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People Living with HIV/AIDS: A Positive Force for Prevention
XVI International AIDS Conference
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[START RECORDING]

SAN PATTEN: Welcome everyone. Hi. Sorry we're starting a little late, I guess the plenary, I don't even know if it's finished yet, but the plenary went a little late, and so it's almost 11:00 and we've been given the green light to go about 15 minutes late in our session as well. So hopefully the room will fill up, we're limited to 300 participants, and we thought we'd have to fight people off at the door, so that might still happen, but welcome anyway to the session People Living with HIV/AIDS: A Positive Force for Prevention. It's really great to see you all. I just wanted to give you a little overview of what –oh, there's Believe, hi Believe- a little overview of what we are going to try and accomplish today in our 90 minutes. It's a big topic, but let me just give you a little rundown of the purpose of the session.

What we want to do is review the existing science base, not in a really rigorous way, but at least get a brief overview of the science of prevention interventions which are aimed at people living with HIV. We want to identify key principles for the provision of prevention services for people living with HIV. These are the outcomes that we are hoping to achieve; we're hoping that as participants you'll gain the opportunity to share some of the existing best practices and key principles on prevention for people living with HIV. We hope you'll have a good understanding of how to apply the GIPA or the greater

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involvement of people living with HIV principles in the context of HIV prevention. We hope that we will be able to identify research directions that are needed to enhance the messages and approaches for prevention with people who are living with HIV.

Before we discuss the process I just want to introduce all of the people on the stage up here with me. This is Isobel McConnan and she's a professional facilitator, we've been really privileged to have her help design the session and facilitate the session, as you can see it's a little different than all of the other sessions, or many of the other sessions at this conference, and that we're really— Pardon me? Isobel McConnan. We are hoping to have a little bit of a different format where we put first and foremost participant dialogue and your own expertise, and then we have a panel of experts who will actually respond to what you have discussed and weigh in with their own perspectives. So we have three highly esteemed experts on the panel here. We have Believe Dhliwayo, Mary Jane Rotheram, and Neil Selth, and I'll just let you know who they are. Believe has worked extensively and intensively with community based AIDS service organizations in Africa and he is a very passionate believer and supporter of the GIPA or MIPA the meaningful involvement of people with HIV principles, he is the founding member of the Zimbabwe activists against HIV and AIDS in Zimbabwe, and he is member of the Pan African Treatment Access Movement, and the International Treatment Preparedness

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Coalition. He is currently a board member of the HIV/AIDS Legal Clinic of Ontario, as well as a Consulting Coordinator for Ethnoracial Treatment Support Network based in Toronto. He has conducting trainings and seminars at universities and colleges aimed at prevention for HIV infection among young people in Zimbabwe, Zambia, South Africa, and Kenya. He is a person living with HIV; he has been open about his status for more than 11 years. He is a community based HIV activist, a trainer, and a qualified systemic counselor by profession. Believe is married, so to all those single people out there sorry he is taken, to Lasungo[misspelled?] who is an AIDS activist as well, and they have three children, two boys and a girl, welcome Believe.

Next to Believe we have Dr. Mary Jane Rotheram-Borus. She is with the University of California in L.A. and she is a Professor of Child Psychology and Behavioral Sciences. She directs the global center for children and families, and an HIV center funded by the National Institute of Mental Health. She has designed and evaluated interventions for HIV positive adolescents, adults, and families in the United States, South Africa, Uganda, China, and Thailand. Six of the prevention interventions that she developed have been selected by the U.S. CDC as evidence-based programs that really make a difference. Dr. Rotheram-Borus has authored or co-authored over 210 journal articles including those published in Science, JEMA, and the

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American Journal of Public Health; and she has received over 40 grants from the National Institute of Mental Health and the National Institute on Drug Abuse to study HIV prevention with high risk adolescent and adult populations, so thanks for coming Dr. Rotheram-Borus.

