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**Getting to Zero Excuses: Understanding and Addressing HIV
Related Stigma and Discrimination
Kaiser Family Foundation
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SUZETTE MOSES BURTON: Good morning, it's nice to see such a full room on the last say. Good morning, welcome to Getting to Zero Excuses: Understanding and Addressing HIV Related Stigma and Discrimination. My name is Suzette Moses Burton and I am the HIV/AIDS Program Manager for St. Martin in the Caribbean and also the Chair of the Caribbean Regional Network of People Living with HIV and AIDS and the Co-Chair of the Leadership and Accountability Program Committee for AIDS 2012.

As we draw to a close today I have the honor and the privilege to have as a Co-Chair of this session, the Honorable Prime Minister of St. Martin Sarah Westcot-Williams and a rather distinguished panel whom we will introduce to you shortly.

HIV stigma and discrimination are consistently recognized as critical barriers to uptake of treatment, disclosure of status, timely entry into care and adherence. Yet investments in community level, stigma and discrimination reduction efforts remain small in comparison to the stated need.

This session will look at critical areas that may be hindering or working to facilitate a more concerted response to stigma and discrimination and thereby influencing the

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successful rule out of treatment as prevention and the elimination of vertical transmission of HIV.

We have with us on the panel this morning, and I will introduce the first three speakers and then I will ask my Co-Chair, The Prime Minister to introduce the last two speakers and take us directly into the session. Our first speaker will be Miss Georgina Caswell who is a community advocate born in Ghana and living in South Africa. Georgina works with GNP+ as a Program Manager, she supports networks of people living with HIV to gather evidence about their lived experiences and use this evidence for advocacy.

Our second speaker Mr. Maurice Tomlinson hails from the Caribbean island of Jamaica and he has been involved in HIV/AIDS and LGBTI activism in Jamaica for over 12 years. He is an attorney at law and law lecturer with current research interests in sexual rights and HIV/AIDS advocacy.

Our third speaker this morning is Miss Shari Margolese of Canada, HIV positive, CBR Consultant, Women's College Research Institute. Shari has been an advocate for HIV positive people since shortly after her own diagnosis in 1993. Her work as a community consultant and researcher with the Women and HIV Research Program, Women's College Research Institute in Toronto includes various community based research projects focusing on the sexual and reproductive health of

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people living with HIV. To introduce the final two speakers I'm going to call on my Co-Chair, Prime Minister.

SARAH WESCOT-WILLIAMS: Our fourth speaker for today is Laura Nyblade. Laura Nyblade is a Senior Technical Advisor on stigma and discrimination for RTI's Global Health Group and the Health Policy Project. She's global expert on HIV and related stigma and discrimination with more than 15 years of experience in HIV and AIDS research and program evaluation throughout Sub-Saharan Africa and South and Southeast Asia. She will speak to us today on the topic; what works for reducing stigma and discrimination? Programs and tools for reducing stigma and discrimination including human rights approaches.

Our final speaker for today will be with her approval, Oanh and she will speak to community response to HIV stigma, the case in Vietnam. Oanh strives to improve public health in her native Vietnam by reaching out to at-risk populations through medical services, advocacy and education.

Oanh co-founded the Institute for Social Development Studies where she works as the Director of the Center for Health and Social Development. She works to improve treatment for HIV/AIDS patients and advocates for harm reduction approaches to prevent HIV transmission from intravenous drug use. It's my pleasure to invite our first speaker to the lectern [applause].

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GEORGINA CASWELL: Good morning everyone. I think I expect more from a big room, good morning everyone, that's more like it. Now I'll pretend you're not all there. My name is Georgina Caswell I'm Program Manager at the Global of People Living with HIV and my task today is to introduce to those of you who don't know about the PLHIV Stigma Index, to introduce the PLHIV Stigma Index to you. And to share with you how, by using this tool we're actually generating solid evidence of stigma and discrimination, where it occurs and how it's manifested.

At the conference throughout this week I'm sure you've heard the word stigma thrown around quite a lot, so when we talk about access to services and people say but why don't women come forward and access services? Someone else would say stigma. Or why do people not take their medication? Someone else would say stigma.

The PLHIV Stigma Index actually measures, it actually documents—it's specific about the stigma and discrimination that's experienced by people living with HIV. Today we have more than 36 countries that have implemented the PLHIV Stigma Index and it contributes to our understanding of the extent and different forms of stigma and discrimination.

It's an information gathering tool and evidence gathering tool that was developed by a partnership of GNP+,

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ICW, IPPF and UNAIDS. Basically there's a methodology and there's a questionnaire, the question looks like this and the questionnaire has over 100 questions in 11 different areas speaking to the experiences of people living with HIV in the workplace, healthcare setting, issues to do with internalized stigma, et cetera.

But this information gathering tool is extra powerful because the process itself is really, really important so with the PLHIV Stigma Index it's led by networks of people living with HIV in countries, so they actually lead the entire process and people living with HIV are the interviewers as well as the interviewees in this research.

What I'm going to do today with my 10 to 15 minutes is to give you a sense of the kind of information that's collected by the PLHIV Stigma Index. I've picked four countries with support from colleagues, we've picked four countries are on the on the stigma index website and we've picked five questions. So this is a snapshot of the data from the five questions from the four countries, so Columbia, Ukraine, Zambia and Nepal.

Starting with Columbia, in Columbia the PLHIV Stigma Index was led by the Columbia network of people living with HIV and there were exactly 1000 respondents which is really great when you're doing percentages. So really, really high percentage, 32.7-percent of people living with HIV that

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responded to the stigma index said that within the last 12 months they felt excluded from family activities, 26.8-percent experienced some form of physical assault.

Twenty nine percent experienced being denied some form of health service, 10-percent lost a job due to HIV and 19.6-percent felt at some point suicidal. If we look at the 32.7-percent, the highest number there that felt excluded, the epidemic in Columbia of course amongst gay men and other men who have sex with men, sex workers, people who use drugs, it's a concentrated epidemic.

But in the analysis in terms of who felt excluded from family activities, the largest number were sex workers living with HIV followed by transgender people living with HIV. So this is the Columbian picture for five questions only, in a very big questionnaire with a lot of information behind each of these questions.

But if we move to Nepal there's a different kind of picture. In Nepal there were 848 respondents which makes it a bit harder for percentages and the Nepalese network of people living with HIV actually led it with the Family Planning Association of Nepal.

In Nepal 7.4-percent felt excluded from family activities and 3.4-percent experienced some sort of physical assault, 7.3-percent denied health services, 11.7-percent lost

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a job due to HIV. And their highest, just from these five questions were those who felt suicidal at some point and that was 15.3-percent of people living with HIV.

