

**Stigma and Discrimination:
The Undoing of Universal Access?
XVI International AIDS Conference
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MARY ROBINSON: Good morning everyone. I must say it's great to see you here in such good numbers. I think I share your sense because you're here but this is an incredibly important issue and I'm glad that we're able to have such an expert group speaking to us.

We've prepared this session well, so I hope it will go well from the panel point of view and then we need you to dialogue as well. So I think when we have heard from the panel, we go straight to the floor.

There are microphones and I'll try and be fair in distributing between and the microphones and I would ask you just to tell us who you are briefly when you put your question or your comment.

I've been at quite a number of sessions as I think you have as well. Not one session that I attended didn't bring up centrally the issue of stigma and discrimination linked to gender-based violence, linked to very often that is particularly bore on women and on girls and the facts that it's underestimated all the time.

And one of my hats that I'm proud to wear here at this conference is I'm a patron of the International Community of Women Living with AIDS. And I've talked to a

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lot of my colleagues and their story begins with the extent of stigma.

At even still, it takes me back, you know, it kind of, it hurts me to think that people get treated the way they get treated, that there are such smears, such an innuendos, if not actual physical violence having been thrown out of the home or whatever.

So we really need to address this and to find strategies that work better because we are not highlighting enough. We're not realizing that it's crucial to prevention. It's crucial to access to treatment.

It's crucial to the living together in communities and neighborhoods and it is deeply an issue that is at the core of a human rights approach.

So without further ado, because we have good panelists and I also want to hear from many of you, I'm going to introduce our first speaker. I'll introduce you to the speakers and as I call upon them I'll sit to do the rest of the introduction.

But it gives me great pleasure to introduce Dr. Mandeep Dhaliwal. As you know, he works in the International HIV and AIDS Alliance and the Lawyer's Collective HIV and AIDS unit.

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He's chair of Para 55, the Commonwealth Action Group on HIV and AIDS, and he's been working on the issues of HIV and AIDS and human rights for over 20 years. And I think what he will do is give us an overview.

He'll refer us the work that came out of the universal access process and he will highlight that political will and funding is still needed to address stigma and discrimination.

And I would really put an emphasis on the political will. Interestingly, you'll hear leaders speaking about stigma and discrimination so much. You hear it always from those who have suffered it because it hurts and it imprints on their soul.

We don't hear it enough at a political will level how we're going to tackle it. So, let's hear Dr. Dhaliwal first and then I look to you help us to create the strategies that will make a difference, thank you. [Applause].

MANDEEP DHALIWAL, MD: Thank you very much. It's an honor to be here and I was expecting a bit of conference fatigue today in the audience.

But clearly everybody's really interested in here and I hope we're going to have an interesting session. I would like to begin by acknowledging a range of people who have

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contributed to this presentation with their intellect and their integrity and their commitment.

And I hope that the presentation does their contributions justice. Just to share a little bit with you, the method of putting together this presentation.

I had the privilege of being involved in the global steering committee process that was led by the Department for International Development of the U.K government and UNAIDS on looking at what were some of the barriers and solutions and potentially developing a roadmap to universal access.

There were a series of meetings and reports. There were 51 country consultations. And I've reviewed four regional consultation reports, though there were nine regional consultations.

Presentations also based on a civil society consultation that the International HIV/AIDS Alliance led on what were some of the barriers and concerns for civil society around achieving universal access.

And also, I've also had a look at the deliberations and the outcomes of the high-level meeting on AIDS. As many of you know, the global steering committee generated a report based on a lot of these consultations, which was submitted to the Secretary General and then influenced the development of

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the political declaration that came out of the high-level meeting on AIDS.

The discussion will also be based on some of the findings and studies and work of Lawyer's Collective HIV/AIDS Unit and some of the discussions that I've been hearing over the last couple of days here at the conference.

So context, it's a particularly exciting time I think. We have historic commitments to universal access by a range of political leaders. With those historic commitments comes a responsibility and an urgency to translate these international commitments to implementation of sound evidence based programs, which address stigma and discrimination at the country level.

Achieving at universal access efficiently and effectively will mean addressing stigma and discrimination. So what were some of the issues that we heard during the country consultation?

Many, almost all, of the country consultations and regional consultations describe stigma and discrimination including fear of stigma and discrimination and violence as key barriers to achieving universal access and also barriers to currently accessing HIV prevention treatment and care.

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Many studies also indicated that national efforts are not sufficiently prioritizing the delivery of the essential life preserving interventions to those at greatest risks.

We know that coverage of prevention services for key populations is less than 20-percent and coverage of treatment services is next to nothing for these populations. And I have to say that we've heard a lot of people talk about or make comments referring to 25 years into the epidemic.

And I am deeply embarrassed and humiliated that 25 years into the epidemic at UN meetings, people find it difficult to name vulnerable populations, to tell the truth that those at greatest risk are sex workers, drug users, transgender, women, girls and children.

If we cannot name these populations, we are not going to make any progress in addressing their needs and delivering universal access [Applause].

Gender and equality were cited as a major barrier and something, which needs to be addressed. According to UNAIDS almost 82-percent of countries have policies in place to assure equal access between men and women to HIV prevention and care.

In reality however, we know it is a very different situation. We know social, legal, and economic factors impede women's access to life saving services.

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Availability and accessibility of services was always raised as an issue. We know that there's a great lack of appropriate sexual reproductive health in HIV services for young people who are at great risk.

And also other populations such as sex workers, drug users, men who have sex with men, transgender populations do not have access to sexual reproductive health and HIV services.

Lack of access to free treatment and [Inaudible] treatment is the major impediment to achieving universal access. We heard in this morning's plenary that those people who have access to free ART do much better in terms of the care.

Over half the countries which submitted data to UNAIDS reported the existence of laws and policies that hinder access to HIV prevention, treatment, and care currently for vulnerable populations.

These need to be addressed if we're going to achieve universal access. Examples of such laws and policies include the criminalization of consensual sex among adults of the same gender, legal impediments to syringe exchange or substitution therapy.

And it was interesting to note in yesterday's press conference that former President Clinton noted his

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administration's mistake in changing the policy to not fund needle exchange.

We can't afford any such mistakes any more and these mistakes must be reversed if we're going to achieve universal access. Another example of the law, which prevents access to HIV prevention, care, and treatment services, is the use of residency status to restrict access to services.

I live in the United Kingdom and I'm embarrassed to say that residency status is used to exclude people from HIV prevention, treatment and care.

Dealing with HIV testing and counseling is something, which came up in a little bit in these, country consultations that I think has been discussed much more at this conference. We know that we need to scale up HIV testing and counseling, but we cannot do it at the expense of human rights protection.

We must ensure protections for discrimination, confidentiality and ensure that treatment and access to treatment is a reality as we scale up testing and counseling

There also needs to be some consideration of the fact that not everyone is equally empowered to off doubt [misspelled?], particularly in a doctor/patient relationship, which is based on dementally [misspelled?] on inequality.

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And as my colleague Suzie McClain there is always says, There's always a slippery slope between off doubt testing and mandatory testing.

And in over 25 years we have seen many examples of this, so we must be very vigilant as we're scaling up HIV testing and counseling that if we are using off down [misspelled?] models, they don't turn into mandatory testing.

And really what's been clear throughout the last couple of days is that there's a real need for more evidence on how VCT routine testing, routine offer of testing are being implemented and will be implemented.

And not just evidence from the provider perspective, we need evidence from beneficiaries as well. All the butts on evidence we've heard at this conference has all been provider perspective.

And I would like to say that is insufficient to really tell us what's happening in communities in terms of the stigma and discrimination related to HIV and AIDS [Applause].

So what are our commitments? What commitments do 192 member states of the UN commit to? They committed to an intensification of efforts to eliminate all forms of stigma and discrimination.

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And I think this is particularly challenging given the multi-layered dimension of stigma and discrimination. They also committed to ensuring full access to services with full protection of confidentiality, informed consent, and a supportive social and legal environment, and the elimination of gender inequalities and gender related abuse and violence.

So what do we need to do to deliver on these commitments? As I said before, we need to increase and sustain political and financial commitments at the global level to sustain action at the country level. That's where the epidemic is, in countries.

