-convert and Maria Waver's [misspelled?] recent Uganda study showing that half of the sera conversions in the multiyear study took place shortly after the first partner sera converted.

And we can link this to growing knowledge of behavior and evidence suggesting that concurrency may be higher within Africa. And we also have greater insights into what this really means, because what I have said is abstract and theoretical.

But look at South Africa. Look at the world's largest HIV epidemic, with some providences approaching 40 percent ante-natal prevalence. And yet 45-percent of South African's ages 15 to 19 are reporting multiple partners.

And move next door to Botswana, where in the world's joint highest epidemic with Swaziland, 44-percent of men aged 15 to 24 report concurrent partnerships, half the population in that age band.

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And I'd like to turn to an island in Lake Malawi, Lacoma [misspelled?] Island, where very careful sexual networking study gives us clues into very generalized epidemics. They found that 20-percent of the population were in mutually exclusive relationships.

But fully 66-percent were in one single network over the last three years. And these networks weren't hub and spoke networks held together by sex workers or high-frequency transmitters. They were decentralized desegregated robust complex chains.

And recent mathematical modeling by Martina Morris and her colleagues gives us an important insight. She found that just small differences in our numbers of sexual partners can create a transmission call, with a mean of 1.68 partners. Two-percent of the population was in the largest network component.

As it rises to just 1.86 mean partners, 64-percent were in the largest component. And Lacoma [misspelled?] Islands mathematically modeled.

And randomized trials have shown us the other key factor determining HIV diversity. Male circumcision, and the evidence is so well known, that I won't repeat it here.

Suffice it to say, that we have to act on this evidence and we also have to use male circumcision to better

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understand epidemic potential and diversity, because epidemics unfold differently in highly circumscribed countries.

So I'm suggesting that concurrency and the absence of male circumcision was the lethal cocktail that created Southern Africa's truly unique epidemics.

I'd like to turn to the historical distinction between concentrated and generalized epidemics, and to argue that the conventional 1-percent definition of generalized epidemics has hindered us knowing our epidemics.

And we need an alternative transmission based definition in which epidemics are concentrated if transmissions made near more vulnerable groups. And to protect invulnerable groups will protect everybody, and generalized if the converse is true.

And armed with this transmission-based definition, we can start to understand our last 1,000 infections. Why is this so important? To avoid blind spots, gaps, misconceptions and mismatches and to make the money follow the epidemic.

Look at this example of a blind spot. A very recent population based survey in Indonesia West Papua shows that HIV in Papua is higher than anywhere outside Africa and this is largely been unnoticed by the outside world.

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And turning to gaps, in 1998 HIV prevalence among sex workers in Addis reached 71-percent, whereupon we discontinued surveillance and programs for sex workers.

And misconceptions, HIV are often characterized as a young person's disease. But in Uganda, the peak ages of incidence are from 35 to 45, a pattern that's reproduced throughout much of East and West Africa.

And perhaps above all, mismatches, wasted programming. In Ghana, where HIV is 2-percent in sex, in the general population and 78-percent in sex workers, and a careful study by Cotardel [misspelled?] suggest that 76-percent of adult male infections were attributable to sex work.

We as the World Bank found that we were investing less than one percent of our program budget on 76-percent of the problem. And with those investments, even if we quadrupled or quintupled our investment we wouldn't make enough difference.

And so I'd just like to consider the diversity of transmission sources in Africa alone. And we've seen Ghana, where we have a steep gradient in infection between sex workers and the general population, and many infections arising in sex work.

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But contrast that with Zambia, where we have narrower gradient between sex worker and general population prevalence. And a careful study by Mark Shields suggests that only seven percent of Zambia's infections today were occurring among traditional vulnerable groups of sex workers, clients, truckers and uniformed services, fundamentally different epidemic.

And I worked on mapping sex workers at Swaziland's borders in a major regional project. Look at the numbers we found, very small. We concluded sex work was hidden and we continued with our programs.

But a year later, these behavioral data came out and they show us that Swazis and their Basuto cousins are having casual sex, not commercial sex.

And let's turn to Asia. And I hope 2007 is the year we finally recognize Asia's epidemics are concentrated and focus appropriately.

They're epidemics that are driven by vulnerable groups and initiated by sex or drugs. And the mathematics of Asian epidemics are extraordinarily robust.

They are initiated by sex if we have uncircumcised men, many of whom - about 10-percent - routinely visit sex workers. And sex workers have large numbers of clients, typically, about 20 a week or more. And so the first wave of

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Asian epidemics in Thailand, Cambodia and India were sexually initiated.