When I looked at amongst those who felt some form of internalized stigma, and there was a follow-up question about what kind of measures did they adopt based on how they felt about themselves. From the analysis the top three measures were A)they decided not to have more children, B)they decided not to get married and three, they decided to become celibate. So that's the kind of impact that they reported on from feeling internalized stigma.

Moving to Zambia where there were 854 respondents, similar numbers to Nepal, 27.4-percent felt excluded from family activities, 35.7-percent experienced some sort of physical assault, 8.4-percent denied health services, 39.3-percent lost a job due to HIV and 12.1-percent felt suicidal.

As you can see, the picture in every country is very different and when you look at the analysis for the 39.3-percent who said that they lost a job due to HIV, they cited two things. That A)discrimination experience from employers and co-workers but B)also due to their poor health they lost their job.

Then finally the Ukraine, in the Ukraine the study was lead by the Ukrainian network of people living with HIV and

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they 1,500 respondents. Seven percent said they were excluded from family activities, 15-percent physically assaulted, 20-percent denied health services, 5-percent lost a job due to HIV and then 8-percent felt suicidal.

So there the highest percentage from these five questions was amongst those who were denied health services and when you do the analysis for the Ukraine, one the of the explanations that was given was the fact that there are lot of migrants in the Ukraine people living with HIV who don't have the residential registration. Therefore their access to services is compromised.

That was a snapshot, as I said there's a lot of data behind each of those questions in each of the countries and that is available to us but the point is that data is being gathered, it's being collected, it exists and we need to be using it.

There's a lot behind the numbers, these numbers very much represent real people, real stories and stories of personal frustration, difficulties, challenges within families, communities, the workplace and in the healthcare setting.

They have an impact, the impact of stigma is also not just at the individual level but also at the community level and at national level and stigma very much affects the quality of care that is provided by family members and by friends. It

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affects access to services and it affects someone's ability and willingness to start treatment or not or to continue taking their treatment and to stay connected with clinics.

Maybe I can just end by saying why is this kind of evidence important? This kind of evidence is very important because A)it helps to direct programs, so when we talk about stigma is a barrier and we talk about what is it that people are experiencing, what is it that will make them feel more comfortable about who they are and what it is that they want for themselves?

It's really important to have that data and it's really important to have data to direct programs and also to influence policy to make sure that policies in countries are supportive. That they're supportive of individuals, that they protect the rights of individuals and it also informs funding priorities. Where is it that we prioritize resources that exist?

Ultimately the evidence that is collected is about building a supportive environment to ensure that people living with HIV have services and that they have the support that they need for positive health, dignity and prevention. Thank you [applause].

SUZETTE MOSES BURTON: Thank you so much Georgina. I think it's really good, this initiative from GNP+ because we continue to hear—especially for those of us who work in the

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communities, that we need to have evidence-based decision making and this tool really is the first attempt at trying to gather data as it specifically relates to the occurrence of stigma and discrimination. And really then begin to build intervention programs targeted specifically to the types of stigma being experienced in the different locations where this research is being conducted.

I just wanted to say that we will take questions at the end of all of the presentations and there should be some volunteers in the audience with questions cards. So if you're interested in writing questions just signal to her so she can get the cards to you and then she will come back and pick them up from you after and get them to us. Our next speaker is Maurice Tomlinson who is going speak to us about HIV criminalization laws and the trends towards increased criminalization of people living with HIV, Maurice [applause].

MAURICE TOMLINSON: Thank you very much. I admit that I feel the least qualified to speak on this topic because my area of focus has generally been criminalization of marginalized communities specifically focusing on MSM and I've met so many wonder persons who are eminently more qualified to speak on this topic, some in the audience and I encourage you to get supporting if I leave out some things.

I'm going to talk about criminalization of people

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living with HIV and I wanted to reemphasize a point; that it is not persons who are diagnosed and are in treatment that are spreading the disease. It is persons who are undiagnosed and therefore more likely to be infectious that are spreading the disease. I would like that message to be drummed home to our politicians or policy makers, we need people to test so that they can be on treatment and less likely to infect. So anything that prevents that is harming public health, that's the take-away if you hear nothing else [applause].

I'm going to try and go through this presentation quickly, looking at the export of HIV specific legislation, the language of stigma and the law, problems we have with proof, pressing all laws into the service of stigma, the common law deadly weapon definition and where we are today. This, I find basically summarizes the ethos of HIV criminalization; fear in the '80's, fueled ignorance which resulted in bad law.

Now as a Caribbean lawyer, as a Jamaican lawyer the fund of our justice is the British System so I refer to the aims of criminal law from the U.K. Criminal Justice Act which has some resonance in the Caribbean. From this you can see that the aims of criminal law are the punishment of offenders, the reduction of crime, the reform and rehabilitation of offenders, the protection of the public and the making of reparations.

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So if that is the ethos, we can then use that as that the lens through which we view HIV criminalization. Does this work in relation to HIV criminalization? Where did all these HIV specific laws come from? In the early '80's we knew that the virus was identified and the hysteria began in earnest.

The San Francisco Police Department equipped patrol officers with special masks and gloves for use when dealing with the police called a "suspected AIDS patient". In 1987 the U.S. has its first HIV prosecutions and enacted the first HIV specific criminal statutes. The Ryan Care Act in 1990 required states to introduce laws criminalizing exposure to HIV as a condition for federal funding and the result was 34 states and two U.S. territories now have HIV specific statutes.

What's the problem with the legislation? I won't go through each, but in some the legislation is vague because of course they were developed in a period of hysteria, nobody sat down and did the analysis. There was a knee-jerk reaction, the public wanted something to deal with this death sentence so the result was you had vague, inconsistent and overly-broad legislation.

Most criminalized the possibility and not actual transmission, some outlaw acts with no significant risk of transmission such as sharing sex toys, spitting or oral sex.

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And some criminalizing non-disclosure even if there's absolutely no risk of transmission.

For example in Michigan, a person who knows that he or she has AIDS or knows that he or she is infected and engages in any form of sexual penetration, and it doesn't mention the use of a condom, you are guilty of a felony. Now this map is a bit challenging—well it's challenging for me but clearly it's much larger on your screen, which gives a graphic illustration of the number of countries that have not adopted legislation specific to HIV or have pressed into service common law languages that criminalizes grievous bodily harm et cetera, et cetera and used them to punish persons who are HIV infected.

We have now seen what I call a tsunami of HIV specific criminal laws overtaking the world. Singapore 1992, the Infectious Diseases Act criminalizing HIV non-disclosure, Bermuda followed in '93, Australia in '93, Denmark in '94, Cameroon, Zimbabwe, Nigeria, Angola and this tsunami was encouraged as everybody now knows, by the USAID Action for West Africa where the modern law on HIV was inaugurated or proposed and it led to 13 African countries adopting a version of the law, 14 have laws which now reflect some of the elements. Of course these are the countries with the highest HIV burden and in 2005 USAID considered this a great success.