We need to scale up specific interventions to reduce stigma, discrimination, and gender inequity. Commitments to this must be built and sustained at country level. And we're going to hear from various colleagues on the panel about specific interventions to reduce stigma and discrimination.

More generally, we need to promote, protect, and fulfill the human rights of those most vulnerable. We need to provide access to medicines, diagnostics, and condoms. Discussions around universal access cannot be de-linked from what happens in the World Trade Organization and discussions around [Inaudible].

And also something, which I think we heard on the first day, but I haven't heard again, and it's a very serious

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issue, is the huge condom gap that exists. If we're scaling up access to prevention, treatment, and care, we need to also make sure that we have sufficient condoms so people can have sex more than three times a year.

We also particularly need to be vigilant of ourselves, the donor community and civil society in addressing the changing faces of stigma and discrimination. We need to pay particular attention to the increasing trends and criminalization of transmission of HIV.

We know that this contradicts public health objectives. We also need to make sure that we are constantly vigilant of the fact that our investments, our hard-earned money goes into evidence-based interventions.

And I know we focus a lot on the U.S government as one of the biggest perpetrators of investments in non-evidence based interventions in terms of funding abstinence only programs and not funding needle exchange.

But I would also like to bring to your attention the Bill and Melinda Gates Foundation who gave a \$5 million grant recently to the International Justice Mission and for those of you who don't know, I encourage you go and look at the Web site of the International Justice Mission.

They rescue victims of the sex trade. We know that this is very much against all of the evidence we've seen in

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terms of how we need to deliver HIV intervention to sex workers. So I would encourage the Bill and Melinda Gates Foundation to be a little more vigilant about what they're spending their money on [Applause].

Concrete solutions, we know what these are and it was very interesting. I'd like to take a minute here, because I've also heard some very disturbing comments about how human rights frameworks and how legal protections and law and policy reform are western impositions.

I would like to tell you that these 51 country consultations were not all western countries but actually they were all developing countries from Asia, Africa, Latin America, and the Caribbean and the Eastern Europe.

This is what they're telling us are the concrete solutions that they require to achieve universal access.

So people who want to rewrite the health and human rights framework and who say that actually if we want to achieve universal access, we should do away with informed consent and confidentiality and not address stigma concretely are people who want to take shortcuts, and no such shortcuts can be allowed if we want our investments and our HIV prevention, treatment, and care to be long-term and sustainable [Applause].

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So these are the concrete solutions proposed by the 51 countries and the nine regional consultations. They called for reform and repeal of laws and policies which perpetuates stigma, discrimination, and inequalities, laws which impede access to HIV prevention, treatment, and care, with a particular focus on issues of access and medicines, HIV testing, criminalization and gender inequality.

They call for the enactment of anti-discrimination legislation which protects and promotes the rights of people with HIV accompanied by education of communities and policy makers and real access to legal services, free access to anti-retroviral treatment and an investment in social mobilization on HIV and AIDS and mobilizing people living with HIV as a crucial part of the response.

They also called for real tools to monitor progress, country level targets for reducing stigma, discrimination, and inequality. So I'd like to leave you with a question and two calls, being a good activist I always have a call.

So the question is, if you were a national AIDS program manager, and as a part of your country's universal access plan, you have to invest in two to three key stigma reduction interventions. What would you invest it?

And my calls are this: call for national universal access plans. I don't know if many of you know, but one of

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the key outcomes of this whole political declaration was that countries, every country has to set a national universal access plan by the end of 2006.

Do you know whether the plans in your countries are being set? Who is involved in setting them? There needs to be transparency in the setting of these universal access plans. These plans must include specific and significant investment of stigma reduction intervention.

And we've heard a lot of very glib statements about putting the power in the hands of women. I would like to call for putting the hands in the power of people to protect themselves in the hands of not just women, but in the hands in those typically marginalized populations in our society that we are afraid to name, sex workers, men who have sex with me, transgender, drug users, and children.

Without these investments and these commitments, universal access will neither be achieved nor will it be sustained, thank you [Applause].

MARY ROBINSON: Thank you very much, Mandeep could I begin with a humble apology? I think I gave you a temporary sex change [Laughter]. I think it was the jet lag from coming down those escalators through all those crowds.

But there were actually a couple of points you made that I just wanted to reinforce, though you made them

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wonderfully about not naming the vulnerable groups and then you mentioned the condom gap. And I find that there's also a gap even in naming female condom.

We do not hear anything about the one practical and protection that women can try to influence if they can negotiate. Actually we need to just be more honest about things and what is this about not being able to mention the female condom?

You posed excellent questions to the floor, which I think was also very good and frankly I just come literally from a press conference at ICW on the opt-out testing and these are women living at grass roots in developing countries.

And they are very worried about the opt-out testing and the routine quick fix and that's a message that we may hear more of here. But I was very struck by those who are living with the issues, living with stigma, living with discrimination are very, very worried about the emphasis that we're seeing here of somehow and that's hardly answer.

And testing doesn't mean access to treatment. They are very different things. It may be a gateway to stigma in fact. Anyway, I mustn't be making speeches, I must be a good chair and, the next person I have the pleasure of introducing

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is Dr. Laura Nyblade who is the Public Health Demographer at the International Center for Research on Women, ICRW.

She's worked extensively on the issue of HIV related stigma through several studies that examined both the factors that perpetuate or mitigate stigma and how those factors affect access to HIV prevention, care, and support.

Laura has also led work to develop, test, and validate indicators for measuring HIV stigma and support of the development of practical anti-stigma tools. She's currently leading work to further develop the stigma indicators and evaluate stigma reduction interventions and in Tanzania and Vietnam.

She holds a PhD in demography from the University of Pennsylvania, Laura it's a pleasure to introduce you.

LAURA NYBLADE: Thank you. Thank you [Applause].

Before I begin I would like to start with a quote from Cannon Gideon Yamgisha [misspelled?] from Anarella [misspelled?], which is the African network of religious leaders living with or personally affected by HIV and AIDS.

He says, "Everyone is now mobilized around universal access which is great. But no one is talking about the fact that to reach this goal we need to eliminate stigma, shame, denial, discrimination in action and mis-action before 2010."

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So I am here to follow the great set up by Mundie [misspelled?]. And I am here to say that we have no more excuses for inaction. We know enough. We have interventions. We have tools. And those excuses have gone away for not doing something about stigma and discrimination.

So what do we know at this point about HIV related stigma. As Mundie has already explained it is a barrier to universal access. We also know it is universal across the globe. It is experienced everywhere.

We also know it is very prevalent and I am going to show some data to illustrate this in a minute. We also know it is differentially experienced by women and men. Everyone experiences high levels of stigma and discrimination but it is experienced differentially.

We also know it is actionable and two of the other panelists will talk about specific interventions to do that. And we also know now that it is measurable. Therefore, we can measure whether our stigma reduction interventions are having an effect which has been unexcused or a barrier to not funding programs to reduce stigma because we cannot measure it.

We no longer have that excuse. I am going to; there is lots of work out there that is on stigma. I am just going to illustrate some of these points from ICRW and partners,

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six-year program on research to action around stigma. This is work that has been focused in four countries initially, Ethiopia, Tanzania, Zambia and Viet Nam.

From that preliminary or initial research we then brought that research back to communities and developed and then adapted stigma reduction tools. I will talk a little bit about that also.

We have also been working on the issue of measuring stigma including field-testing indicators for validity and reliability which another colleague on the panel is going to talk more about. And we are in the process of evaluating stigma reduction interventions. We are at the point where we can have action.

This is from our study in Tanzania and this is a survey of people living with HIV and AIDS and this is just to show you that it is prevalent. And you can see it is also, it is prevalent for everyone but it is experienced more by women than men in this sample and so that is just to make the point.

I would like to say that from our qualitative work which was based in four countries and we had over 700 interviews that went into that analysis, that although there are some notable variations in stigma that stem from differences in language, culture and epidemic history, these

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difference are largely of nuance and degree rather than substance.

Instead we find commonalities across all settings in what causes stigma, the forms in which stigma is expressed and the consequences of stigma. Stigma is common at its core. It is in all of us.