But elsewhere in second-wave Asian epidemics, injecting drug use has been the spark that's created sexual transmission, then sex work the motor that maintains.

And this map clearly shows that the majority of eastern Asia's epidemics are initiated by injecting drug use. And injecting drug use can fundamentally amplify epidemic potential.

But it also means that Asia's a vast land of opportunity, where effective injecting drug use programs today can radically reduce future epidemics.

And simply look at these very recent data from Vietnam from Hi Phuong, where among sex workers who don't inject drugs, HIV prevalence is 2-percent, but among those that do, it's 55-percent.

And if we dissect the figures this way, we could easily mistake a primarily injecting epidemic for a primarily sexual epidemic.

And we have to greater weight to temporal chains in epidemics. In early or unabating [misspelled?] epidemics, primary prevention. That is a behavior change among those at risk is crucial.

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But as epidemics mature and behavior change occurs, new infections occur increasingly among already infected individuals and their stable partners. And so we move from primary to secondary prevention with a far greater emphasis on testing and counseling, especially among couples.

And this is beautifully illustrated in this Thai graph, which shows in Thailand's early severe epidemic, 90-percent of infections were attributable to sex work, but as sex work intervention succeeded, today, spouse transmission is responsible for 50-percent of a far, far smaller epidemic. And we're seeing this pattern throughout mature epidemics.

Simply look at Uganda's last 175 infections, which Dr. Apuuli will elaborate upon. Sixty-five-percent were among married people and 50-percent of those were among discordant couples.

I'd like to turn to what we can learn from declining HIV trends. And it's clear that Asia's sexually initiated epidemics in Thailand, Cambodia and India have fallen. And in Thailand, condom use soared and visits to sex workers plummeted and HIV prevalence fell.

And Cambodia shows an identical pattern. Condom use soared, visits to sex workers fell and prevalence fell. And if we look at this map of six East Asian cities, we see good news. We see declines in each of them.

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But contrast this with Southern Africa, where there's so little evidence of a decline. And it's clear in Uganda, that were major reductions in numbers of partners leading to a threefold decline in HIV prevalence.

But look at that recent data from Masaka, showing that HIV prevalence and risk behavior have resurged among young Ugandans.

And turn to Kenya, where we have equally persuasive evidence of major reductions in numbers of partners, translating into an almost threefold decline in HIV prevalence.

Let's ask ourselves briefly why condoms haven't played as large a role as we all hoped they would in very generalized epidemics. I think this data from Rakay [misspelled?] is part of the answer. HIV was higher among inconsistent condom users than non-users, perhaps because other risk behaviors persisted.

And take this graph from Nigeria, which depicts almost any country in the world. And it shows us that condom use declines as we move from commercial to casual to boy or girl friend and spousal relationships.

It's extraordinarily difficult to get high rates of condom use in stable unions, which is why we see these

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remarkably low rates of condom use among women in regular relationships in the DHS'.

So does this mean we abandon condoms in generalized epidemics? Of course not. But where most transmission is in the general population, condoms contribute most in higher risk relationships and among discordant couples.

What are the major lessons for generalized epidemics? Well, we have to reduce concurrency, intergenerational sex, sexual coercion, cultures of alcohol abuse and the vulnerability of couples.

And we have to move beyond individual behavior change to create safer environments, particularly for women. Look at these data from South Africa. Twenty-percent of young South African women have a partner five or more years older than them.

And HIV incidents is sixfold higher among South Africans whose partners five years old, decisive difference.

And turn to sexual coercion. Fifteen-percent of women in Rakay [misspelled?] have a coercive sexual debut and 35 percent have ever had sexual coercion, and HIV incidents are two-fold higher among women with a coercive sexual debut.

And look these data on alcohol use and HIV incidents also from Rakay [misspelled?]. And we see that alcohol use is associated with a 40- to 80-percent increase in HIV

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incidents. And we also have to understand the psychological landscape of our epidemics.

And look at the countries that have seen HIV form. People acknowledge knowing someone with AIDS. Look at the denial belt of southern Africa, where in the highest epidemics in the world, people don't acknowledge knowing people with HIV.

So in summary, we need improved surveillance and analysis. We're not using the data we have well enough to understand our epidemics, and we have to respond more rapidly to new evidence.

Generalized epidemics need fundamental community change and safer sexual environments. But globally, they are the exception and will always remain the exception. And the good news is that we know what to do in concentrated epidemics.