Now in the absence of specific legislation, many

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countries have used as I said, common law interpretations of grievous bodily harm or assault, reckless endangerment, attempted murder, bioterrorism. Sweden says that consent is invalid if transmission occurs, however a condom may be a mitigating factor. These are just some of the examples of language or legislation or definitions of crimes which have pressed into service to criminalize HIV positive individuals such as poisoning. So that's the sad history.

In my country we have inherited the Offenses Against the Persons Act from Britain and more than likely we would, we haven't yet, but we would use grievous bodily harm as the classification of crime for transmission.

Now all is not doom and gloom, this is the level of persecution and prosecutions we have seen. The United States of course, everybody knows by now, leads the world following by Canada. So one has HIV specific legislation; the United States, Canada uses common law definitions, although British Columbia recently introduced specific legislation but we'll get to that.

So what is being prosecuted under the legislation and also in the common law? As I've said biting, spitting and other bodily fluid assaults. In 1998 a HIV positive prisoner's mouth and teeth were considered deadly and dangerous weapons. In 2008 a mentally ill African American was sentenced to 35

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years for spitting at an officer and this is 2008, I would understand if it was 1988 but 2008? I really am surprised.

Vertical transmission has also been prosecuted and in France and the United States, men have been convicted for vertical transmission. An HIV positive sex worker has been prosecuted for aggravated assault, it's an aggravating factor if you're HIV positive and blood donations have also been prosecuted.

The response from the international community has been to loudly, well not loud enough but, begin to push back against this trend of criminalization so the U.N. Human Rights Commissioner in International Guidelines on HIV and Human Rights said you should apply general criminal offenses to these exceptional cases when there's intentional transmission.

In 2002 a UNAIDS publication said that you should use alternative to HIV specific criminal law, in 2007 a UNAIDS and UNDP expert meeting spoke to the use of non-specific HIV laws to prosecute intentional, malicious transmission, that would be the preferred option. The Global Parliamentary Committee also spoke that HIV legislation further stigmatizes HIV positive individuals.

We know about the Swiss Statement which was confirmed in HBTN '05 too that persons on treatment are 96.something-percent less infectious in the heterosexual context at least

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and the U.N. Special Repertoire on the Right to Health said there's little if any benefit to HIV criminalizing but there's a real potential for alienation, stigmatization and fear and refusal to test, I should add. Criminalizing non-malicious HIV transmissions is inconsistent with the right to health. The most recent pressure we have seen is the Global Commission on HIV and the Law's recommendation that countries must not enact HIV specific laws.

The push-back and been negative and positive. We have seen Nebraska and British Columbia, as recently as 2011 passing HIV specific legislation based on bodily fluid assault. In 2011 Belgium has its first conviction under the poisoning law and the Congo also had its first HIV conviction under the same poisoning law which they obviously inherited from Belgium, in 2011 Romania passed an HIV criminal statue.

But there have been some positive developments which is where the metaphor of the tide turning has been used through this entire week and we must all feel seasick by now. Positive developments; 2005 the Dutch court used scientific evidence to narrow the scope of law to only intentional HIV exposure or transmission.

New South Wales also repealed their HIV specific statue, 2010 Guinea, Togo and Senegal restricted the criminal liability to intentional transmission of HIV, which is where it

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should have been in the first place and in 2010 the Austrian Justice Ministry said the HIV positive individuals who have oral sex and used a condom were no longer criminal. In Canada, a judge in 2011 said that HIV is no longer an automatic death sentence and I'm very proud of my region where in 2011 after a very contentious debate, the Ghanese Parliament reject an HIV legislation as being disastrous for public health.

[Inaudible] revoked criminalizing of HIV transmission, Denmark has suspended its notorious HIV law and Norway is considering a repeal. In the United States, we've seen Congresswoman Barbara Lee's efforts to repeal the HIV law [applause]. We are very hopeful that this will pass.

Now what's the verdict? Is there a trend toward criminalizing? As an attorney I'm of course, very cautious and I think it's too soon to say. Yes, the science is there, the science is clear but we know that evidence sometimes doesn't win over ideology in certain context and that's the challenge.

So as activists and as persons people living with HIV we need to consistently drum home the point to our politicians, our policy makers; positive people who are on treatment are not the ones driving the epidemic, it's undiagnosed individuals who are driving the epidemic. So we need to remove all impediments to seeking testing and seeking treatment. Criminalization does not work. Thank you [applause].

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SUZETTE MOSES BURTON: Thank you Maurice. Indeed you have made it very clear that the jury is still out and you have tied in your presentation so aptly to today's theme of understanding and addressing HIV related stigma and discrimination. It's because of that ignorance at that the beginning where it started and now the push-back still must be in a positive direction in terms of getting laws repealed and ensuring that no new laws are made that criminalization HIV and especially the patients of the epidemic. So we thank you once again Maurice and we go immediately over to our third presentation by Shari who will speak to the topic reproductive justice people with HIV, Shari [applause].

SHARI MARGOLESE: Thank so you much, it's a great honor to be here and like Maurice I'm very humbled. I've met many people and know many people who I feel are far more qualified but I'm going to try to bring them here with us today. You'll notice I have no slides on the screen today, I've been making presentations all week and I would be happy to share one of those PowerPoints with you if that's what you really want to look at.

But what I really want you to look at today is I want you to look at me because I'm a woman people living with HIV and I face stigma and discrimination. Not only am I going to share a little bit of that with you today, but also some of the

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ways that myself and my colleagues, mostly people living with HIV like myself have been working on to try to achieve what has been described here today as reproductive justice.

I really appreciate the lovely introduction that I got today with all the credentials et cetera, but really I'm here to speak to you today as a woman people living with HIV and as a mother. When I've told people that I have a child yes, I'm HIV positive, I am a mother, usually the first reaction I get is; but he's okay right?

Well yes of course he's okay, he's almost 20 years old, he's been living HIV since he was born and he rocked the house here on Wednesday in a plenary session on Children Growing up with HIV [applause]. Due to a flight delay he's actually still with us here this morning, so I'm really glad to hear that.

Yes, this young man is living with HIV and people ask that question because they expect me to say oh yes he's fine and by that they mean he's not HIV positive. But because he's HIV positive, does that make him any less of a joy to behold? Does that make me any less of a mother? I don't think so.