And this has also I think been an excuse for inaction. It is too culture specific. It would cost too much to actually do something about stigma because it is different everywhere. It is not. It is common at its core.

Again I just want to talk a little bit about the differential experience that we measured between men and women. Women and men are experiencing stigma at high levels. but women are experiencing the more severe forms in greater percentages.

We have to address violence if we are going to reduce stigma. We need to look at these issues together and as you can see here women are much more likely to experience assault, abandonment by spouse or family, to be threatened with violence or to have their property taken away.

So that we need to in our response also recognize these differences and start addressing them. I would also just like to say that some of the underlying causes that we see for HIV related stigma and discrimination remain high.

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In the survey in Tanzania, around 47-percent of the survey respondents in the community based random sample expressed fear of HIV infection through casual contact. We measured 12 different items there.

That leads directly to isolation, physical isolation that is experienced. We also know that stigmatizing attitudes remain high. 50-percent of our sample agreed with one of three shame items. For example, "I would feel ashamed if someone in my family had HIV or AIDS."

66-percent agreed with one of four judgment and blame items. For example, "HIV/AIDS is a punishment for bad behavior."

So you see some of the underlying issues that are driving stigma remain high and need to be addressed.

Now I'd like to turn to say we can have action. Anti-stigma tools and intervention modals exist and I'm just going to talk briefly about these. I don't have a lot of time.

There is a tool kit that we've developed through participatory materials development workshops in three countries in Africa that has been widely used effectively. It has been adopted through many contexts. It's out there; it's available for people to use and people are using it with lots of success.

So we have tools. There are also other tools out

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there. For example, for health care workers there is a tool kit that EngenderHealth has put together. Horizons has some materials around that. We have tools to start helping us respond. This particular tool kit is available in multiple languages. And is an ongoing process in improvement. There is actually a second addition in process that the International HIV/AIDS Alliance is leading out of a regional initiative in East and Southern Africa.

We also know that there are practical interventions that are being implemented in multiple settings. Some using this tool kit. And with different groups so we can have interventions with multiple groups.

I'd also like to say on this past Saturday we had a one day consultation on the issue stigma discrimination and heard from three different intervention programs that have been ongoing. One from Vietnam, which the Institute for Social Development Studies is leading. One from Tanzania; Combara [misspelled?] Pure Education and Promoter Trusts were leading; and one from Mexico, and we heard from Juan Hernandez from Colectiva Sol.

And I wanted to just share with you a few of the key take home messages that they presented from their experience in actually implementing stigma reduction programs.

The first is that you need to start at home. Just because you think you've been working on HIV for years that

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you don't need to do anything first within your own organizations or your own institutions. The message was start at home. Recognize what stigma and discrimination is.

Often times we don't realize, for example, when we gawk that that is a form of stigma that can be extremely damaging.

You need to build skills to address stigma and you need to listen, let go and learn. From the groups that Mandeep has mentioned; Men who have sex with men, commercial sex workers, vulnerable women who are experiencing violence, children and transgender people. We need to listen, let go and learn if we're going to have effective stigma reduction interventions.

The second is open the gate and build capacity among leaders. In particular, we heard from our colleagues in Vietnam, how effective opening the gate at the top levels of government has been. Work with policy makers and community and religious leaders.

The other lessons were that you have to involve groups experiencing stigma. People living with HIV or AIDS, men who have sex with men, sex workers, transgender people, injecting drug users and carers. You need to enhance the visibility and raise awareness of stigma among these groups first. And work on addressing self stigma and then build skills for advocacy, the defense of human rights and

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education of others.

The other lesson was how powerful networking between stigmatized populations for joint solidarity can be.

All of these groups found that you have to target the media, police and health care workers. You need to have a participatory approach. Two of these have used the tool kit with great success. You need diversified activities and you need to use positive images of people that are living with HIV and AIDS.

And a key message that came out from all of the groups and which is a real challenge is that you need sustained activities over time. You need to incorporate stigma reduction in to all existing activities. For example, the program in Tanzania has incorporated in to home based care activities, pure education, counseling and a number of other activities that makes it more sustainable over time. And that you need to provide ongoing support and refresher training for those who are implementing these interventions.

So I will wrap up now. I was asked to talk about remaining gaps and next steps in both research and programs.

We need studies that examine the relationship between what happens when you really reduce stigma to the uptake of HIV services, treatment and prevention to universal access to all of these things.

We also have been hearing that perhaps all you need

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to do is provide A.R.T. and stigma will go away. We need studies that look at this in a rigorous manner. I think all of those who work on the ground will probably say that this is not the case. But this is what we're hearing again, an excuse for not funding stigma reduction intervention. Just provide treatment and stigma will go away. We know that that is not the case. We need studies that document that in a rigorous way that we can use for evidence based advocacy.

We need to look at the nexus between gender stigma and violence. We can not address each of these individually. They are interlinked. We need more understanding of how the linking happens and how to have programming that addresses these three things together.

We need to look at layered stigma. The groups that are experiencing stigma the most are groups that are already experiencing stigma before HIV. And now you add HIV stigma and more violence on top of it. We need to understand more about that.

And we need operations research to rigorously evaluate stigma reduction programs so that we can show that programs are effective and learn what are the best ways to move forward with this.

We need to have a standardized set of stigma indicators that works across the globe. I think there has been initial work that shows that this is possible and

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Charles will talk more about one of those efforts. But I hear again and again, particularly from the policy makers and the donors, "if you can't measure it, we can't fund it."

We can measure it now, we know that. So that excuse is no longer there. We need to find a forum for sharing best practices and collective learning. At this conference I've heard of numerous programs around the globe that are working to reduce stigma, but we don't have a very good forum for sharing that knowledge and learning from each other.

We need to adapt those successful tools and practices so that we can scale up. And we need increases advocacy for the issue of stigma and discrimination. Particularly, at the leadership level in governments and on the international stage.

Just to end, I want to say, it can be reduced. We have no more excuses for not addressing stigma. We understand enough to act. We have practical tools that we can use; we have measures to evaluate our progress. And each of us sitting here can make a difference. Thank you.

[Applause]

MARY ROBINSON: Thank you very much, Laura, for that very practical contribution to the issues of how to address stigma. And the fact that we now have tool kits, we have ways to measure. We have steps that need to be taken that all of us can contribute to and I'd like to link that with the

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call that Mandeep made for attention to the fact that there need to be national, universal access plans by the end of this year. Because they need to include the ways of measuring the tool kits, the addressing and so all of that, I think gives us the beginnings of the kind of strategy that has to emerge from this session if we're really going to help to advance.

I like your last point, Laura, about learning from each other and learning across and I'm very pleased to see this, in this session at least, we are being very open about vulnerable groups and repeating them in a way that I think is right.

So I now would like to call on Anuar Luna; he's the project coordinator of the Mexican network of people living with HIV and AIDs. He's been living with the virus since 1991 and he's an access treatment activist and he's also a consultant on stigma and discrimination for USAID policy project, M Costella Feutrez, [misspelled?] You have the floor. [Applause]

ANUAR LUNA: Good morning everyone. Thank you for this opportunity to talk in this conference. I want to start my presentation sharing with you some consequences of the internal stigma. I will focus on internal stigma. Also, as Laura said, self stigma.

Also, I have accepted the virus myself. The thing

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is, I don't want anyone next to me.

It is a kind of life not telling the truth. Like if they don't ask, I don't tell.

If I said that I have HIV, they could fire me and then many possibilities in my life will be over.

When I learned that I have HIV, I cut myself off from the world because I felt bad about myself. I locked myself in the house and I didn't answer the phone. All day I slept. This is some examples of how internal stigma affects the lives of the people. But I want to go to the issue.

So what understand about internal stigma? So internal stigma refers to the self perceptive stigma or the internal manifestation of acceptance of the stigma or negative social perceptions transforming in to such things such as fears and anxiety are hard.

In order to understand, we tried to develop [inaudible] to put clear best ideas. Then we understand the internal stigma is that shame that is associated with HIV and AIDS and the fear of we being discriminated against.

So we understood that this phenomenon has three key issues. The experience of the context, which refers to the environment. The self perception, which refers to how the people perceive the context and the protective action. The protective action is how the people try to defend their self against the context.