Last but not least I have my fellow Canadian Neil Selth. He is a current member of the Board of Directors of the British Columbia Persons with AIDS Society where he chairs both the Positive Prevention Standing Committee and the Support Services Standing Committee. He currently volunteers his time with the BCPWA retreat team, and he took the lead in developing, coordinating, and implementing the sero supportive of workshop for HIV positive and HIV negative couples. He has previously volunteered with the Cranbrook AIDS society, the Vancouver Pride Line, and the Advocacy Office in Vancouver. Neil has been positive since 1990, and like many HIV positive people he has reevaluated his life when his health improved in the mid to late 1990s. He returned to the University in 1999 and completed his BA in 2003 and a Bachelor of Social Work in 2005. He has been accepted into the Masters of Social Work Program at UBC, University of British Columbia, in September of this year. He lives in Vancouver with his partner Jason and they have been in a sero divergent relationship for ten years, so thanks for coming Neil. So I will hand it over to Isobel who

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will explain why you are sitting like this and what our process is going to be.

ISOBEL McCONNAN: Thank you San and welcome. Okay this is what we are going to do, at the moment you are sitting in groups of ten, or perhaps a bit less, and in a minute the whole room is going to be talking. We wanted to flip it around because we felt that it was important that you the delegates have a chance to start sharing your experience around these questions. You're going to be talking about five different questions about prevention interventions and people living with HIV. The purpose of this is really to get this discussion going, and you're probably seeing now all of the different colored sheets, so there was a group of people in a circle here who have a blue sheet and that is question one, then question two is the green sheet, I think at the back, and then three is red, and so on and so forth. These questions compliment each other and we'd like you to talk about those. The process that we are actually going to be doing is, I'd like to ask you to have a conversation together for about 15 minutes, for exactly 15 minutes, and in order to do that, well if you're a large group of ten it might be a good idea to identify a facilitator. The key thing here is that it's not about getting the answers; it's about generating and sharing a little bit of experience and ideas. There is no right answer; it's about you sharing your own experience. We'd like you to write on the back of the

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sheet, just before the end a key point, and we'd like, we'll be hearing a selection of those key points, so if you flip it around on the back you have a space for key point, and also some e-mail addresses. I'll give you a little notice three minutes before the end of the 15 minutes, just choose one point that you think is important in your group, and then San will ask to hear about those at random, and we'll be typing those up so that you can see them here. After that our presenters here will be listening and responding to that, and taking that into account when they give their presentation. That was just the main points, your facilitator will guide the task, and our speakers are also going to, the reason that we have it open like this is just because we will come and join you and listen in a little bit while you are speaking.

I'd like to run through the questions with you just so that everyone has an idea of what the main questions are, and I wonder if I could ask each of those speakers to read one of them. Are you all linked up? Can I start with Neil, or Believe you go first. Neil you go.

NEIL SELTH: Is this on?

ISOBEL McCONNAN: I think it should be on.

NEIL SELTH: What is the most effective way to engage peers in promoting or implementing positive prevention strategy?

ISOBEL McCONNAN: Thank you, and question two.

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MARY JANE ROTHERAM-BORUS: What is one important way that healthcare providers and community support workers can work with persons living with HIV to reduce risk behaviors and maintain safer practices?

ISOBEL McCONNAN: Thank you Mary Jane, and San, Believe.

BELIEVE DHLIWAYO: and question three is what is the one message that PHAs must communicate to other PHAs with respect to reducing the number of new HIV infections?

SAN PATTEN: Okay, question four, the white sheet, is what is one research question or issue that needs to be addressed with respect to the interface of HIV treatment and prevention?

ISOBEL McCONNAN: Then question five on the orange sheet is what is one recommendation you would make in terms of meaningful participation of people living with HIV in prevention? So 15 minutes, have a conversation, write down your key point, and if there is anyone alone or you would like to join up with others please shift around, and your 15 minutes starts now.

[Multiple group discussions taking place]

LOLITA CRISHNA: If I could have your attention for one moment, my name is Lolita Crishna, and I just wanted to let you know about the filming crew that's out here. We are making a

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short documentary on the youth participation in this conference, and Lena here is one of our subjects so we are confining ourselves to this group, and they have all consented to be filmed, just so that all of you know that, thank you.

[Multiple group discussions resume]

ISOBEL McCONNAN: Hi everybody, you now have about another three or four minutes, so could you choose a key point and write that on to the back of your sheet. Then we will be coming back to share some of those in about three or four minutes time.