In Canada where we have decent treatments and people are living longer, healthier lives, lots of people are planning pregnancies and having babies. In other parts of the world people are having babies too and our big efforts have been around preventing vertical transmission, I'm not going to call

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it mother-to-child transmission because that blames the mom.

That's stigmatizing language [applause] and I'm really, really--this is why I don't have slides today folks, because I've been taking it all in and now I'm going to give it all back. I'm really tired of hearing that and hearing that not only from science and policy makers, but hearing it from within our own community, PMPTC blah, blah, blah, it's vertical transmission.

And you know what? No mother, no father wants their child to be HIV positive but the bottom line is we need to keep moms and dads healthy because you know what, sometimes those kids are born HIV positive. And you know what? It's okay because they still were born and still have an opportunity to live a long, healthy life. So let's stop stigmatizing people for having children. Even if we are not given the means to be able to protect both ourselves, our partners and our children, we still have the right to have children [applause].

But truly there's a gap, there's a gap between what people need and people want to protect themselves, people want to protect their partners, people want to protect their unborn children, But in many cases we don't have the means to do that.

So in Canada what we've done is actually tried to develop some guidance and take a first step towards some sort of reproductive justice for people living with HIV and in fact,

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just this week in the Women's Networking Zone we launched Canadian HIV pregnancy planning guidelines.

Clinical guidelines written by people living with HIV along with colleagues in all our different disciplines, infectious diseases specialists, fertility specialists, champions in their own communities to go back to their communities with a little peer pressure and say look we can help these people, those people as you like to call us sometimes. We can help people living with HIV have safe and healthy pregnancies, here's the roadmap.

So that's one thing that we've been able to do to try to achieve reproductive justice and as Georgina was saying and the work that's being done at GNP+, again with people living with HIV in the lead. Other areas of the world there are also huge injustices going on.

For example in Namibia, I met with my good friend Jenny Gatsi the other day who's seeking reproductive justice for women who've experience coerced sterilization or coerced termination of their pregnancies. In her quest to do this, she brought forward to her policy makers a small number of women who'd had this experience and she was told sorry, there's just not enough women who've experienced this. So what did Jenny do?

Jenny mobilized the community and she went into the

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community and she found more women who'd experienced coerced sterilization [applause] and in fact at the end of the month July 31st Jenny and her team again, people living with HIV in lead have a court date to actually try to seek justice for those terrible injustices that have occurred.

I mentioned having allies and champions in other communities, people living with HIV can't do this alone. We need research champions, we need policy makers, we need people behind us. But even when we find allies they face barriers. A really good example is right here in the United States, how many of you have heard about Vaginagate? Not too many.

Well let's say the word out loud together just to get this day going vagina, everyone say it vagina. Thank you. Well you're not going to believe this if you haven't heard about it, two female U.S. politicians were banned from addressing the Michigan House of Representatives, this was recently, after one used the word vagina and the other tried to argue for regulation vasectomies during a controversial anti-abortion bill. Can you imagine? And I really loved what was going around on the social media, and it said "vagina, if you can't say it, don't legislate it" [applause]

Along with difficulties accessing contraception, difficulties accessing safe abortion, difficulties accessing good, comprehensive pre-conception planning so that we can plan

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to have healthy families, those are some of the issues of today.

I found myself preparing for this talk and wondering what was some of the reproductive justice—I have a hard time sort of taking sexual and reproductive health aside from each other because usually there's sex involved in reproduction. Not always, but usually. But what will the issues of tomorrow be? I think about men on the African continent who are lining up for circumcision.

Are they lining up for circumcision here in the United States of America? No, because they are being coerced to remove their foreskins instead of being offered less invasive methods to reduce their risk of acquiring and spreading HIV like antiretroviral therapy and other prevention alternatives.

In my mind these will be the people who are seeking justice just as now we're seeking justice for losing our ovaries and our wombs have been removed from us without our permission. Just as we're seeking justice for all children who were not born because we were forced to abortions or coerced to have abortions, those are the people who will seeking justice. It's going to affect all walks of life.

But until we can walk into legislature, until we can walk into Congress, until we can walk into all the places that we need to walk into to advocate for our rights to have

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children or not to have children if that's what we choose. Until we can walk in and say words like vagina, this isn't going to happen.

So I ask you to go and talk about these things, say words like vagina, don't be afraid and talk about my son who's living healthy at almost 20 years living with HIV. You know what? As much as we want to prevent that, it's not the end of the world and these children are still our children and they deserve the respect and they deserve not to be stigmatized and they deserve to live their lives and reproduce when they're ready, not yet please. And have a world and walk into a world that's free of this kind of stigma so they don't actually have to be concerned about that and that's why I do what I do. Thank you [applause].

SUZETTE MOSES BURTON: Thank you Shari for not only presenting your own personal story and perspective on the impact of stigma and discrimination particularly in the area of reproductive rights but for really reminding us of what I think is the very sad and disconcerting trend that seems to be happening.

Sort of this move to legislative reproductive health and rights for men and for women, I'm not too sure that we're heading in the right direction with tread. But let me not get up on my soapbox here today, that's not my task. It's my

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pleasure now to introduce our next speaker Laura Nyblade who will speak to us on what works for reducing stigma and discrimination, programs and tools for the reduction of stigma and discrimination including human rights approaches. Maybe Laura will tackle some of the things that are beginning to irk me [applause].

LAURA NYBLADE: Thank you very much and thank you for this honor to be here speaking with you and thank you for having a full room, I really am honored that all of you have come here this morning to listen to us because it is the last session of the conference and I know it's been a long one. So thank you to you.

Before I start I want to say that it's very difficult in 15 minutes to talk about reducing stigma and discrimination programs as well as human rights approaches so I'll apologize for the broad brush strokes that are going to happen but to say that I'm happy to talk in more detail later. Also to say, as others have said that there are many people in this room who are working on this issue and what I talk about today is really building on their work and the honor that I've had over the years to work and learn from people around the globe on what works for stigma reduction.

I'm going to talk briefly about human rights approaches and I'll say a bit more about that and that the fact that

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that's not my area of expertise and then look in a little bit more detail around general principles for successful stigma and discrimination reduction programming that we've learned from around the globe.

Then try to make a little bit more concrete for you by just giving one example from the healthcare sector and then wanting to share with you some of the tools and resources that are out there to help you in your efforts to reduce stigma and discrimination.

So human rights approaches, I think that has already been discussed by the previous presenters and I'm not a lawyer but to say that one of the things that we struggle with in our goals to reduce stigma and discrimination—and often the human rights community and those working on stigma and discrimination that isn't legally actionable are not talking with one voice and we're not working together.