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I'm going to go through each one of these issues. The experience of the context. The experience of the context focuses on physical and environmental situations. Several interacting elements that lead to an overall sense of loss of control. Some key elements include [inaudible] and negative produce, misinformation, economical and social pressures and physical deteriorations such as hyper dystrophia.

And in a Mexican society where it is very common where homosexuality is very bad viewed behavior. So if the rest of the population perceives the homosexuality as a bad thing that creates an environment that effects perception of the self stigma.

I'm going to go through the self perception which includes the recurring the deepest feelings of shame, guilt, fear to being discovered, for dying or infecting others, blame and anguish.

And I will come back to the examples of the homosexuality in society. If the rest of the society thinks that homosexuality is something that is dirty; something that I have to feel guilt for; I will assume that the society is right and I will feel guilt and I will feel dirty.

So the next component of this process is protective action. And for me, in order to link this with the access is the key issue.

The protective action includes absenece and self

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exclusion, avoiding long term plans such as buying a house, asking for a job, asking for a scholarship for school. Avoiding activities in general including for example, seeking health services. I am going to this example more exclusively, more in detail. Isolation and self withdrawal. Keeping to himself and avoiding social activities. Avoiding intimate intercourse.

And this is very, very important doing the work that we carry out in Mexico. We found that many, many people express that when they discovered that they are HIV positive that they decided to stop an intimate life. They decided not to fall in love again, for example. They said, "I don't want to know anything about love because my love, my sexual life is over." And for us, this was a very key issue about this protective action. They want to protect their feelings.

[Inaudible] and deny. Hiding or misleading others as to sex status or sexual orientation. For example, this situation that I had told you about. The homosexuality in Mexico.

So, what is the impact of the internal stigma in the context of the access? Well, one example is the fear of being tested. People don't want to be tested because they know the bad consequences of the stigma and discrimination. They want to be accepted by their family, their friends and their partners. Afraid of being seen in [inaudible] related

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facilities or receiving HIV services. Many times the people receive HIV positives are [inaudible] and many times they don't want to go to the hospital because they don't want anyone to see them around the hospital or the line to receive medicines or the line to go to the clinic that they know that it is the doctor that provides services to people with HIV. Loss others to treatment; the people didn't want to take pills in that type of environment. They just hide the pills and they don't want to go to any party or any social event because they are just afraid of that.

The loss of the opportunity to receive adequate treatment, no matter if it's available in Mexico. Now we have more access to treatments but we realize that the stigma and discrimination now is a barrier to the access because many people don't want to go to the health facilities. Again, for the fear of being linked to HIV.

Refer to the side effects and very, very specific is [inaudible]. The people don't want to suffer the side effects because they know that if they look a little tired that people will realize that he or she is HIV positive so they just don't want to take the pills because of that fear.

Shame to talk with the health service providers on sexual issues. And this is a very bad issue because many people just don't talk about this and they wait until the sexually transmitted disease is too bad to receive attention

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and this is a great barrier to improve the quality of the people.

Refer to the disclose of relative issues with health service providers. Yesterday I was in at a table where my colleagues discussed widely the issue about how some health providers just deny the right the women and men to have that [inaudible] rights.

So, with we to define some ways to reduce internal stigma. One of them is enhancing the capacity to building the social capital and personal belovement. Build capacity [inaudible]related to the personal and social growth, increasing self esteem and sense of self worth, improving individual social capital, environment and social organizations and groups; sense of [inaudible]and social [inaudible] and central social integrated or choosing social institution and [inaudible].

We think that this is very important to help people feel more integrated. To create more supportive environments in order for people to reintegrate their selves in to their society.

Improving support services for persons living with HIV, ensuring quality of the care and comprehensive care and support. Developing economic independence and maintaining confidentiality in work place, health settings and various social spheres.

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We are working more specifically in health facilities because we have found that most of the important fears that people are suffering are related with health facilities. So we think we have to stress that kind of [inaudible].

Number three is increasing the visibility of persons living with HIV as productive members of society. Providing more positive morals, building leadership skills, accessing more self support groups and social networks.

We think this is a very important issue in order to create more supportive environments. But if, for example, if the media is still providing the rest of the society with a very bad image of people living with HIV, this work just can not do. So we think that we have to create positive models to encourage people to keep the faith. But tell them to consider pros and cons to keep the faith and try to provide safe environments to do that.

So, where to from here? We think we have to strengthen capacity building of people living with HIV networks. But not only form the networks, also inform a networks such as family, friends, partners.

Internal stigma and strengthening support groups of social support networks again. And trying the [inaudible] of health professionals and base line to [inaudible] internal stigma. This is a great challenge because this is a very complex issue and we need to develop the specific indicators

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that can help us to measure that complexity of that elements involved in that phenomena.

To develop and implement the stigma mitigation, [inaudible], communities such as sex workers, such as men who have sex with men, women and junk people.

So, as I show this in this vicious cycle, I invite you to put these three issues into a viscous cycle. We think that internal stigma represents an obstacle for HIV visibility. The lack of HIV visibility in this society or in the community is an obstacle for access. The lack of access reinforces all the elements linked with the stigma.

So we have to break down that vicious circle in order to improve the environment.

And I would like to finish my presentation with a positive voice that shows how if we come to deal with this internal stigma, we can create leaders that can contribute in the response of the HIV epidemic.

I am like any other person. Being positive does not stop or limit me but on the contrary, it [inaudible] to me. This is my friend, Juan. This is the thing that I want to show you. I want to acknowledge all of the people that helped us in this presentation with their photos, showing how the stability contributes to better environments, how the voices of the people living with HIV also creates to helps to create a better understanding about the stigma

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discrimination.

And also I want to acknowledge to my colleagues and to my friend Ken Morrison who helped me to prepare this presentation. So thank you very much.

[Applause]

MARY ROBINSON: Thank you very much Anuar for this excellent presentation. As I listen to you talk so eloquently about the internal stigma, the cell stigma it made me think again about the link between stigma discrimination and human rights the universal declaration of human rights.

I was thinking if we reflect back to Article 1 which says, All human beings are born free and equal in dignity and rights and actually dignity comes before rights. And it's the undermining of that self worth, self dignity that is at the heart at the core of why stigma is so eroding and so difficult and so.

And you made a very good point I think towards the end that we must bear in mind and later increasing the visibility of persons living with HIV as productive members of society.

Now I relate very much to that because a lot of the positive women in particular ICW positive in local communities that I meet I've learned so much from. And they are extremely productive. But they don't often get enough visibility and enough space and air time.

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And it now gives me great pleasure to introduce Dr. Glenda Gray who will give a clinicians perspective including PMPCT as she's a pediatrician from RSA, a director of the Perinatal HIV Research Unit.

And she has been awarded a number of awards including the Nelson Mandela and Health and Human Rights Awards. And for her work in PMTCT. And she also worked in Sueto [misspelled?] in the 90's demonstrating women children in poor settings could take ARV's meticulously.

So and also you've come across lots of discrimination issues. So you have the floor.

GLEND A GRAY, M.D.: Thanks. [Applause] Just trying to find the forward pointer. Yes. Sorry, I didn't see it. Sorry. I'd like to thank the organizers for inviting me to this important session. And I'm going to present data from healthcare workers from 2000 so we can look at what is happening in cases in the developing world where hard access was available.

And also while walking around the conference and attending sessions it seems to me that the issues that we see in London are the same as in Lagos [misspelled?] and that discrimination in [inaudible] is pervasive in all settings.

I wanted to begin underlining fortunes of what stigma is. And it's a complex social phenomenon which results in a powerful and discriminating social label that changes the way

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people view themselves which is experienced as self stigma or internal stigma or externally which is seen as indiscrimination.

And internal stigma is very important because it can actually lead to a person's unwillingness to seek help or access resources. And external stigma in the form of discrimination actually can lead to one's perceived or actually [inaudible] being discriminated against in the healthcare setting.

So I'm going to ask four questions. I'm going to pose four questions in this presentation. And one is to ask the question; are there discriminating practices in the healthcare setting? What constitutes this? And how do we get into healthcare workers heads to try to understand why they're discriminating in the healthcare setting and how their impact on access to care and can health care change the attitude?