We have to do a better job of understanding temporal chains and mature epidemics involve a lot of transmission in spousal relationships. We can't test our way out of this epidemic without major behavior change.

But as this happens, then testing is vital to prevent further infections among couples. We have to make sure the money follows the epidemics. Many central and West African

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epidemics are far more concentrated than we realized, but our programming has sufficiently recognized this.

And consider Abigione's [misspelled?] famous clinics du confiance [misspelled?] program. One major goal should be to have similar programs in every major city in the region.

We also have to recognize mixed epidemics that either have mixed transmission sources or geographically mixed, such as Kenya, where we have a highly generalized epidemic in Ganza [misspelled?] and more concentrated ones elsewhere.

And we also have to recognize low intensity generalized epidemics with stable general population transmission.

So in conclusion, in my final slide, as a guiding principle, in generalized epidemics we lead with partner reduction supported by testing and counseling particularly in mature epidemics.

In concentrated ones, we lead with condoms and clean needles. But many epidemics are mixed enough to need both, based on understanding of our last 1,000 infections.

We have major temporal chains. As epidemics mature, our programs move increasingly from primary to secondary prevention.

And finally and above all, let's understand our epidemics better but not over complicate. In many cases, we

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either have or we can rapidly assemble sufficient evidence
for intelligent action. Thank you.

[Applause]

DR. DAVID WILSON: It's now my pleasure to introduce
Dr. Apuuli, the general of the Uganda AIDS Council, the
former director general of the Uganda Ministry of Health and
the former director of the National Teaching Hospital.
Sorry. It's running a virus scan, which is why it's slow.
Our apologies.

DR. DAVID KIHUMURO APUULI: It is my pleasure to be
able to highlight some few aspects of prevention and how risk
continues throughout the world and understanding factors of
grave epidemics.

I'll share with you some few slides and aim of my
presentation and why I was asked to give some context
prevention and understanding the epidemic using Uganda as an
example. A lot of things that I heard Michelle say yesterday
are valid and some of them I shall repeat.

As I traveled, particularly the road of the night, I
remember the words of a friend of mine with whom we had
shared the platform in Madrid four days ago, addressing the
Spanish Parliament, parliamentarians in some European Union
parliamentarians.

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And he said, we have not inherited this world from our parents or the parents of our parents, but we have borrowed this world from our children. And I think that's why we're here.

We're here to be able to understand that despite all the efforts of the world, this virus we see, which helped transposed the mark on Uganda and that is [inaudible] electron microscope picture of what the virus looks like, if you've never seen it.

That is what is causing the problems mankind. And I put it there to show you that in fact, as we sit here, the epidemic is rampaging the whole world and we have not succeeded despite all the efforts and science. More than 60 million people infected, more than 25 dead.

But why have we failed, despite all these resources? And I'm going to share some issues with you because a lot has been said about Uganda. And that we seem to be going backwards.

You see at the bottom there near Rwanda, where the virus exploded with the vast forecasts just over two decades ago. But you can see the havoc and damage that it has done to Uganda just in this snapshot, over one million people dead.

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Today more than 1.1 million living with the virus, more than 2 million children orphaned. In 2006, there were 136,000 new infections and only about 90,000 people in [inaudible].

I put up this map of Uganda speak a lot, because that map is a list of everything in Africa and in the world. You can put that virus in Rwanda, you can put it Kenya.

I can assure you that the most important thing that I'm going to highlight today, what my colleague David says is that we need to understand our epidemic.

We need to be able to know what is driving our epidemics. And what I'm going to say, some of the people in this room may not like it. But I know a typical African culture, please those who come from Europe and America, forgive me and Asia. Because in Africa as we wait, elders are allowed say anything and get over with it. And being elderly is judged by the color of your hair.

And I'll continue talking so basically the first phase in Uganda in realization that we are the problem was massive modernization of our community by our president. The next picture is going to be the president of Uganda going through the forests of banana trees in Uganda and arguing the people that raise the problem in the community that we need

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to respond in the typical African way, so that every leader and everybody understands and takes up the challenge.

I have put a drum in the background, a typical African drum that rallies people when there is trouble. But that response in the early '90s was premised on the understanding of the epidemic at that time. That, in fact, was sexually transmitted.

At that time, we did not know much about other transmission. It was not part of the agenda in terms of the response. There were a few drugs, hardly there. And some of us as I stand here among the braves scattered in Uganda, my two brothers and one sister.