[Multiple group discussions resume]

SAN PATTEN: Okay everyone we are going to wrap up our group discussions, and we're going to do a really brief report back. So hopefully you have your one or two key points, and I'm going to randomly pick groups to report back within one minute I want to hear what your key point is, okay, so it's very brief. There are microphones numbers one and two, you can run up to the microphone, or I might just hand you the microphone. Okay, let's go over here to these lovely gentlemen, and there still talking, who's reporting back? So this is the white group, what is one research question or issue that needs to

addressed with respect to HIV treatment and prevention? Are you ready to go? Okay, let's go over here, one key point.

MALE SPEAKER: We're still working it out; let's start with another group that already knows what they are going to say [laughter]. Okay, well we've got a few points over here, I wish we had more time to talk, but one of the points that we can summarize, it seems to be the last thing we talked about here, it's to get people who are living with HIV and AIDS into meaningful participation and prevention. One of the things that seems to be important to all of us culturally, we come from many different backgrounds in this group, is instead of dwelling on the negative impacts of what it means to live with HIV and AIDS or what the stigmatic impact is on others, the mixed messages about AIDS is no picnic, but it's also something you can live with, maybe what we should be getting back to is what is beautiful about being a sexual being and what our rights are, and what our responsibilities are in protecting ourselves, and kind of lessening that dichotomy or the difference between an HIV positive individual and an HIV negative individual, and simply looking at us as human beings.

SAN PATTEN: Okay, I'm going to go over here to our research group. You're talking about research right? So what's one key research issue?

FEMALE SPEAKER: One issue that came up for us was the question of when your viral load drops to undetectable do you

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really have to keep using condoms when you're in a permanent relationship, or an intimate relationship, long-term with someone who is, in a discordant relationship. What is the actual risk, do I have to use condoms for the rest of my life?

SAN PATTEN: Great, that's a good one. Let's have another research issue.

MALE SPEAKER: Well we, we also, I mean I'm sure all of us here we come from different backgrounds, we have different experiences, but I think the one thing that's come up here is that there needs to be an integration between the prevention and the treatment work. I know a couple of us have mentioned it, but there is, there seems to be two different movements. There is a movement of trying to do the prevention and there is a movement of working with treatment, working with the infected, and there needs to be a marriage between these two, people that are working with treatment and people that are working with prevention need to work together because I know from where I come from in South Africa, the prevention programs, the people, the awareness campaigns, and the media campaigns, it's almost perpetuating the stigma because they're saying don't get HIV, don't sleep around, use condoms, and this message, the underlying message that is being put across is that people with HIV are bad, and there needs to be an integration between these two movements for us to have a

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broader picture of success. So I think that's the one thing that came up with us.

SAN PATTEN: Thank you very much. Are you gentlemen ready? -A handsome group-

MALE SPEAKER: Hi. We talked about disconnection that came up a lot in our discussion; and two points in particular came up, and it was the disconnection between treatment and prevention. Where does care and support finish and where does treatment begin, I'm sorry, where does care and support finish and where does prevention begin? How do you actually connect those two things? We were a little unclear. There were several thoughts about that but we didn't actually come up to any consensus. The other point was around how prevention for positives exclusively causes a disconnect within community. That is between positive and negative, and we were talking about the need to integrate prevention between positives and negatives.

SAN PATTEN: Thank you, and make sure everyone, that you are writing down, even if we're not capturing your points in the oral report back, make sure you capture it on your sheets, we are going to be collecting them and writing them up, if you've put your e-mail address down on the back of the sheet you'll get a report of all of the reports that were brought up. So make sure that you write them down if you want them to be shared. Here is a big red group, what did you guys talk about?

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Your question was around what is the one message that PHAs must communicate to other PHAs, so do you have a point?

FEMALE SPEAKER: Yeah, I think we had a very hard time with this question, it was unclear whether, what exactly was being asked because we felt like you would communicate with other PHAs but also be communicating with maybe folks that aren't. I think our consensus of the points, we had a great discussion I think, was to encourage and support people to live their lives as they would otherwise, and so that positive people can show others that this can be a very normalizing experience and that this should be just the norm of just something else that folks live with.

SAN PATTEN: I should just mention that Ron Rosen[misspelled?] is the Conference Co-Chair and he is madly typing up there, so thanks Ron, it's nice to have you here. Okay, the question on the blue sheet is what is the most effective way to engage peers in positive prevention, who has a main point?