I've start off with a study done in India which is a study done in about four hospitals in India that shows that nearly two thirds of all staff fell into the market stigma category and almost one quarter fell into the high stigma category. Doctors displayed similar stigma profiles as to other healthcare workers be they nurses or counselors.

And as posted yesterday from London, Alfred and colleagues also reported that almost 5-0percent of HIV

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infected people who they had studied had reported discrimination by a healthcare worker and dentists and GP's were named as the top people who discriminated against them in that setting.

It's important to try and understand why healthcare workers are discriminating in the healthcare setting. As you can see that we start to believe that HIV can be transmitted by casual contact. They have much higher stigma scores than those who did not have.

If you have a look at the data from hepatitis C, the people who knew how hepatitis C was transmitted would have low stigma scores. Staff also scored very high on the stigma index when the staff that scored very high on the stigma index were more likely to report discriminating practices.

We can see that people who had high stigma avoided near people who were HIV infected or touching HIV positive patients. A recent study that has just been published in plus and from Nigeria looked at the healthcare practices towards patients.

And this is a very recent study. And you can see that in people sampled, almost 10percent had refused to care for a patient with HIV/AIDS. And 10percent had refused hospital admission.

What's also very concerning is that other healthcare workers had observed healthcare workers had observed other

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healthcare workers refusing treatment and refusing admission. And 66-percent had observed the refusing of care and around 42percent had refused the access to hospital admission.

And this data is very important because it's rated a possibility that patients with HIV/AIDS may not will utilize healthcare services because they are denied access. And that is the one thing we need to address.

Looking at another list of studies and try to understand why healthcare workers are discriminating. You can see that there's a direct relationship between knowledge regarding high HIV transmitted, the adherence or availability of universal precautions, and the perception of HIV acquisition by occupational exposure.

And if you overestimate your occupational exposure and risk of occupational exposure or you have put availability of universal precautions or you don't adhere properly to them you will have stigmatizing attitudes and behavior from current team from people in Madagascar.

And team setting saying HIV infected people should be quarantined to having reservations of keeping HIV infected people and viewing them with fear.

And the worst part of the study for me was that doctors didn't do as bad as other healthcare workers in their discriminatory practices.

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We also see because of discrimination people use universal precautions in inappropriate fashions and these are just quotes from people from qualitative data saying that in some settings nurses would wear double gloves.

They would wear a mask when they change linen. They would keep the sheets separate. They will burn the linen. And they will even throw away the utensils of people living with HIV and AIDS.

Looking at healthcare workers perception on ARV access and PMTCT settings two studies one from Zambia and one from Vietnam show that 84percent of healthcare workers in Zambia believe that the diagnosis of HIV was associated with negative images such as prostitution and marital infidelity.

Forty seven percent of them said they personally felt that HIV was something to be ashamed of. And what's very scary in this study was that 60percent of healthcare workers had chosen not to be tested. They would rather not know if they were HIV infected.

So in Vietnam some of the healthcare women who were HIV infected who were trying to access care in [inaudible] settings said that HIV related stigma was a major hurdle for them to access care. And in this stating none medical staff were identified as perpetrators of discrimination.

So as you can see even in Zambia it just seems that healthcare workers are influenced by the discrimination

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that's seen in communities. And that their perception and education may represent a significant barrier to help people access health.

If you look at further attitudes of healthcare workers you can see that the issue of the layers of stigma that we've seen. You know, if you're HIV infected you have extramarital affairs, you're drug users, and you're sex workers.

A person living with HIV has refused [inaudible] people so they don't have faith. They don't examine patients. They forget to do their dressings and then give them medication.

So stigma as you can see the different layers of HIV of stigma the different layers that people experience. So how does this all affect treatment? And I think that's a very important issue.

And you can see that HIV positive persons may not seek treatment or delay going to doctors due to a real or perceived discrimination against them, and looking at a survey done in the US, 36-percent of [inaudible] experiencing discrimination by a healthcare worker, including 8 percent who had been refused medical services.

Those who had experienced stigma were also more likely to miss an HIV clinic appointment, less in adherence,

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and missed the appointment [inaudible]. There has also been actual denial of care that has also occurred.

In the study done in Botswana which has been recently published it seems that access to heart has appeared to reduce stigma in Botswana. So here we have an example that at a community level the introduction of heart possibly we can start seeing reductions in stigma.

Looking at some work done in Toronto as I just want to show you the issues around layers of stigma, you know, and the perception that there are good ways of getting HIV and bad ways of getting HIV.

And to say this is a clip from Ann Silverside who was told the story, Why don't you tell us you're a hemophiliac? And those in downtown Toronto teaching hospital heart activist James Cretna [misspelled?] when he was in hospital with an AIDS related illness in 1990's. We would have treated you much better.

This is one of the most important slides that I'm going to show you. And it shows you the layers of stigma in access due to heart. There's an estimated 36,000 intravenous drug users who are receiving heart by the end of 2004. And of these 36,000 30,000 lived in Brazil.

In Eastern Europe and central Asia 70-percent of HIV cases are attributed to intravenous drug use. And this slide

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shows the abysmal lack of access of intravenous drug users to treatment.

So what contributes to discrimination? And I think something a thing that's coming out of this conference is the low morale and lack of resources in healthcare settings.

And there was a study presented yesterday from South Africa and it was a quote from a nurse that said If I had wanted to be an undertaker, I wouldn't have trained as a nurse. There's also a lack of understanding how HIV's transmitted in a healthcare setting. We overestimate our risks. We don't have access to use universal precautions. We're not supported with good HIV/AIDS policies and programs.

And the lack of access to materials to augmenting universal precautions and to protect healthcare workers against occupational exposures seems to be a major factor to discrimination.

So the important question is can healthcare workers change their attitudes? Can you teach an old dog new tricks? And I think we've seen from previous speakers that they are instruments that can look at and measure stigma.

And also there are interventions that you can put in place that'll help healthcare workers address the issues of stigma. And these are the results from a study in India that showed that often intervention doctors and healthcare workers were more likely to seek informed consent before voluntary

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counseling and testing to always seeking formed consent to arranged pre and post-test counseling to use gloves to draw blood in people whose faces they did not know.

And improve access to post exposure profalactives. So in conclusion stigma and discrimination can impact an effect of prevention care and support and litigation of HIV/AIDS. People living with HIV/AIDS have identified stigma and discrimination amongst healthcare workers in UCT and STR facilities as a major deterrent to use these services.

Healthcare workers appear to play a role in exacerbating stigma and discrimination. The support and training healthcare workers can position themselves as key partners to improve the healthy environment for people living with HIV/AIDS.

And I'm going to end with a quote from Nelson Mandela. And talk about [inaudible] and decency. And it's an elemental matter of human decency and history will judge us where history was once in thanks.

[Applause].

MARY ROBINSON: Thank you very much Glenda. I think you've brought another important piece to what we need to consider in looking at strategies to combat stigma and discrimination and the prevalence of stigma in doctors and healthcare workers.

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And that we can do things about it. So we have to build that also into the universal access plans. That's another component. And I'm very glad to say that our final speaker, Dr. Charles Katende is in fact a particular expert on monitoring and evaluation and on measuring that stigma.

He has a Ph.D from the University of Pennsylvania. He's worked on stigma and issues for programs of USAID and supporting their HIV and AID programming. And he has contributed to the development of indicators for stigma and strengthening of measuring and evaluating systems.

And he sits on the UNAIDS monitoring and evaluation reference group. I haven't tried to curtail any of our speakers because I think the content of their PowerPoint presentations re so good.

I'm not going to curtail Charles. I hope he won't abuse this. But we will have at least a half an hour or near a half an hour afterwards. I want you to be thinking about your questions, your comments because I think this has really been a very expert panel.

And that we have learned a lot already. So over to you Charles to be disciplined because I'm not going to discipline you. Thank you.

CHARLES KATENDE: Thank you very much. It's my pleasure to be presenting to you this experience on through testing stigma measurement tools. We have heard about, the

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various speakers have talked about the stigma's. How it is happening in different populations, healthcare providers, in the general operations.

And now one of the challenges that remains is how do we adjust stigma. Stigma needs to be measured because stigma is an evil that we need to track and know where it is so that we can address it with the appropriate strategies.