You know, when technology fails, you must use the hard disk. [Laughter] [Applause] So what kind of message in terms of prevention was premised in a, b, b meaning zero grazing at that time?

And if you that - you can do those two, use a condom. We have now adjusted the message to mean a, b, c, plus because there's provision of [inaudible] transmission, other strategies including new ones like circumcision, the question of dealing with vulnerable groups and so on and so forth.

That message helped us in the '90s and perhaps you have seen. That's showing you that, in fact, the prevalence went down from an average about 18.6 percent to about six

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percent. Yes, and Uganda was an example for all countries and we went everywhere. And everybody was being told, look at what else Uganda's been able to do.

But over the last four years, and I come to the most important part of my presentation. What did we notice, that in fact prevalence had stagnated and as David assured, there was some studies in some of the cohorts we use that incidents was starting to creep up.

So we embarked, and I think this is the most important message out of this room. We embarked on understanding why. Why was this happening? We did a comprehensive survey covering the whole of Uganda.

We followed up with a Uganda demographic health survey and questions. And what we found was surprising. And that's why it is important that PERFA, Global Fund and everybody help countries to study the epidemics and understand them in order to craft the programs.

[Applause]

DR. DAVID KIHUMURO APUULI: And that, it is not perhaps right and I said if you don't like what I say, please forgive me, because I come from Africa and I have gray hair. It is perhaps not right to craft a program for us in Africa based on benchmarks set outside the country. [Applause] That in fact that is after understanding the epidemic and the

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factors that are bringing the epidemic in Rwanda. That, in fact, the finding then follows the major drivers of that epidemic in that country. [Applause]

David just talks about a few things about what we found. Surprisingly, we found that in fact, in 2005 and because we believe that, in fact, privilege is the best proxy for measuring the epidemic in our countries, we need to understand new infections.

An incident, we found that the biggest new infections are carried through marital sex. We found that the next biggest cause of new infection was commercial sex. We found that the five biggest cause was mother-child transmission.

Oddly enough, casual sex contributed only 14-percent of the new infection and the remaining was more of the same, was blood transfusion and so on. So that means that you must not ignore this in what you craft.

And we also found that the center of gravity of the epidemic had shifted. Whereas four years ago, the main new infections used to occurred between 20 and 24, we know found after the biggest new infection were occurring between 30 and 40, and that in fact a man will mate between 30 and 35 and a men mate between 35 and 40.

We also found that, in fact, discordance and I hope those who are not doctors and those who are doctors if you

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have somebody that doesn't understand this please explain this to them.

We found that discordance had gone to about 48-percent among couples from just over 22-percent in four years. This whole translates you to being able to understand therefore what we must craft.

We also found that sexually transmitted infections had gone up. That in fact between the ages of 15 and 49, herpes simplex type II was nearly 50-percent.

And those of you who are doctors and epidemiologists know that in fact this is some of the major drivers of an epidemic. So if you do not know what's happening in your country, how can you craft a program?

And, in fact, we found when we looked at the core founding factors of the zero surfing, that the prevalence in the country collated very well with the prevalence of STIs and herpes simplex type II.

I was talking to the bank, World Bank, David, I was talking to an official of the World Bank, there was a big program on from the World Bank and others forecasting on sexually transmitted infections.

When it stopped nobody wanted to deal with sexually transmitted infections and yet we find that is a very important driver of the epidemic.

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So what am I saying and why did I come tell you in Chicago. That in fact perhaps we need to go back to our drawing boards and craft our programs for support best on facts, and that countries must be helped to find out these facts which then influence policy and findings.

I don't think I'll ever get the technology to help me and I really have missed out. I think - [Applause]

I think the problem I have - I see the Honorable Minister from Rwanda is here. I am half from Bostwazi [misspelled?] and you always have some few things that follow them wherever they go. [Applause]

And in fact [inaudible] the technologist and I bet as soon as I finish their work. [Laughter] I'm trying to end there, unfortunately without the help of technology.

But the most important thing is understanding your epidemic, understand the factors, we have tried to do that and our next plan that we have crafted we have picked the major drivers and what we're concentrating on.

The next thing is finding, please find out how much money you require for your program. And that's what you should use. I would stop there, there's nothing else I can say and I say God bless you. [Applause]

JALI: Yes, it's working. Let me thank the two Davids very much for their presentations but particularly to

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Dr. David Apuuli, who I think showed enormous resilience and aplomb in presenting his paper and getting across the messages so clearly when his power point presentation went down. I think it's all of us worst nightmare. [Applause]

And I want to thank you very much for that excellent presentation. I also think it was a good example of partnership and practice.