FEMALE SPEAKER: We talked about the populations that we work with within this group and we're a small group so some of what we talked about was working youth, many of us work with youth, and we were also like the red group, we weren't clear on whether we were talking about HIV positive peers or all peers, some of us here work with survival sex workers in Vancouver as well, so we were saying that in that population of women you

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really need to engage everybody to make it meaningful. The point that we came up with was that by utilizing existing networks you need to engage the population from the very beginning, and one of the things we talked about, we talked about everything from logo design to the name of the project, everything needs to involve the population that you are working with, and empower the population to be involved in every aspect.

[Gap in audio]

MALE SPEAKER: promote the message about what being a PHA is all about, how it works, and how preventions work.

SAN PATTEN: Alright we have a green group. Can you remind me of the question on green?

MALE SPEAKER: So we dealt pretty much with healthcare providers and what people can do in the health field to help. The two points that we came up with were to escalate foreign healthcare providers by providing education, and then the second one was providing positive education to support persons, making decisions, and then empowering them when they're on their own, so when they leave the doctors office.

SAN PATTEN: Another green group.

FEMALE SPEAKER: Okay we had a hard time coming with just one key point, but we narrowed it down to that the

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healthcare providers should be a resource, a resource that provides hope, empowerment, just focusing on the patient's choice, being approachable and non-judgmental, providing accessible tools, education and support while incorporating different strategies at different times, thanks.

SAN PATTEN: That's a good catch all, pardon me?

FEMALE SPEAKER: Incorporating different strategies at different times.

SAN PATTEN: Thanks Ron you're doing a good job, we're testing Ron's typing skills. Okay we have time for one more over here, the red one.

FEMALE SPEAKER: We are from the red group and our question was about the message that people, HIV positive people, must communicate to other people living with HIV/AIDS with respect to reducing the number of new HIV infections. We discussed lots of aspects of the lives of people and we discussed internal stigmatization, and sharing responsibilities in safer sex, and positive prevention, and finally we got to the point where now we decided to put it in one message, a real message, and that is don't stigmatize yourself, live a full life, enjoy safer sex, use condoms, use clean needles, and care for others.

SAN PATTEN: Somebody was waving wildly over here. Orange group, you don't have two minutes, don't write it down just say it.

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FEMALE SPEAKER: Our point is HIV positive people should be trained and educated to do prevention for themselves, then for others to be educators. They also need stable life conditions, that means they have to have drugs, they have to have empowerment because life doesn't stop with being HIV positive, and then they can be role models and nobody can do prevention better than HIV positive people themselves.

SAN PATTEN: Okay last chance, oh green back there, what's green again?

FEMALE SPEAKER: Okay ours really follows on from the last one, what healthcare providers and community support workers can do, and we agreed that the best thing that we can do is to enable and support PHAs to offer peer support in a safe, supported, confidential, and consistent way, both individual and group; and our job is to build trust and relationships, to know it may take time.

SAN PATTEN: Thanks everyone and let me just remind you that all of your points will be captured as long as they're legible and on the back of one of those sheets, and please put your e-mail addresses down. So I am going to hand it off to our presenters, I believe that Believe is going to speak first.

BELIEVE DHLIWAYO: Yeah we would, I'm realizing that most of the things have already been captured within the groups, some of the points that have been raised from the discussions in the floor are basically coinciding with exactly

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what I have on the few slides that are there. I will look briefly, I think within ten minutes time, on the Peer-Based Approaches to Prevention with Positives. I just, amongst the group, wanted to acknowledge the presence of my one fellow comrade from Zimbabwe, [inaudible], she has been one very young women, very courageous and bold to be in a position to be where she is living with HIV. I'm remembering where she has come from and where she is now, and I think we need individuals like her who are bold to come out in the open and being young engage themselves in prevention.

One of the things, one of the points that I heard from the floor was the creation of [inaudible] so it's the creation of an enabling environment. One of the things that has really worked is engaging individuals from the communities and creating a safer space where they can actually share their experiences, and so we are talking about prevention there. I think that's one key thing that is very important, and when we talk about prevention from peers to peers, it starts when there is an enabling impairment where they can actually share their experiences. The second thing that again I heard from the floor was to do it building capacity, building capacity among the PHAs themselves, it is not only the capacity from program planners that should be taken into cognizance, but it is the PHAs themselves who can basically mentor and train other PHAs to take care of themselves. I know that a participation

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certificate to some of you who are social workers and who have PhDs and so forth, a participation certificate does not mean a lot, but it really means a lot to a community based individual who has never been to a college or has never been to a university, and the mere fact that they were able to be there for three days or for five days to share their experiences, and be given an opportunity to go through the process, that is to be in a position to reflect, and that to them is really rewarding and it's a motivating thing that they will have for the rest of their lives. So training and building capacity, it ends, it's one of things, and it's an approach that we could actually use for prevention from our peers to other peers who are living with HIV.