We also know that we need to measure stigma because as you know the donors would like us to be able to measure progress on stigma reduction problems before they can give us the funding.

So it is very important to come up with some measures that can help us measure stigma reduction. And measure progress of stigma reduction programs. Unfortunately stigma is a complex phenomenon.

It will cause in different populations. In manifest in different ways. And even when you focus on a particular population it's difficult to measure it because stigmatizing acts can't easily be accorded and measured.

If and when you ask people to report them people do not likely to be separate report if they stigmatized, so if here's an accomplice in and you need to find some ways of how to go about it to actually get a handle on measuring it.

In this regard some progress has been made on how to measure stigma. In this progress includes, for example, a

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stigma framework has been developed. As you know in program monitoring a stigma framework is a basic tool that we need for you to be able to do any indicator, development, or measurement.

So I'm glad to report that at least there is an emerging framework that you can use to measure stigma. And using that framework, stigma indicators have been evolved and actually a few tested.

And of course from the field testing we now have some of these tools that are available for people to use to measure stigma in their own programs

Now let me say up front that we still need further field testing because the field testing needs to be done in different contexts, at different sites. So the struggle continues.

Now let me talk about the framework that is emerging. And this is my presentation of the framework that has been used to field test stigma indicators.

This framework shows basically events as in their cultural ordering in terms of background, the underlying factors to stigma, the enacted stigma itself, and the manifestations that is the results of the stigma.

The underlying factors are actually some of the elements that programs focus on when they want to implement stigma reduction programs. They focus on the knowledge and

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fear and they focus on the value-based stigmas, which are basically sitting ashamed, judgment, blaming.

And they know so it is legal reforms and policy frameworks. Then the united stigma of course is the actual stigma itself, gossiping, avoiding, discriminating, isolating and so forth.

And then there's other. This is the self-isolation, disclosure and decline to use services and this is what actually fuels some of the epidemics and prevents our progress on the universal access.

In terms of measuring, you would want directly measure an active stigma. Okay because this is the gist of the matter. However as I said before it is difficult to measure, this active stigma because the stigma plays in arts are not there for you to measure them.

They are kind of heated. So you need to also to look somewhere else. But also remember that programs mostly focus on the underlying factors.

So that means that for measuring we need some indicators at the level of the underlying factors because programs would need to measure these to further progress their stigma reduction programs before they can claim they actually reduced stigma.

Of course there is also the manifestation level where one could measure stigma using at a disclosure, declad

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[misspelled?] use substance. But this is now as a proxy because you assume that for example if this disclosure increases then you are sure and somehow the stigma must have reduced and probably claimed that the program was successful.

Now we're going to share with you some of the experience that I've used in this framework to develop indicators. The first experience is the through testing of indicators in Tanzania and my colleague Laura has mentioned about these.

This was an effort to basically improve what was called existing indicators. You know, we used to use indicators like would you by food from an infected person and would you later teach a teach.

And these are the kind of existing indicators that we try to look at and it's thought that they were not good enough and we went to try to make improvement of these indicators.

The proper social was too few tests indicators, focus specifically on the dimensions that I have shown in the framework. The field testing was based on three populations, a community which is like a general population, the healthcare providers and people living with HIV/AIDS, these who are basically [inaudible] in this populations.

Let me now present some of the results from this. I begin with a fear dimension. The idea here was to field test

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an indicator that you would say the percentage of people that have fear of casual contact.

People have a lot of fears of casual contacts with who are living with HIV/AIDS ranging from fear of saliva, even a child playing with another child, sharing utensils, caring for a sick person, sleeping in the same room, sitting next to a person who's infected, sometimes live in fear talking to a person who's infected.

So all these fears now have to be measured in order of you to capture to what extent there is fear because it is that fear that leads to stigmatization. The results show that of all these fears, you know, these are different results for the different fears.

And overall for 46.6 had a fear of one of these. And the analysis, the indicated involvement analysis showed that you could actually give up an indicator that uses only about five of these items. Those five items would actually capture all of the fear that was actually reflected using all the items.

So in terms of the whopping indicators, the recommendation was you need to get items that actually measure the fear because that is an improvement from the previous indicators. Here we say do you fear X, Y, Z?

And then you need to measure several of these items and for these items you can get at least a five that will be

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sufficient to capture the level of fear prevailing in a community.

The next one was about the value based stigma, which is has if you're feeling ashamed, blaming and judging. Again, we field tested several stigmatizing attitudes and the results actually showed that to develop indicators using this kind of segment, you need actually to involve two indicators.

One indicator focuses on items that focus on shame. And another indicator focuses on items that focus on blame and judgment. So there are two indicators.

But also what is interesting with this stigmatizing attitudes was that when we ask people if they individually accept it, you can see the results for example for accepting that HIV is a punishment was about 39-percent.

But we asked them, do you think people in this community would accept this sentiment? A lot of them say, yes I think in a [inaudible]. So this was a very interesting finding but we haven't explored more of that.

But the ideals that the indicator here was the two indicators, one was shame and one was [inaudible] judgment. And each of these indicators requires at least a three items to measure properly.

We measured other dimensions experiencing stigma. And these were many items. The key thing to notice here is the difference between male and female and from this the

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indicator recommended is that an indicator that uses at least one item from the different forms.

All these items belong to about four forms of stigma. Basically it's just, you know loss of respect, isolation and [inaudible]. And the [inaudible] was that if the indicator should indicate at least one item from each four.

These are the conclusions of which have mentioned and I will not repeat that since I'm out of time. Maybe to mention that when we measured the not have stigma we found that it best was for the population people living with HIV/AIDS and not so well with the general community.

The full report for this field testing is available on ICIWCD's and on the site. And on the [inaudible]. Briefly let me talk about another effort of field testing indicators.

And that is the future index. The future index is being developed to focus on the people living with HIV/AIDS. This is best on seven stigma dimensions and it has an approach which emphasizes using the people living with HIV/AIDS like it would be the interviewers and the [inaudible] people living with HIV/AIDS.

It also provides an opportunity for people living with HIV/AIDS to actually self calculate an index. And that empowers them because if they know how much stigma they have then they can catch some actions.

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The field testing for this would be done late this year. And of course the people living with this the UNA's ICW IPPF and ENT. I mentioned that so let's, I'm out of time.

These are the dimensions that have been measured using that effort. Did that experience of stigma [inaudible], the internal stigma, rules and policies, productivities [inaudible] to confront stigma, disclosure and confidentiality, point of care, and [inaudible] stigma this condition.

I want to conclude by saying the progress we have made in measuring stigma indicators is that we have some work and the framework has been used to field test indicators. And indicators are actually now available under the sources I've mentioned.

So programs can actually go to those resources and adopt some of those tools to measure stigma disconnection in their own programs. It is important to remember that the indicators recommended for specific populations and they're recommended for specific dimensions.

And whereby in each dimension you have several items that measure stigma. Did I mention specific approach enables programs to focus on specific items because programs may be focused on fear so they will have an indicator to measure fear?

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If they focus on value based, they will have an indicator to focus on value based and so on and so forth. Also it is important to desegregate by gender as we have seen and there is a big difference, gender difference in the stigma discrimination.

I would also say that they are complete now tools available. So feel free to visit those sites And I think we have also here some, I think Laura my colleague here from ICW has those CDs so people can access them.

But those CDs have the tools that you can use. But lastly we still need to field test because, you know, the field tests we have done have been in a few sites. And we still need more sites.

But we are on the way and there's hope. We have the indicators in place. Thank you very much.

[Applause]

MARY ROBINSON: Thank you very much Charles. I'm really sorry I had to cut you slightly short having said I wouldn't. But I've got bad news which is that we have to finish by 12:15.

So I see the people already moving to the mikes. And I would actually urge anyone who wants to contribute to move to one of the mikes. I'm going to start with the middle mike, mike two because there seems to be a crowd gathered there.

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And I'm going to take as many questions as possible. Leave less time for answers because actually your points, your questions are important for all of us to hear. So start with two and then I'll move to three. And so anybody on one yes and one. We'll get a whole line on one there.

So I'll start it I'll start it will two, three and then one. Yes.