It went down. David Wilson was busy on the machine, Dr. Inisen [misspelled?] provided his machine, so small and big things, we can all work together. So thank you very much.

Great pleasure in introducing our fourth speaker today, who is Sarah Kambou. Sarah's the vice president of the Health and Development Group at the International Center for Research on Women in Washington.

And her work centers on building a program of research, policy advice and technical assistance on gender, sexuality and HIV/AIDS that will reduce women's vulnerability to HIV/AIDS, increase their access to prevention, treatment, care and support services.

I haven't had the opportunity yet of reading Sarah's paper, but I think this is an absolutely critical issue for all of us with the increasing feminization of the epidemic. But also the huge and central role that women and indeed

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female children play in terms of their support as careers and impact this has on them personally in their life choices. So thank you very much Sarah.

SARAH DEGNAN KAMBOU: Good morning, Jali.

JALI: Thank you.

SARAH DEGNAN KAMBOU: I am honored to have been asked to join this panel and to have this opportunity to speak to you about addressing gender dimensions of the epidemic. Everything I share with you this morning comes from ICRW's experience collaborating with organizations implementing HIV/AIDS programs with an edge.

These are programs that are going beyond the public health response, seeking to increase their effectiveness by addressing underlying causes that heighten women's risk to HIV and prevent them from accessing prevention and treatment.

These programs are addressing the very real and potentially fatal effects of persistent gender inequality. As experienced by women and men, boys and girls in economic, social, educational and political life.

My talk today rests on the premise that as programmers and service providers, we know what we need to do in order to contain the epidemic while addressing the unique vulnerability of women and girls. We know that in addition to facilities-based HIV/AIDS services and outreach, we must

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also catalyze and sustain community processes for building women's social capital, developing women's leadership and mobilizing communities to take action against gender inequality.

More specifically, we have come to realize that in order to begin to dream about sustained reduction in the vulnerability to women and girls, HIV/AIDS programs should be linked interventions addressing women, poverty and social injustice.

We now talk of the role of microfinance in providing credit and building women's skills in business development, property and inheritance rights in building women's asset security, education attainment in building knowledge, life skills and resiliency and elimination of violence against women for reasons that are all too clear as essential components of a comprehensive HIV/AIDS strategy.

We know all of these things and yet we are not satisfied, nor should we be, with the results of our efforts. So rather than spend the rest of my time repeating what we already know, my talk today will focus on a systemic weakness. That generally speaking, the depth of knowledge necessary to integrate gender into programs and services is deficient. So there's a significant whole on the how to side. And furthermore, and perhaps more significantly,

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honest and productive engagement on sensitive issues relating to sexuality is viewed as a cultural minefield - better to be avoided than trod upon.

The fact is people all over the world, people framing laws, people implementing policies, people delivering services, carry around a lot of gender and sexuality baggage. And despite substantial financial investments and a strong desire to succeed, this baggage is under minding efforts at every turn to contain the epidemic.

If our goal is to increase the effectiveness of HIV/AIDS intervention, a key strategy in the response must be normative change. Tackling obstructive gender norms and breaking the silence around sexuality at multiple levels and on multiple dimensions.

The good news is that evidence from the field suggests that it can be done. And the recommendation is that it should be systemically and at scale.

Oops. Okay, we wing it. My talk is organized in three parts. First I'll briefly set the context, then explore the gender disconnect and discuss how jargon comprises the design and implementation of HIV/AIDS programs and services. Then I'll turn to a discussion of the critical intersection between gender and sexuality and follow up by summarizing points and suggesting a pathway forward.

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Okay. Next slide. There is no debating the point that women and girls are now at the center of the global HIV/AIDS epidemic.

We all know the statistics, of the 17.2 million adults who have died of AIDS, 52-percent are women. Forty-seven percent of those who are living with HIV globally are women and girls. Over 60-percent of those who are living with HIV in sub-Saharan Africa are female.

And globally of the 16,000 new infections each day, 60 percent are among women and girls. And young women, between the ages of 15 to 24 are the most vulnerable for reasons that are very well known to us.

We all recognize that AIDS is not just a public health problem, but a broader development issue. Research shows that women's vulnerability in the context of HIV goes well beyond public health factors.