In order to [inaudible] condoms, condom usage, risk reduction amongst peers, as much as we appreciate the technology, as much as we appreciate the issues being explained by doctors with regards to safer sex harm reduction, I think it's better done by us living with HIV than by being told by someone who is not living with HIV because we have all the experiences of living with HIV and we know what it is like getting infected and having to live with HIV, so we are in a better position to explain that. All of the things that have utterly been happening in Zimbabwe, train peers in terms of how condoms should be used. I am just showing you slides of pictures of peers living with HIV, I talked to them before I

came here and they all consented and said it was fine, so they engaged right now in training other peers in terms of better ways of using condoms. Unfortunately, up to today we still have a gap in terms of condom use, what we have more of is the male condoms, and the female condoms are still not as widely available as they should be, and I'm sure it's still a gap with prevention. That takes away the right of women to decide about safer sex issues, and I'm sure when we talk about time to deliver, this conference we are talking about female condoms also being made available.

For sharing experiences as well, sharing of experiences is one way that would scale up prevention as well. The other thing is peer to peer counseling. There is a point that was raised that was very interesting with regards to where do we start? How do we talk about where the treatment starts? How do we talk about prevention messages? When do we link the two? So when I run into individuals I encourage them to uptake verbal counseling and testing, a place for them to confidentially share issues that are rising with them, and their empowered to critically look at issues that are rising. It is such that [inaudible] process. Also, gender sensitivity can utterly be taken into consideration where you have women who are living with HIV, especially are not comfortable sharing their experiences with men because she might be coming from an abusive relationship, and to go and face and talk to another

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man might bring a reflection of what she went through, and as such, the best approach would be having a female or having a male or having someone of the same sex who they would be able to feel comfortable with in terms of confiding, and basically having this individual take them through the whole process of coping with issues arising with them.

The use of a responsive model is a point that I heard from the floor. That we should actually be sharing responsibilities within families, and I'm sure sharing responsibilities does not only end within a family setting, it runs down to the institutional level with a group of pastors who are trying to start to address the question what is it we can do in a church setting to scale up prevention messages within this community. So the other thing also would be about mobilizing, mobilization and providing education and this can be better done by people who are actually living with HIV. [inaudible] changing the pastors [inaudible] they were supposed to go and do something about the setting up of support groups in their church based communities. There have been a number of support groups being set up within a faith based agency up to date because we have challenged them to do so, and I think that this is the best approach that we should actually take in terms of setting a pace in getting prevention messages across by PHAs to other PHAs as well.

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Then of course prevention, I want to talk about prevention and I want to talk about the best peer-based approach. We are talking about, I think, drugs and food. In developing countries, for people living with HIV and AIDS, the biggest issue for them right now is not about coping, they know their status, right? We are tired of all of the talking, we want the food and we want the drugs. If the food cannot be sustained to be supplied we need, we need mechanisms, we need strategies that are such that we can have a stock away at home, and then we can have gardens that are sustainable, and we can grow vegetables. There, in the picture there we are seeing individuals helping to get some food and who have worked from [inaudible] in Biramambo[misspelled?] where people actually grow some food, get it together, and then they share it within their village. We also have the phenomena that we have actually developed collective budgets known as Pan African Treatment Access Movement, and all that we are saying is that we need access, we need the drugs; and I will talk a little bit more about that subsequently. That's along the way, again, of prevention.

What are the lessons learned? People living with HIV and AIDS are as just as good caregivers, as much as social workers. It's not about going to school, that made us, it's not about going to college and being taught how to take care of someone living with HIV. What I have found, that which has been

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most useful over the years that I have lived with HIV, it is only an issue of just going there and sitting, and just having someone in your presence living with HIV and listening to them talk, to me that is what inspired me to live with HIV the way that I am today; and I'm sure that most PHAs have got people that have inspired them to live the way that they are. So HIV individuals are experts in taking care of each other, and they need to be, their capacity will need to be built, holistic care and support. So when we talk about holistic care and support we are talking about how there should be adequate food, but it is not only the food because I know that individuals have been putting an emphasis on food, but it also emphasis on management of opportunistic infections, we are talking about the drugs being available for prophylaxis. We are talking about taking care of our self, and all of those issues are lessons over the years that we have learned over the 20 years that if someone is eating well and there is a provision of drugs and they exercise well, they can live for a very long time.