So when I was asked to make this presentation and it said talk about stigma reduction and human rights approaches, I thought wow it's coming back to me because I talk about this all the time. That we're not doing enough to work together and speak with one voice and now I've been asked to put that together which I have to say I struggle with a bit. I want to thank Susan Timberlake at UNAIDS for these slides that you're going to see and for helping me with this.

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A rights-based approach to HIV, we've heard very clearly from our speakers some of the challenges and trauma that's caused by the fact that we don't have a rights-based approach in most of our countries and when we do stigma reduction work it has to be grounded and founded in a human rights approach.

And these again, are just basic principles but are rights-based approach to HIV, a rights-based approach to stigma and discrimination reduction programming, supports governments to realize our rights, people's rights. It supports people to take up and demand rights, these are the rights we have; we have the right not to be stigmatized in the healthcare setting, we have a right not to lose our jobs, so we need to take up and demand those rights.

We need to ensure that the HIV response addresses vulnerabilities and the needs of those who are most affected by this. We have to ensure that that response is non-discriminatory, inclusive, participatory and accountable, these are basic human rights principles and any work you do in stigma reduction, I ask that you think about these because we often stigmatize unintentionally and there are many programs out there that have good intentions but that actually the end result ends up being that it's stigmatizing. Whether it's in the use of our language like PMCTC, the intention isn't bad but

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we do it, so we need to think about that and we need to keep these human rights principles at the foundation of everything we do and it has to empower individuals and communities to respond.

There are certain programs that promote a human rights approach and that empower, and UNAIDS has a set of seven that they talk about, I think only managed to get six up here, I think I collapse two of them. Within that, they talk about programs to reduce stigma and discrimination and that's really what I'm going to focus about today because that's what I know best. They include things like know your rights and law campaigns, legal literacy, human rights education for our service providers, programs to change harmful gender norms and violence and women and others, provision of legal aid and economic empowerment.

So this is where I'm going to stop with the focus on human rights but as I go forward I want you to think about the fact that stigma reduction programming is based in this and is part of this human rights approach and approaches to human rights.

With that I'm going to shift to now speak more about key principles for stigma reduction programming. This comes from learning from across the globe, we may not have the strongest science yet, we don't have randomized controlled

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trials that show if you reduce stigma you're going to increase uptake in the services. But we know that stigma reduction is a fundamental human right and we should be reducing stigma in and of it's own for it's own good because this is what it is in addition to what it does for improving the response to HIV.

We've heard throughout the week about how stigma is a barrier to treatment, it's a barrier to prevention, it's a barrier to human rights. So we need to reduce stigma not because of those examples but because it's common good, it's a right.

So what do we know from all of the programs that have happened around the globe in communities that are showing that you can actually change communities and you can change the experience of people living with HIV and other key affected populations that are heavily stigmatized? One of the things we've learned from our programs is the first thing is that we need to raise awareness.

We to help ourselves and others understand what is stigma, what does it look like, what it is in our concrete daily lives, what is that I do that stigmatizing other people? We've seen in a lot of the researches that people's intentions are not to harm, they just honestly don't know that when I gossip about someone, when I ask someone how did you get HIV? That that's stigmatizing and so there's a gap between our

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intentions which are not necessarily to stigmatize and the end result of what we're doing.

We've found among programs that, if something as simple as helping people understand through a participatory process, what is stigma and discrimination, what does it look like, what is it that I am doing and what does it do to another person, what does it do to our communities, to our families? That that is very powerful and creates motivation for change, so it's a simple thing, it seems like a simple thing but we don't do enough of it and it has a very powerful effect.

We need to address transmission fears and misconceptions, I couldn't help but thinking as I was looking at Maurice's presentation about there's lots of forces around criminalization but how much of that is also driven by the fact that 30 years on people still think that you can get HIV through causal transmission? It's still common and you'd be shocked when you see studies around the lack of knowledge around how HIV is transmitted and not transmitted and the fear drives behaviors that are stigmatizing and discriminatory.

So programs that are looking to reduce stigma and discrimination need to address, you need to understand in your communities what is it that people fear in their daily lives? Then respond to those specific fears to help people understand why there is no risk of getting HIV through that. There is no

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risk of getting HIV from buying food from a vendor who is people living with HIV, a lot of people fear that and as a result the person whose selling the food is losing their economic livelihood. So programs need to create awareness and they need to address the fears and misconceptions about transmission.

Lastly they need to discuss and challenge the shame and blame that underlies and drives the stigma and discrimination. We need to talk openly about the values and beliefs that are driving this. Where do they come, why are they there and what do they do? And help people in safe spaces discuss this. Now this might seem really hard, but we've found through participatory tools that even with religious leaders, politicians, you can actually open up the space to start discussing this and it makes a difference.

This is a very simple explanation but we've found in all programs no matter who you're working with, where you're working, these things are common across the globe and need to be address. Yes, there are differences and there are other things that need to be added, but these are fundamental.

Now I'm going to change from specifics about the content of programs to broader principles and all of our speakers have spoken to this. The first is that affected groups need to be at the core of the response and they need to

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lead the response and we need to work to provide the tools and the capacity and the safe space to lead that effort.

One of the things we haven't talked in terms of definitions here today, but really on the issue of internalized or self-stigma, so all of that external stigma that's out there and that's coming at people becomes internalized. This can be a real barrier to actually accessing services but also being in a place that's safe to come out and lead the response. So I won't speak more about this we've had examples already today about how this can be done and how important this is.

It's important to build and create alliances. So looking at different kinds of partnerships for influence and expanded reach, the stigma, the shame, the blame, the fear of casual transmission, you need to have opinion leaders out there modeling the kind of desirable behavior that we want. So it's important to create different kinds of alliances to do that.

We need to be acting at multiple levels with leaders in our families, in our communities and I think one thing I want to point out, because I think this was brought up but youth in particular as an incredible source of leadership for changing the way we work and the way we live. Also contact strategies and this is part of creating those alliances but stigma reduction programs that have been successful, and I'll give you an example of this in the healthcare setting, are really ones

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that work to foster interaction between those who are experiencing stigma and those are perpetrating it.

If you go back to basic conceptual models around the process of stigma, if you have a relationship with someone it's much more difficult to stigmatize or discrimination against them. If you understand that this person is just like me and has the same aspirations and hopes and dreams, it becomes much more difficult to stigmatize. A lot of the successful that we've seen has been specifically around trying to break down those barriers and create opportunities for dialogue and interaction.

We also know that we all learn and change in different ways and what we know from the programs globally is that those are most successful are those that use multiple approaches, that don't just have one thing. So not just a media campaign, not just written materials, but ones that incorporate different ways of learning and understanding. The core of this has really been creating opportunities for participatory learning which then engenders that contacts strategies that I was talking about.