The tragedy is that we knew at least a decade ago that gender inequality would place women and girls at special risk.

And their vulnerability would fuel the AIDS epidemic. And that knowledge has been translated into a great deal of very evocative and forceful rhetoric, but too little action.

To ensure that we're all on the same page as I move forward with my remarks, let's do a bit of an overview on

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gender and sexuality. Gender is a social and cultural construct that refers to the widely shared expectations and norms within a society about appropriate male and female behavior.

Roles and responsibilities and the ways in which women and men interact with one another, gender, no, yes, gender is a culture specific construct. There are significant differences.

Okay, thank you. There are significant differences in what women and men can or can not do in one culture as compared to another. In most societies, gender norms dictate that men are responsible for productive activities outside the home, while women are expected to be responsible for reproductive and productive activities within the home.

And women have less access to and control over productive resources than men as evidenced through persistent gender gaps in education, employment, income, ownership of land and housing and access to credit.

In interaction with sexuality, gender inequality greatly undermines women's ability to protect themselves from HIV infection.

Sexuality is distinct from gender, yet intimately linked to it. It is the social construction of a biological drive. Therefore, it is more than sexual behavior. It is a

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multi-dimensional and dynamic concept. It is who you are in terms of your sexual identity and preferences, but also how you outwardly express and use your sexuality in day-to-day situations.

Visual expressions of sexuality, such as jewelry or tattoos serve to attract and initiate social interaction, and not just sexual interaction with another human being.

In heterosexual interactions, inequality and sexual decision making is perpetuated by gender norms of femininity and masculinity that curtail women's sexual autonomy and expand men's sexual privilege place greater emphasis on male pleasure over female pleasure and cast women in a passive rather than in active role.

The complex interplay of gender differences combined with the unequal balance of power in sexual relations that favors men significantly increases both women and men's vulnerability to HIV.

The HIV/AIDS response, the public health approach typically situates sexuality within the frame of illness and disease, instead of frames within which sex occurs in reality, pleasure, desire, power, pain and procreation.

In an attempt to clarify different approaches to addressing gender inequality and women's vulnerability within HIV programming. Geeta Rao Gupta, president of ICRW,

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introduced a framework that distinguishes five types of strategies that fall along a continuum of increasing degrees of responsiveness to gender inequality: Do no harm, gender neutral, gender sensitive, transformative and empowering. All can be undertaken with an HIV/AIDS programming as traditionally defined. But the success of the higher-level strategies, which involve triggering transformations in gender roles and relationships and empowering women and girls, are pertinent to effectively addressing the intersection between HIV, gender and sexuality.

When designing programs and services that seek to transform and empower an essential ingredient is to be fully informed about the locally specific gender based realities of women and men, girls and boys, and the ways in which gender dynamics intersect with sexuality and factors such as mobility or social conflict that increase vulnerability to HIV.

There are an increasing number of examples of transformative and empowering strategies across the world, the image project in South Africa, which focuses on micro-finance and violence, program H in Brazil, which focuses on transforming masculinities and stepping stones which promotes couple communication.

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Okay. All of this sounds very encouraging, but why doesn't it happen more often? Well, the information age has greatly facilitated global sharing of knowledge, tools and methodologies.

We are, for all intents and purposes, drowning in information. Most of us have become very adept at web searches and know how to download information on best practices in gender and HIV programming.

It takes time and expertise, however, to be able to shift through all of that information and identify what might readily apply or be adaptable in a different setting. Time and gender expertise are commodities that are not always available in sufficient quantity.

In truth, a best practice is only a best practice if it's effectively tailored to address prevailing norms of gender and sexuality and accounts for local social and economic factors, exacerbating vulnerability and inhibiting access to treatment and services.

Another factor contributing to the conundrum, along the way through our interaction with various channels of information, we pick up technical jargon which facilitates discussion on issues of gender and sexuality but tends to mask differing depths of understanding around concepts, theories and application.

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We think that we're talking the same language and have the same understanding but, in fact, we're talking at cross purposes.

This is one of the reasons why the how-to of gender analysis and integrating gender concretely into HIV/AIDS programming remains a challenge.

We all need to be aware of the potential traps of the information age and should perhaps devote more time to processing the information that we ultimately select.

I'd like to turn to a second issue. As professionals working in HIV, many of us undervalue and may try to submerge our lived experience of gender and sexuality.

Lived experience of gender and sexuality is what we think, believe and do as women and men, at home and in our community. And it is more often than not at odds with how we as professionals integrate gender and sexuality into the design and provision of programs and services.