What am I recommending to you? That which can be best practiced, so we can talk about accessibility, it's a major very important, affordability, acceptability, and also availability. All of these are important, and of course we can only ask you to join hands together, the young and the old, to advocate that we need people to be treated now, thank you.

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SAN PATTEN: Thanks Believe, so we will leave some time at the end I hope to have some questions, maybe, amongst the panel members as well as if any of you have any questions or comments for the speakers. Mary Jane, can you go next?

MARY JANE ROTHERAM-BORUS: Sure. Now is the time to deliver on the mountains of scientific evidence that we have that we have been gathering for the past 25 years to improve the lives of 21 million HIV positive youth who need care now. In the time that we are sitting here today 360 young people have been infected with HIV, and another 360 have died. This year two million more will be infected, and then next year two million more will be infected. These 21 million HIV positive youth need care now, and it's the people in this room, the HIV providers, who can dramatically improve the lives of HIV positive youth; yet we find that every community invents its own solutions slowly over time. As I was walking around the groups this morning I heard about a program in Ohio and I thought gee this is exactly the same program that I know about in South Africa in Cape town, and the same program that I've seen in daycare centers in Thailand. Every community is reinventing their own solution, as every donor has reinvented their own solution slowly over time so that it has taken us 25 years to reach a funding level for 75-percent of what we need, and that we know that in the next two years it's going to be 40-percent more than what we need today, it's gone slowly.

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My role here today is to talk as a researcher; every researcher reinvents their own solutions slowly over time. It took us 12 years to come up with the first prevention program with evidence for people living with HIV. Now we have 150 evidence-based interventions and 25 of them are for HIV positive people. I was asked to talk about youth today, we have five programs, evidence-based programs for youth. We brought you the list of the 25 programs, but how many people living with HIV are getting these programs, about one percent. My message here today is that in those 150 programs, evidence-based interventions which have been published and evaluated independently, that there are common proven solutions that are common across every one of those evidence-based programs; and that are job now is to take those proven solutions and broadly adopt them and tailor them to your local community. It’s actually much easier, I think, than what we think in the sense that I don’t care where you are globally Asia, Africa, or South America, all HIV positive young people face four challenges that are always the same. You have to do something about your health, you need to stop transmission, it’s likely that you are going to be depressed and feel some despair so you need to build the high quality life that focuses on living with HIV, and you’ve got some very predictable challenges: disclosure, losing income because you’re ill, how are you going to take care of your kids while you’re ill. These challenges are highly

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similar, and while the challenges are similar the answers, the solutions need local adaptation; but based on those 150 programs that we have, those 25 evidence-based programs for HIV positive people, and my message here today is that we have a road map. Every single one of those evidence-based programs share three characteristics, there is a set of common components, everybody who does it well does it the same way, there are best practices, and everybody uses the same strategies or common learning principles. They are the same, and if they weren't to analyze them and we could come up with these common factors. Again we have provided a summary of that to you in the back.

What do I mean by common components? Well I was really happy to see Believe's first main point, if you don't address environmental barriers you're going nowhere. You can't expect condom use unless there is access and availability to condoms. You can't encourage circumcision unless there is a safe surgical environment. First you have to take care of the environmental issues of what your program is to be about. The second issue is how are you going to frame that? This entire conference is about how we frame, and how the world wants to see HIV be framed, not as an issue of despair but as an issue of hope, encouragement, and a celebration of what we've done. To me, and we heard one of the groups here today, HIV prevention for positives needs to be framed as an issue of

living with the disease, not desperate or dying. The most brilliant example of framing an issue for me is the Sonigutchi project in India. In the last week this was written about as a program that really is about empowerment for women, today it is, it's a trade union for 60,000 sex workers, that's global; but that's not how this was framed and that's not why it was successful. The Sonigutchi program is about sex work as work, it is an occupational health program, and it was not, and it was framed and it only succeeded not as an empowerment program, but it was the fiscal monetary incentives to the people who controlled the sex workers. A very high status foreman went and told the brothel owners, the police, and the political parties if your women get infected your profits are going to go down, and so in the first five years of that program it was the brothel owners, the police, and the politicians who demanded 100-percent condom use among sex workers, it wasn't about empowering the women. How we frame the issue depends on whether we will be a success or not.