So I'm going to try to bring this all down, these very general principles into an example from the healthcare setting just to give you a sense of how this might work. I'm going to take and tell you a little about a stigma and discrimination

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reduction intervention that was in a hospital and was actually led by Wang so it's kind of funny that I'm standing up here presenting this but I think it's a really important example of how you can start bringing all of this together.

It started by building partnerships with the hospital gate keepers, with the administrators and part of that was getting agreement to go in and do baseline data because what we find is that in a lot of places we hear well, we don't stigmatize, we don't discriminate. So that baseline data is really important in helping to show what the issue and that's why the Stigma Index is so important because it really shows what's there and it can give the data for advocacy for moving things forward.

Then having a participatory steering committee that helped to design the actual intervention and how to make this possible in a busy healthcare setting. Then there was participatory training and the key here is participatory—and it was for all hospital staff.

So what we know in healthcare settings is that the stigma and discrimination that's experienced isn't necessarily just from the doctor or the nurse, it might start at the gate with the guard or with the receptionist. So the importance of providing training that deals with the principles I just talked about, creating understanding, addressing fear and dealing with

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the moral or value driven parts of our stigma for everybody.

Then the other piece that was really important was the staff then designed their own hospital policies about how they were going to behave, their code of conduct. So everyone at a same level of knowledge and then making a joint decision that this is the way we're going to behave in our hospital, this is our policy and we own it.

The other part that is important when you're thinking about healthcare facilities is really the importance of structural changes to support universal precaution. So there are fears of transmission risks in healthcare settings and ensure that the supplies that are necessary for that are there. Then some m-line data, there's a report out there that shows the changes that happened as a result, this is a way to show to you how this can all be brought together.

Then, I want to change – also to say the participatory training was co-facilitated by people living with HIV. That was a really an important part of that participatory training. Again, thinking about the opportunities to create contact strategies but also to have those experiencing stigma leading the response.

Just to give you a quick sense, the training was three to four half days. It was half a day of basic HIV knowledge, a day on universal precautions, and half a day on the social

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stigma just to give you a sense of what that training would look like. I'm running out of time so I'm going to go quickly, then the policy which I had already talked about.

I'd also like just give you some other examples from India. These are both collectives of sex workers in India who had small grants to do stigma reduction. They designed their stigma reduction first by training their own colleagues and building capacity to actually and the safety to then move out and lead these efforts. In one, they trained pure-patient advocates which they negotiated with the hospital so these became official positions in the hospital.

These sex workers were placed in the hospital as staff who then worked to help their colleagues navigate the hospital system but also to ensure that respectful care was given. What was really interesting about this was that this created an incredible opportunity for increased opportunity for contact and understanding and discussion, and it really made a difference in the hospital because it started breaking the barriers. As a result, they saw that members of their collective found it much easier to access services and were much more willing to come forward for testing and treatment as a result.

The second one focused on different kinds of advocacy campaigns. I just want to share one with you. I talked about

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the principles instead of always talking about how bad stigma and discrimination is we need to talk about the kind of behavior we want to see and to hold that up and reward it.

I thought it was really interesting at this group. This is what they focused on. They had a rose campaign. They went into the hospitals and gave roses to the doctors that had treated them well and with respect. This created an incredible buzz in the hospital. Why are these doctors getting roses? This opened up this opportunity for discussion and dialog.

What's really interesting is one of these hospitals is a teaching hospital and they actually have created a rotation for medical students now who go and spend time in the sex worker collective to understand what are the health issues and other needs of the collective.

Just to give you a sense of how these principles can be played out in actually programming. Simple programming, it's not that expensive. It has a huge effect in people's lives.

Just to end by saying there are lots of tools and resources. We've made a lot of progress in the past decade on how to reduce stigma and discrimination. Just to give you a sampling, we have a lot of tools for working with lots of different kinds of populations.

It started with a Challenging and Understanding Stigma Reduction Toolkit. The first edition came out in 2003. That

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came out of, actually, a multi-country research study and was developed collectively with over 50 groups from Tanzania, Ethiopia, and Zambia.

Since then it's grown, it's been translated, it's had modules added. We've actually found that this is such an effective way to have participatory work on addressing stigma that we now have tools that address specifically stigma towards sex worker and stigma towards men who have sex with men and stigma toward drug users. There's versions now that focus specifically on those stigmas because I think as we've addressed a little bit here the need to address the intersecting stigmas that are experienced. There's also many for the healthcare setting. All of these tools are available and I'll show you on the website.

There's also a lot of work that's going on around measurement. We had a workshop yesterday so I won't go into it. We've heard from Georgina about the stigma index. There's also efforts at the general population and also for measurement and health facilities. These tools are also available.

Just to say that there's a global effort to try and bring together everything we know in one place to create a collective voice to speak about this so that we can be more effective and efficient in our quest to reduce stigma and discrimination. I would ask you, if this is an area that's dear

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to heart and is affecting you, to please join the Stigma Action Network. If you have tools and resources, please post them. We're trying to put all these resources in one place. With that I'd like to thank you for being here today. Please go out and reduce stigma. [Applause]

SARAH WESCOT-WILLIAMS: Thank you, Laura. Indeed, the rights based approach is an effective answer to addressing stigma and discrimination. Human rights principles for all and exercised by all, in fact, how can these principles be exercised by all? Thank you once again for that presentation. Now, we go over to our last presentation for this session. I'll still make an attempt to introduce her by her full name, Khuat Thi Oann. With her permission again, Oann, welcome to the lectern.

KHUAT THI OANN: Thank you very much. Good morning everyone. It is really hard to be the last speaker on the last day of the conference. I try to put a lot of forethought and picture in my presentations so that you will not be put to sleep. I would like to share with you some of our experience working with community to tackle stigma and discrimination. I will speak in three parts. One is a little bit of the background about the situation in Vietnam, our approach to address stigma, and share with you some results.

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The first thing we did, it was 10 years ago in 2002 with Laura Groves [misspelled] is to study to understand HIV and AIDS related stigma and discrimination in Vietnam. We all learned that in Vietnam HIV is linked very much with social evils. We have the National Committee on AIDS, Drug, and Prostitution.

The committee is still acting today. It's also because of the fact that majority of people living with HIV in Vietnam got it from drug use, sharing needles, through the unsafe sex with sex workers. In our country, drug use and sex work are considered social evil. Eventually, HIV is linked with social evil and stigma is not only about the fear of transmission but also moral adjustment, like a bad people things.

In over the last 10 years, we see clearly in Vietnam that stigma against people living with HIV has reduced, but stigma against drug user and sex worker remain very heavy. We also note that among drug user and sex worker and their family, the self-stigma is also very, very high.