NADINE FRNACE [misspelled?]: Okay. Two going first. Hi my name is Nadine France from Health and Development Network based in Thailand. I have two questions. One for Mandeep.

And that is we heard today and we know well that the worst forms of stigma are experienced in the health setting. Also in form from research by Shelly Nee Barrett [misspelled?] which I'm sure most people are familiar with.

Could I ask Mandeep for you to describe the PWA friendly checklist that's based on the baby friendly model? Just a little bit so that people know a little bit about that. And also if you know something about plans to scale that up what they are.

My second is more a comment with a question on the end. Recently in Thailand we had a very well known activist and very good friend who passed away. She passed away and the circumstances of her death were not clear. She was refused an autopsy because she was HIV positive.

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It was clear and it was on the autopsy. This is in a place in Thailand which is often sited as a place where stigma and discrimination are quite low. What can we do about that? We're devastated, her family is devastated. Thank you.

MARY ROBINSON: Okay. Thank you. Mike three.

RHADIA MATAI [misspelled?]: I'm Rhadia Matai representing a paid base organization. I just wanted to draw the attention of this group to the fact that in any developing country and in most developing countries 40 to 50percent of the healthcare is given by faith based organizations.

And faith based organizations are very important gatekeepers of communities. They can either make the trust of the communities or break the trust. And I think to shake this giant and tap their resources is very important.

Unfortunately in many cases the churches are the one that promote stigma and discrimination. We have to systematically work with them in many communities. Thank you very much.

MARY ROBINSON: Very good point. [Applause]
Microphone one.

SUSIE MCCLAIN: Thank you. My name is Susie McClain. I'm from the international HIV/AIDS alliance. And I wanted to raise a question or a concern really that when we talk

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about the root causes of stigma, I was surprised that there wasn't more discussion about homophobia, misogyny, stigmatizing attitudes towards drug users as many of the root causes.

Not the only root cause but many of the root causes of stigma. And I accept that fear of virus is an important drive or stigma. But I also think while many of us know that homophobia, stigmatizing attitudes towards drug use are at the base of HIV stigma.

And then I just wanted to it's point for the final speaker really to urge that when we describe the manifestations of stigma that we not forget violence and indeed murder.

And a reminder that openly HIV positive activists in places as diverse as South Africa, China, Mexico murdered for being openly positive. Paying the highest price of all for stigma.

MARY ROBINSON: Okay. Thank you. Microphone two again.

KATHERINE DODS [misspelled?]: Hello my name is Katherine Dods. And I work with Stigma Research in the UK. And my point follows on directly from Susie's. I just had a question possibly for Mary actually. And as well as Laura and Charles.

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What practical examples have you seen where governments recognize that addressing stigma is not about just funding poster campaigns but actually adjusting the inequalities that Susie was talking about?

For instance in the UK our department of health strapped action plan of stigma and discrimination which is meant to be an action plan has no actions that address law and policy. And like Mandeep said that makes me very embarrassed to live in the UK.

The Department of Health's views that they can't tell other government departments what to do. So do you got any practical examples of how that kind of internal situation has been addressed successfully?

MARY ROBINSON: Good. Very good question. And did you want to jump in there? Okay.

FEMALE SPEAKER 1: A couple of points. I mean I think countries that have enacted positive legislation, model legislation around HIV are a good example of countries that are making a commitment to addressing stigma and discrimination.

However, that said if legislation and changes in law and policy and action plans are not combined with community level education, education of policy makers, and real access to justice and legal services, it falls short of a response. So I think it doesn't go far enough.

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I want to say two other quick things. One about the stigmatization of healthcare workers. So I'm quite a bit of work in Zambia. And talk lots to healthcare workers who are terrified to get access to treatment. And they're giving out treatment.

They know they need it but they refuse to get it because they're afraid. I think that's an important thing to remember. The other thing is the re-stigmatization of tuberculosis because of HIV.

And that's another dimension which I think needs further exploration and challenges around addressing TB and HIV in an integrated manner. If we're restigmatizing TB in our scaling up of HIV services is also something we need to look into.

MARY ROBINSON: Thank you. I'm feeling the challenge of the chair. We're really going to get as many things in as possible until they tell us that we have to stop. Microphone three.

SARAH EPSON [misspelled?]: Yes, my name is Sarah Epton. I'm from Duke University in North Carolina. My question is about when you're measuring stigma even in populations where the knowledge level might be relatively high about means of transmission and that sort of thing.

How do you address the issue of resonance, trying to give the right or the correct answer in an attempt to try and

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please whoever's conducting the survey and therefore not really getting an accurate portrayal of what the stigma issue might be in that population. Thank you.

MARY ROBINSON: Laura do you want to jump in on that one?

LAURA NYBLADE: Yes. I think you're talking about does our ability bias. I'm sorry there's an echo in the mike so it's a bit hard for us to hear you. But I think, you know, Charles but up the slide that where you ask the questions both of the individual and then how they perceive that the community would respond is one way to get around that.

And as you saw in that slide there's a huge difference in the response there. We don't have a way of knowing whether that social desirability bias or whether that is really a difference between actual stigma, and perceived stigma, the perception of what's out there.

I would argue that the perception of stigma is what really counts because that's what keeps people from addressing services. So it's very important to measure what people think is occurring in the community.

MARY ROBINSON: Okay. Mike one.

KALADOM MIRA [misspelled?]: Hi. My name's Kaladom Mira. I'm from South Africa. In South Africa many studies are showing quite low levels of stigmatizing attitudes in the

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general population but very high levels of perceived stigma and internalized stigma amongst people living with HIV.

So in that context surely of activists of consistently highlighting high levels of stigma in a general population. This is actually contributing to increase perceptions of high levels of stigma from the perspective of people living with HIV. And actually contributing to the problem.

MARY ROBINSON: Okay thank you. Mike two.

DEEPAH ROW [misspelled?]: Hi my name is Deepah Row. I'm from Northwestern University in Chicago in the United States. And my question is for Dr's Nyblade and Katende.

I wonder if you could speak more to how women experience stigma differentially. And my question is if they do experience stigma differentially, how do we measure it and intervene in a universal way if in fact it is different.

MARY ROBINSON: Okay. Quick answer?

LAURA NYBLADE: Sorry. We're having a really hard time because of the echo. So you're asking how can we have universal measures, differential measures if it's experienced differentially.

DEEPAH ROW: Right, right.

LAURA NYBLADE: I think what we did when we were trying to look at sort of developing indexes was actually in which we were looking at which items to keep we looked

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specifically at whether there were differences in experiences by men and women. I think there's also an issue of age perhaps there that we weren't able to look at because of our sample sizes.

But in those measures that and in the report where we present, you know, of the we started with 17 measures which ones remained. We looked specifically and made sure that items that men or women were experiencing substantially in different ways those were kept in so that you had those so you had an average.

I think, you know, the basic also that you just have desegregate all your data by always by the experience of different groups. And I think also the point about, you know, needing measures of homophobia and measures around stigma around drug use. I think this is one of our big challenges is actually the layering of stigma.

And we're actually doing work in Vietnam right now where drug use is sort of the underlying stigma in a big way. And so we're trying to keep that apart. But we still have a long ways to go on that.

MARY ROBINSON: Thank you. Mike three.

JOHN TUMANO BUSIER [misspelled?]: Thank you. My name is John Tumano Busier. I work for Handicap International Bus in Kenya. During the whole station you

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mentioned so many times [inaudible] other group. But I did in fact about people living with HIV/AIDS. And --

MARY ROBINSON: I'm going to actually stop you there and say quite honestly if you hadn't done that, I was going to do it before the end. I promise you because it came up yesterday in something of that as well. And you've made your point, honestly. You're right.

JOHN TUMARO BUSIER: Okay.

MARY ROBINSON: So I'm going to go to mike one now because we have to get as much in. But you're absolutely right. Well done. Okay.

RON STRAUSS: Ron Strauss from the University of North Carolina Chapel Hill in the US. And this is for Glenda Gray. Clearly we're all very concerned about the experience with healthcare workers that are stigmatizing.