We can observe how tensions between personal and professional spheres compromise the effectiveness of HIV and AIDS programming. We see it as pure educators struggle to speak persuasively about changing sexual behaviors that go against the grain of community beliefs and practices.

We see it when health care providers gloss over a discussion on sex. It is better to acknowledge and address

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the tension rather than to continue implementing programs as thought that tension did not exist.

Moreover, our lived experience of gender and sexuality is an invaluable resource offering insights that maybe especially useful when designing locally relevant HIV/AIDS prevention and control programs.

As we look towards the next 25 years of this epidemic, what is needed is a paradigm shift that accepts a broader discourse on gender and sexuality which helps us contextualize our interventions, services and messages within people's lived experience with all its complexity and messiness.

Now, concrete examples of how three organizations have begun to address these challenges and craft innovative solutions to trigger transformation in gender roles and relationships.

In all three cases, the project strategy included an initial three step component focusing on staff, outreach workers and service providers where they, one, reflected on their lived experience of gender and sexuality.

Two, learned in far greater detail about the concepts and theory of gender and sexuality and their intersectionality of gender and sexuality.

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And three, through rapid participatory exercises gain insights into the context and culture of their target or client populations.

This preliminary stage didn't take a lot of time or resources. It did require some what specialized expertise in sexuality and adult education that was usually available either nationally or regionally.

They're to broaden the immediate discourse on the intersection of gender, sexuality and HIV and created a new platform for program activity.

The first case involves a large Indian NGO called APAC or the AIDS Prevention and Control initiative. And a community based organization called the Brother Segga Social Services Guild, which is the brainchild of a group of residents of Brayer sparty [misspelled?] slum in Shani [misspelled?].

As part of its strategy to promote gender mainstreaming and HIV programs, USAID India invited ICRW and APAC to broaden the scope of Brother's Segga existing HIV/AIDS slum intervention program in order to address the gender differentiated risks and vulnerabilities of resident, unmarried adolescents.

Quite understandably there was resistance initially from both APAC and Brother Segga, who were under enormous

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pressure to produce contractual deliverable. Felt that they had in any event taken gender into account during the original design and couldn't quite imagine how addressing both gender and sexuality would improve project performance.

Thanks to the efforts of a very tenacious and politically savvy APAC staff member, we were able to move the gender mainstreaming strategy forward.

A hallmark of this case study is the systemic nature of the initial training in gender and sexuality. All APAC technical advisors participated in a two day interactive workshop, while all Brother Sega's staff participated in a similar kind of training and then received on-going technical support and resource materials.

Unfortunately, I don't have time to describe in detail the other components of the six-month pilot project. But Brother Sega's staff undertook all activities with adolescents as part of their daily program of work, including exercises to take apart and question prevailing norms of gender and sexuality.

I would like to share a couple of indicative results from the project evaluation. A full report is available from APAC or ICRW.

As part of our evaluation methodology, we use the gem scale, gem stands for gender, equitable male. That had been

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developed and validated by Barker, Polerwitz [misspelled?] and others in Brazil and adapted for use in India.

This chart compares base line and end line data desegregation by sex for one of the statements from the gem scale. Women who carry condoms are easy. This statement evokes a negative stereotype of women. Of course, it's meant to provoke and challenge respondents as part of the attitudinal survey.

Note on the far right-hand side of the chart, a considerable shift in the number of women and men reporting it that they do not agree with this statement. Many of these people were sitting on the fence at base line saying that they didn't know how they felt about this statement.

In this second slide, the shift in attitudes around negotiating sex indicates mixed results for men. But a strong trend has emerged for women.

Those young women who may have been unsure at base line are sure at end line that they would prefer to discuss the timing and nature of sexual interaction with their partner.

The base line and end line findings provide a snapshot at two points, in an evolving debate among youth on norms and behaviors, convinced by the end of the project that

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integrating gender and sexuality systemically into HIV/AIDS programs can improve performance.

APAC is planning to scale up the pilot approach in its next phase. The second case study again involves two Indian NGOs of substantial size. Baruka [misspelled?] Public Welfare Trust and Prepare, which provide HIV prevention and clinical services to mobile populations along National Highway 5 in Ondraprudent [misspelled?].