The third component is providing information, if your goals, if you're an HIV positive pregnant woman you need to know about ARVs you need to know about testing your baby, you need to know about only one feeding method, every pregnant woman needs to know that. There is specific information depending on your goals, but that's not enough, we need skills; and the matter analysis of evidence-based programs say we need

active participatory environments where everybody does the same thing. The challenging situations that positive people are going to face are very predictable, everybody is going to face stigma, and everybody is going to face disclosure issues. The skills are feelings, thoughts, and actions; and if you can find those predictable situations and help people anticipate and practice what they're going to feel, think, and do in those situations they're going to succeed. Finally, every evidence-based program builds support. That's been a big theme today, and we've talked about peer-based programs, I want to play the devil's advocate for a moment and it doesn't matter how you build the support, anonymously on the internet, in communities, in couples, in families, among gay men in support groups, but our group actually has learned a number of lessons about some of the cautions about pure HIV positive pure to pure issues, especially for young people. When we looked at peer-based programs we've seen that it's often a problem that young people who are peer leaders, especially since they are so young, they are having trouble taking care of their safer sex and their drug use behavior, and sometimes these young peers lead the guys they are supposed to be helping into trouble. There are also conflicts, role conflicts, they're your clients but in fact now they are supposed to be the counselors, and how do they come to you? Are you their boss or are you their counselor? These are challenging issues that I think as we

endorse these peer programs we need to think about, but once we've attacked those problem components, there are organizational, there are provider level, and there is client level best practices that all of you practice if you're successful. We have to have programs that build on strengths not deficits. If you have a punitive, controlling, authoritarian staff member it's going nowhere. You need to frequently reward people if you expect them to change their behavior. These are, as everybody knows, best practices; but we often don't specify them for people. Finally, everybody learns the same way. How do people change their behavior? They change it with new opportunities in relationship with practice and over time. I don't care whether you call that social learning theory, self efficacy theory, theory of reasoned action, or health belief model, it's the same way that people learn globally. These principles are a roadmap that is present in every evidence-based intervention. Now if we have that roadmap the challenge is how are you going to tailor that roadmap to your local condition to change the lives of HIV positive youth? We have strategies for how to do that and it's been done in hundreds of communities with rapid ethnography, to tailor those elements. Then we can experiment and encourage a wide variety of delivery formats to deliver the same messages, skills, and framing. It can be on the internet, it can be in individual sessions, we've provided some examples from our evidence-based

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interventions. We tried it out in individual sessions, in small groups, and on the telephone, and it worked all three ways. What we're doing today as an example is we took our 300-page manual for mothers living with HIV and we took that manual and changed it to DVDs, to daily planners, to very different delivery formats. It's that kind of experimentation with the roadmap that can begin to change. For us today, our real challenge is will providers and researchers implement broadly and quickly evidence-based solutions. We've been moving very slowly while HIV positive youth die, if we adapt proven solutions and then tailor that roadmap to your community, what I would argue today is that you can and will improve and save lives with the evidence-based care for young people living with HIV, thanks.

SAN PATTEN: Thanks Mary Jane. We are going to turn it over to Neil South now from BCPWA.

NEIL SELTH: Good Morning, I would like to thank San and Isobel and the organizers here for inviting me to talk at this wonderful conference, and at this exciting symposium. I've been asked to speak for a few minutes about prevention in the context of sero divergent couples, or sero divergent relationships. I use sero divergent here because when we sat down and talked about it, everyone else here at this conference is using sero discordant; but when we sat down and talked about this sero discordant just sounded like the couples were

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fighting all the time, so that's we got sero divergent, it means the same thing. I've been asked to speak from both the northern perspective and from the perspective of an organization that currently has programs or services in the area of positive prevention.