And I'm wondering if there couldn't be some discussion about the use of health professions education, medical school, dental school, nursing school as a vehicle to respond to attitudes and to relinquish the people who have stigmatizing orientations to rethink who they are and what their values are.

Are there any exemplars? Are there examples of that happening?

MARY ROBINSON: Yes. Yes.

GLENDDA GRAY, M.D.: No I think the training --

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[Inaudible]

GLEND A GRAY, M.D.: The training of nurses and doctors is around HIV/AIDS is abysmal. And the issue around looking at stigma has not occurred. And it is an interesting thing. I think we need to look at the levels of stigma and start working on how to address. I mean it's quite (motifectolian) for the epical.

It's a lack of the low morale of stuff, the lack of political leadership, the lack of ongoing support and training, the, you know, the human resources, some all to treat factors. But our medical schools and our nursing colleges have not identified HIV/AIDS as an important part of training. And that's I think that's the core problem.

LAURA NYBLADE: Can I just add to that I think that medical school is too late. And it was born out in some of the consultations around universal access where in countries where homophobia exists so strongly where HIV activist have been killed.

Those are the countries that are suggesting that actually we need to start much earlier in school with specific education not just on HIV but on gender and sexuality and sexual orientation. But it has start when people are much younger because medical school is just far too late.

[Applause]

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MARY ROBINSON: Mike two.

ROBERT PLITSMAN [misspelled?]: I'm Robert Plitsman from Columbia University in New York. Thank you for an excellent panel. I have a little sense of déjà vu since a lot of these issues came up in the United States in the mid and late 80s and early 90s.

And there was quite a bit of work done on it then by Greg Harik [misspelled?], Scott Burrs [misspelled?] et cetera, might help inform some of these efforts. Just two quick things.

One to follow up on the last question is that it turned out in the US I think that professional organizations did a lot of important work. I mean the AMA and other groups in state medical associations came down quite hard on doctors typically surgeons for instance that refuse to treat people with HIV.

And I think that's the degree that professional organizations and professionalism as a concept to be mobilized I think would be great.

And secondly some work that I and others did found that if you ask people, have you felt stigma? They'll say no. They really don't. Stigma is our term. I think it's very important to keep in mind those of us who have been trained in social science to some degree.

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And patients don't think of stigma as a concept. But if you ask them they'll tell you about time that they've been denied services or that they weren't treated the way they should so in terms of methodologically going forward I think it's important to keep in mind. Thank you.

MARY ROBINSON: Very good point. And we're actually getting very good points and very good questions. And we have in fact in some method another five minutes. So I hope we get to most of you. And if necessary I'll get quick answers if I can. But mike three again.

MALE SPEAKER 2: Okay. Thank you again. I was saying no body mentioned about people with the ability just because really retain that they are not eligible for sex. They are not eligible for sex and therefore they cannot be a vulnerable group for HIV/AIDS.

[Inaudible] me please from now getting these of that's changing. [inaudible] that's people with these ability account for almost 10percent for any given population. How can we fight this intensity with stigma?

How can we achieve universal access to care putting aside 10 percent of all the population?

MALE SPEAKER 3: Could I make a suggestion because your points are absolutely right? Could I suggest to our panel that when you talk about vulnerable groups in the

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future you do actually specifically refer to those with disabilities because the point is absolutely right.

MALE SPEAKER 4: Okay. Thank you.

MALE SPEAKER 3: Okay. Thanks.

DAVID MARTO [misspelled?]: My name is David Marto who is working with the AIDS support organization in Uganda. My concern or question is can we include children as a special group and those people who are being discriminated against?

As infected, affected, or orphaned, I think we need to have a special group of those special people to be considered when we talk about discrimination.

MARY ROBINSON: Very good point. I'll ask Laura to respond briefly.

LAURA NYBLADE: Yes. That's a very good point. I just want to point out that tomorrow afternoon I think it's the -- if I read the program right at the last session of the day there is actually a session on stigma and discrimination in children tomorrow.

So it's great to see that the conference has put a focus on that.

MARY ROBINSON: Yes and actually [inaudible].

MANDEEP DHALIWAL, M.D.: I just want to answer the question about the checklist that was first asked. And there is a very interesting tool that's been put out by horizons

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and population counsel in India called PLHA friendly checklist about how to improve the quality of services so that they're destigmatizing and more friendly.

And there are many, many such tools out there. And I think, you know, while we call for evidence and research and the development of new tools, I'd like to echo some of the points that have been made about using existing evidence and tools that are out there to scale up.

We're only 3-1/2 years or 4 years away from universal access. I wouldn't invest too much more in new research, I'd get out there and work with what we have.

[Interposing]

MARY ROBINSON: In fairness it's the organizers. I'm going to take one more from each mike. And then we'll just have to leave it so yes, two.

ELENA VIETA [misspelled?]: My name is Elena Vieta from Argentina. And I am here for AIDS care watch campaign health and development network. I'm really happy to see Anuar and to see Latin America which is being really forgotten for many years.

And as a matter of fact since Pan American Health organization had a multi center study on sigma in the healthcare setting. Then afterwards nothing was done with it and with the results.

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When we have stigma and discrimination in all of your healthcare settings in Latin America throughout it. So we'd actually [interposing]. And--

MARY ROBINSON: Very briefly.

ELENA VIETA: -- the question is the toolkit is it available online first? And second is it available in Spanish? Please, the second language spoken in the world. Thank you.

MARY ROBINSON: I think the answer is yes, but Laura?

LAURA NYBLADE: Yes. We have been struggling and I think this goes to your point about Latin America being forgotten. I will say right now we've been struggling to find funding to put the toolkit in Spanish. And that makes your point completely.

MARY ROBINSON: Okay. You might even get a volunteer somewhere out of here. Yes, mike three.

LIZ FROSTIOCON [misspelled?]: Hello. Thank you. My name is Liz Fristiocon from the BBC World Service Trust. I'd like to thank all the presenters for a very good session. Very challenging and very heartening as well.

I support and agree with all of the points been made about the need for accurate and positive portrayal of HIV positive people, people living with AIDS in the media. But I'd also like to express a concern specifically about unintended effects and perhaps stigmatizing effects.

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Indirectly communicated by prevention campaigns and other campaigns. And so I was going to ask a question. But now I'd just like to pose the comment that I believe these materials are not just going to be valuable for anti stigma work.

I would just encourage anybody doing education to consider these issues at all stages of their education work. Not just when it comes time to do anti stigma work. Thank you.

MARY ROBINSON: And also maybe since you're speaking from a context of media. And a lot of what we've been talking about is also something that the media needs to be very much on top of. And, you know, and mike one. Yes.

AMI BISHOP [misspelled?]: My name's Ami Bishop from Pass. And I just wanted first of all to thank Mandeep for mentioning the TB and HIV connection. That was something I was going to raise and now I don't have to. But it's very important.

The main point I would like to make is just quickly that while I share Laura's observation and belief that the issues of stigma are universal as someone who works predominantly in Eastern Europe I notice a complete and total absence of dimension of that region.

And I think that in some ways that region is probably a decade or two behind any of the other regions of the world

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in dealing with these issues and it has to do with all sorts of structural issues, political issues. As well as the topic at hand.

So since you put out a call for interested people to or interested groups that might want to help pilot test or evaluate some of your tools, I'm just making an offer that our program in Ukraine would be more than happy to collaborate with you.

MARY ROBINSON: Thank you for a very good point. And for a very good offer. I think you'll probably find it's going to be taken up and if anybody wants to make one last comment from the panels because I haven't really [Inaudible]. But we really have to stop then.

FEMALE SPEAKER 1: My last comment is to go back to my plea at the end of my presentation. For everybody who is in a country where universal access plan is meant to be made by the end of 2006, get in touch with your UNAIDS office.

They're meant to be supporting countries to develop their universal access plan. And that these plans must include adequate concrete stigma reduction interventions and a budget to go with it. Otherwise we're not going to get where we need to go.

MARY ROBINSON: Okay. And I think I'll have to take that actually as the last point as a very good strategy point. And I have to thank an excellent panel. I learned a

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lot [Applause] from the presentations. And it's very good listening audience.

I'm sorry we couldn't take all the questions and very good comments were made. Come up afterwards if you've got other points. Thank you.

[END RECORDING]