Both Baruka [misspelled?] and Prepare serve the needs of truckers and sex workers. At the proposal stage the Bill and Melinda Gates Foundation was interesting in expanding the traditional strategy for HIV prevention among mobile populations to include field-testing strategies for stigma reduction, with a view to incorporating additional transformative and empowering elements, ICRW and its partners expanding the strategy to address gender-based violence and to include a less visible population at risk for HIV, the spouses of truckers.

As with the first case study, the project addressed gender inequality and other harmful norms and practices that exacerbate vulnerability.

Essential strategy was the use of interactive theater to stimulate public discussion around these issues and to

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draw local authorities and opinion leaders into the debate so that consensus could be forged on the way forward.

The next two slides compare base line and end line on two dimensions, reported tolerance among sex workers and trucker spouses for men perpetrating intimate partner violence if women refuse to have sex. And personal experience of at least one form of violence over the past six months.

By the end of the project, the data showed dramatic change in attitude regarding tolerance for intimate partner violence and an appreciable drop in personal experience of violence particularly among sex workers.

These are encouraging results from the projects first phase and partly served as the spring board for the project's second phase which shifted its focus to registered medical practitioners and building their capacity to integrate stigma and violence reduction into their ongoing HIV/AIDS services.

The message to implementers and service providers is that you can in fact address harmful practices that are anchored in deep rooted gender norms.

She's calling my time, so let me just go through to the pathways for greater impact.

JALI: You have another five minutes because you had such a [inaudible]

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SARAH DEGNAN KAMBOU: That's lovely. I'll take it.
Okay. One final case before I draw to a close.

While this talk has focused on the feminization of the epidemic and reducing the vulnerabilities of women and girls, gender norms and structures negatively affect both women and men and increase the vulnerability of both.

This project based in four states of the former Yugoslavia is seeking to understand the perceptions, behavior and underlying drivers of male violence towards themselves and other men, girls and women.

As with the other two case studies, the project strategy creates space for staff and service providers to challenge their beliefs and attitudes about prevailing gender norms.

This project targets young men for the time being but will expand to include young women, because gender and equality is about the ways in which women and men relate to each other, about both women and men reinforcing traditional gendered structures and enforcing sanctions against those who do not comply and about men and women falling prey to gender norms of sexual behavior.

Such an understanding of gender even while acknowledging that gender inequality puts women at a significant disadvantage in society requires both women and

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men to change their behavior, calling for the social transformation of the definition of masculinity and femininity and the role of the individual in fostering that change is clearly a new priority for HIV and AIDS programming.

Before closing with suggestions for a pathway forward, I'll quickly throw up slides recapping my main points. If we are going to move beyond the jargon and the rhetoric, if we are going to increase the effectiveness of public health interventions by addressing underlying causes that heightens women's risk of HIV and prevent them from accessing prevention and treatment.

Then we must address the detrimental effects of persistent gender inequality and we must break the silence surrounding sexuality. That being said, we need not wait to resolve gender inequality before we can hope to accelerate progress towards containing the epidemic.

The good news is we know what works. Now we must bring these interventions to scale and replicate them in countries and communities world wide. By addressing AIDS in ways most relevant to women and girls, we are advancing broader efforts to reduce gender inequality and social injustice.

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Based on field experience, research findings and the documented potential of mason, transformative and empowering strategies I propose six recommendations. We should expand significantly efforts to address inequality between women and men and harmful gender norms as major drivers of the HIV epidemic, HIV efforts to gender equality and social justice efforts, broaden the HIV and AIDS discourse to include sexuality and its intersection with gender.

We should also build local capacity to design interventions and services informed by and responsive to prevailing constructs of gender and sexuality. Measure the impact of integrating gender on changing gender norms and on sexual and reproductive health outcomes. And build on programmatic successes and scale up.

A short while ago, I reviewed the statistics which showed that women and girls are now at the center of the global HIV/AIDS epidemic. It is a cruel irony that in AIDS related illness and death, women now have equality with men, equality that has been denied them in life.

We know what we need to do to reduce the vulnerability of both women and men. And we recognize that we need to do things differently. We do not need to be daunted by the challenge of normative change. We can imagine

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a world where gender roles and norms are transformed and
where sexuality is viewed as positive and fulfilling.

My ardent wish is that with the conclusion of my talk
you entertain the notion that addressing gender inequality is
not a pipe dream but practical, powerful and possible. Thank
you very much.

[Applause]

JALI: Thank you very much to the four speakers, not
only for extremely interesting and quite diverse
presentations, but also for your tolerability in the face of
technological challenges and I'll ask you to join me in
thanking them.

[Applause]

[END RECORDING]

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