Until 2011, our government approach, the main approach, to drug user and sex worker was – the main approach was still compulsory rehabilitation center. That contribute partly to stigma as well because the people were sent to the center between one to four years. They are away from the family. It is

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written in their record and that doesn't really help for people to reintegrate to their life.

When we talk about addressing stigma, we think that stigma actually exists at different levels and we need to address on the level if we want to reduce stigma in a very sustainable way. First stigma exists in each individual, people with living with HIV, drug users, sex workers, MSM, and their family member. Self-stigma is the first step we need to tackle. Then, there's a stigma in the microenvironment of the people. It's in their family, at the workplace, in the community. Then, at the macro-level, society at large is the value, it's the social norm, it's the policy, it's program.

Intervention at personal and group level we try to have some concrete intervention that includes peer counseling, includes self-skill training to improve people's self-esteem, to help them to be able to cope with stigma, to deal with their own past, to cope with their own behavior, and to have some self-skill like communication skill or anger management.

We also realized that for these marginalized people the sense of belonging, the sense of community, the fact of having some people listen to them and share with them the experience is very important. One important part of our intervention is community building. Then, there's some practical support like

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assist support, people [inaudible] to methadone to HIV testing, to treatment to get jobs, [inaudible], etcetera.

For community building, we support the population to get organized to build on the existing network of people living with HIV and support the development of drug user and sex worker organization. Until 2009 in Vietnam, there was no organization of drug user. Until 2010 in Vietnam there was no organization of sex worker.

We support them, help them to organize, and now they are a very active organization of these populations. The movement of MSM in the country start to get very strong and as much as we can we try to support them. Here is some picture about the activity of drug user and sex worker organization. Now, they get organized and they have their own program, different program.

In the building community, we also work together with people living with HIV to produce their own magazine. There's a magazine called *Living with HIV* that distributed in Vietnam since 2007 to all provinces, to all network of people living with HIV, to each HIV facility and organization working with HIV, and 80-percent of the content of the magazine was produced by people living with HIV.

We get a great support from journalist and from people of the [inaudible] administration to edit and to make it really

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professional and nice looking. It's not just like some sort of crap material for people living with HIV but it's really beautiful. It helps to build the confidence of people living with HIV and help them to feel that they're really worth it. The magazine for them is a beautiful one. It's well written [inaudible].

There's many activity organized by drug user and sex worker group that really to create the sense of belonging, sense of connectedness. Our organization host the Vietnam Civil Society Partnership Platform on AIDS. It is a platform that brings together 270-plus civil society organization across the country.

In the platform people living with HIV, drug users, sex worker, MSM have opportunity to interact with each other but also interact with other civil society organizations including NGO, faith-based organizations, students group, women's group, etcetera. It's also the sense of community, belonging, and empowerment.

There's a whole series of workshop and training to improve self-esteem and self-skill. In this photo, you see a performance by three men. They are either sex worker or people living with HIV or the wife of drug user or drug user themselves. They are now very confident to go on the stage and

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perform and very happy and very proud about that. We try to support that.

There are livelihood support that people already mentioned. I don't want to use the word economic empowerment because it sounds like a big word. It's really important for people to gain confidence and to reintegrate into the society.

Here, I just share some scientific data just to give the scientific side of the things. The [inaudible] public health school did an evaluation on the impact of drug user organizations in Vietnam. They felt that for the people who are member of drug user organization, they self-efficacy has improved significantly, have much higher self-efficacy than the people who don't participate in drug user organization.

They interact much better with family, with friends. They also found the people who are member of drug user organization have much significantly higher quality of life, and 100-percent of the member of the drug user organization reported use of new needle in the last injection. Their self-esteem on getting new syringe or refuse to share syringe is also significantly higher.

We can say that those groups they are not only to improve their own life or social life but also have a significant impact on the HIV transmission and prevention. We also implement in the country a number of interventions that

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address macro-environment. These are sensitization, promote positive image of people living with HIV and those marginalized people and address structural factors.

There's [inaudible] toolkit to tackle stigma and discrimination. It is HIV specific intervention that Laura already mentioned for people living with HIV, drug user, sex worker, and MSM that is produced by NGO called ISDS in collaboration with ICOW and Laura's team. It's like a sample of program. The toolkit is a fantastic tool that have many different exercise, like a big menu that you can pick and choose for different audience. There is a toolkit for drug user and a sample menu.

We try to do quite a bit on promote positive image of people living with HIV and those marginalized people. In this picture, you see the stage of the beauty contest for women living with HIV. We call it Positive Charming. It was the first time that is was organized in the country. It was broadcasted live on TV and got huge media attention. It really helped to shift the paradigm for people in the country to see women living with HIV as beautiful women and for women living with HIV and people living with HIV to feel confident that they can stand on the stage. They can be on the TV and on the media.

Here's some photo we've taking from the launching of our photo-book, Face to Face with Drug. The people who got the

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flower as a drug user were featured in the photo-book. For the structural factor we try to work on improved understanding about HIV addiction, homosexuality, and sex work among policy maker and the public, promote harm-reduction approach, advocate for voluntary community based instead of center-based compulsory approach to drug user and sex worker.

Up to more than 10 years and with efforts by many partners, we have got some reason to share. In 2007, our HIV law prohibited stigma and discrimination against people living with HIV. Our country also legalized harm reduction including methadone, needle and syringe, and condom in 2007. Drug use was decriminalized in 2009. Compulsory rehabilitation center for sex worker was abandoned a month ago. Our [inaudible] was simply just pass a law stopping sending sex worker to the compulsory rehabilitation center. [Applause]

Our government also approved an action plan to redo the sending the drug user to compulsory rehabilitation center from this year. We got somethings. Of course, there's still a lot to do. In this photo you see that it is a photo of a visit of our senior government officer to an organization of sex worker and drug user. They are from the ministry level and from the city level to discuss about how community and the government can work together for community-based model intervention for drug user and sex worker. It is happening.

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In summary, we believe that tackling stigma and discrimination is a long-term battle. We cannot set like one-year goal or two-years goal; it is a long-term [inaudible] that require [inaudible] approach. Some stigma and discrimination specific, some need to be blended in personal and organizational development and program intervention, communication, and advocacy.

We should always need to wear stigma sensitive lens to see if our intervention [inaudible] stigma or in which way it can reduce stigma and discrimination. I would like to end my presentation with this photo and to state that most importantly communities is the heart and brain of any intervention. In this photo, [applause] just to introduce this photo, here you see the women, some of them are drug users, some of them are sex workers, some of them the wife of drug user. The children in here are their children. Thank you very much. [Applause]

SUZETTE MOSES BURTON: Thank you so much Oann. Okay, I'm going to right into the questions. We have a barrage of questions and not much time. What I've done is the majority of questions have been targeted to Georgina. I've tried to consolidate them, the ones that were repetitious, etcetera or just try to collapse it all. Then, we have one specifically for Maurice and one for anybody from the panel to respond. To Georgina here goes your marathon of questions.

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I'll give you the easy ones that are kind of yes or no first. Do you have the data disaggregated by sex, male and female and if so what are the differences in stigma experience faced by men and women? Oh my god, more questions coming. Has the index been conducted in the US? Are there plans to revise and shorten the tool? Where can the questionnaire and the results be found? Is there a global report on where can that be found? I suspect all those will have the same answer.

Let's see. Do you have comparative controls with the general population and if so how does it compare the results of stigma been experienced by the general population as opposed to stigma being experienced within the community of persons living with HIV? Of the four countries that you presented, or maybe even perhaps I would say of all of the countries where the index tool has been implemented, do any of these countries have strategies to reduce stigma and if so, what?

Related to the question about the consolidated version of the tool, do you have a consolidated version for use by agencies and community-based organizations? Can it also be used as a pre- and posttest tool to measure changes? Do you have or do you know about a similar tool to measure stigma in religious communities? Okay.

GEORGINA CASWELL: Some quick responses. First to say that I see several faces of those who have actually implemented

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this stigma index so afterwards if wouldn't mind just joining me here at the front in case people would like to ask you guys some questions, because some of these are really in depth.

In relation to data disaggregation, most national networks, in fact, every report that I have seen has always disaggregated the data according to gender. There's some particular national networks that actually when they're doing their analysis take a gendered perspective such as the Ethiopian Stigma Index.

In the US, yes those discussions have actually started and the partnership is being built. If you're interested in finding more about the Stigma Index for the US, please let me know and I'll connect you with our colleagues at GNP+ North America.

In terms of the questionnaire itself, we're actually looking at moving into a second phase of the Stigma Index where we're going to be reviewing the process and the questionnaire. In terms of shortening it, just to say that although there are 100 questions what happens is that a lot of networks actually pick certain issues that they want to focus on and so they actually zoom into certain areas. Then, the data is available for analysis as advocacy needs arise.

Yes, all the information is available on the Stigma Index website. That's www.stigmaindex.org. Please have a look

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there. The data that I presented today, the four country reports are on the Stigma Index website.

With regards to pulling together the Stigma Index website with other research about general population and attitudes, in many countries there is DHS, demographic health survey data and also in some countries there are public attitude surveys. The idea is actually that the Stigma Index, the experience of people living with HIV, this is like the missing piece. The idea is that it all comes together when stakeholders at national level are discussing stigma reduction strategies.

With regards to countries and how they've used it, maybe to give the example in Zambia. In Zambia, the data we had from our colleagues this week, from the network that they've really used the data to feed directly into the development of the last national strategic plan and operational guidelines which involves who to reduce stigma in the workplace, in the healthcare setting, etcetera. As the country is looking to review some of its laws right now, the network in Zambia plans to use the findings from the Stigma Index to inform that review process.

The tool, is it available for community-based organizations and others to use? No. The tool, the idea, the principle behind the tool is that this process is led by

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networks of people living with HIV. If you are a network of people living with HIV at country level and you're interested in leading this study, then please do get in touch and we'll work with you. I think I did quite well. I know there are others.

SUZETTE MOSES BURTON: Yes, I think you did.

GEORGINA CASWELL: I think that was quite good. Yes. I'll stop there, yes.

SUZETTE MOSES BURTON: In the interest of time, let me apologize to anybody who doesn't hear any form or permeation of their question. There are just too many questions and some of the questions are too long. Maurice, I think, I'm going to throw this one at you and then I'm going to open one that came for everybody on the panel. It's to give everybody a final opportunity. This could be a quick one. How do you operate in a country like Jamaica, known to be one of the most homophobic countries in the world?

MAURICE TOMLINSON: The fact is in my situation as a university professor I'm able to be relatively insulated from most of the homophobia. I have received quite a few death threats but I don't take public transportation, I don't do social events. I basically go from work to home. I operate under the radar most of the time. That's how you're able to insulate yourself from much of the homophobia. If I were from

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the lower socio-economic context I expect I would have a more difficult time.

SUZETTE MOSES BURTON: Thanks, Maurice. In the final two minutes that we have, a question to the entire panelists and maybe we can hear from Laura, Shari, and Oann. Please share any experiences, studies or references that shed light on the role of stigma in the poor coverage of infants and children accessing testing and treatment.

SHARI MARGOLESE: I'll be honest. I don't actually don't know of anything in particular. I will say that there's some really good work that's been done in Canada with the Teresa Group. I think they are a good place to start looking. One thing that really didn't get addressed here today, there's been some excellent work done in Canada by a colleague of mine, Carmen Logie on the intersectionality of stigma.

Most of her work's been done in the African, Caribbean, and other women of color communities. One thing that I thought that was really missing here that we didn't talk about today was that intersectionality. While we face HIV stigma, we also face stigma related to our race, gender, socio-economic status, as drug users, and a whole range of other things. Then, children again, as far as I'm concerned, as a mom of a child who is HIV positive. For a young man in my country, there's basically nothing available to him.

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LAURA NYBLADE: I can't think of any specific studies that come right to mind, but there are studies that look at how stigma is a barrier to accessing treatment both for women and also for infants and the challenges around disclosure in particular and how that leads to challenges in bringing children forward for testing and for treatment which is then related back to the fear of stigma and discrimination.

I think there are more studies that are also showing and looking at the programs that are working to reduce new infant infections and keep their mothers alive. That if you look at that cascade of where you enter for these programs and leave, where we're really falling short is in transitioning women to care beyond those prevention programs and getting their infants and children into care. This, I think, is an important area of study to understand more around what's going on there. It's an issue that has been raised quite a bit at this conference.

SUZETTE MOSES BURTON: Oann, final – anything on this question?

KHUAT THI OANN: To be honest I'm not aware of any study in Vietnam on this. I know that there's documentation on the access of the children to education in Vietnam. The children living with HIV or the children of people living with HIV in some place in Vietnam have been heavily stigmatized and

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rejected from school, not because about government policy but because of the implementation at local levels. Many children could not go to school because of that reason. In the real life, there's a lot of children living with HIV have difficulty to access to medical services, but I'm not aware of any study on that.

SUZETTE MOSES BURTON: It is my final task to, of course, thank everybody on the panel, to thank my co-chair, the Prime Minister, and to thank all of you for filling out our session, for all of the great questions. We apologize we couldn't get to all of them and to wish you all of the best for the remainder of the conference and your journeys back home safely. Thank you very much.

[END RECORDING]

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