Just to give you a little context about BCPWA and our positive prevention department. BCPWA, or the British Columbia Persons With AIDS Society, is the largest HIV and AIDS organization in Western Canada, we have about just over 4,300 members, and while it's notable that our Board of Directors are all HIV positive, it's really the committee structure of our organization that ensures that all of our members have direct input into the development in policy and procedures of all of our programs and services. While most of you probably know what positive prevention is I have provided a brief reminder, it focuses on tertiary prevention, efforts are directed toward people living with HIV and AIDS, and are intended to reduce the negative or challenging effects of the illness, and maximize the quality of life. The picture that I've presented here is one of a series of posters that our positive prevention department developed some years ago, and marketed in its complicated campaign. A campaign that encouraged both positive and non-positive people to discuss their status; this particular campaign was directed at the MSM community.

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With respect to sero divergent relationships there are very few supports and services. Just to give you an example, in British Columbia which has a population of about four million, of course we have 4,300 members and we've got about a third of the whole HIV population in our membership. There is one support group that allows couples, that allows the partner of a couple to be involved, so one in the whole population; yet we have evidence thanks to a study by Ramian and all in 2003, that partners of HIV positive individuals have higher levels of psychological distress as compared to the general public. In fact it is similar to the distress experienced by HIV positive individuals, clearly there is a potential need for couple focused prevention services or supports. What about prevention campaigns aimed at sero divergent couples? Again, there is not a lot that I can find, at least in the North American context. It appears that sero divergent couples relationships and safer sex practices are taken for granted. It seems as soon as you hook up you're on your own. Most of our efforts are focused on the single or individual in single environments (I.E. gay men in sex environments) or specific groups like intravenous drug users or sex trade workers. A perfect example is our campaign, it's complicated, and it was targeted at men who have sex with men in sex environments. Yet the sexinal[misspelled?] survey from the community based research center in British Columbia in 2002 found that half of positive gay men that were in

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relationships were in sero divergent relationships, so that's 25-percent of our population of positive gay men. Now there was no data in B.C. in opposite sex couples, but findings could probably be extrapolated, and in fact when we ran the sero supportive workshop half of the applicants were same sex, the other half were opposite sex.

One of the discussion questions for the groups was what is one research question or issue that needs to be addressed with respect to the interface of HIV treatment and prevention? I would say we need to ask what supports and services do sero divergent couples need to maintain a healthy and sero divergent relationship? In other words, how can we support them in staying healthy and staying together? As far as the BCPWA response, we developed a sero supportive workshop which is a three night, four day, residential workshop for sero divergent couples; it is designed, coordinated, and implemented by a team of HIV positive individuals. Another discussion question in the group was what is the most effective way to engage peers in promoting or implementing positive prevention strategies? I would say including positive people in developing and implementing prevention strategies is critical, and this is not tokenism either, this is not do a focus group with you and we'll run off and do the program. It's getting them involved right from the start, right through the whole process, and right in through the evaluation. Also we should apply, in the

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elevation aspect we should actually be applying [inaudible] empowerment evaluation principles.

In terms of specialized help, again another discussion question from the group was what is one important way that healthcare providers or community support workers can help work with PHAs to reduce risk behaviors and maintain safer practices? Again I think we need to support PWA directive efforts and prevention strategies. We need to provide outside expertise as required or be the links to these external resources. In developing the sero supportive workshop we had a system of BCPWA staff, body work, practitioners, counselors, prevention experts, and a community based research technical assistant. The sero supportive workshop was designed as a spring board to develop other supports and services or identify prevention challenges. Things like support groups, social groups, forums on health and treatment such as a possible forum on how couples can work collaboratively to address issues of adherence, or management of side effects, or perhaps we can enlist the couples in the design of a prevention campaign directed at sero divergent couples. In the discussion room there was a couple other points on this as well. One of the points from the group over here was the focus, you need to focus on groups that are alike minded. The example that was given there was clear positive women, we did that with sero divergent couples, we had an amazing experience in that when we

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got 21 sero divergent couples from all over British Columbia together in one room for the information session it was just an amazing buzz going on. I can't explain to you here, I can't put it on a slide, and I can't explain it to you; but just having them all in the room so they are in the same area, in a safe environment was just an amazing thing to watch.

We conducted a needs assessment at the information session for couples interested in attending the sero supportive workshop, we had 18 couples from all over B.C. and here they listed their top five responses to the question of what issues are of importance to them. There are no surprises with the top three, my partners health, my health, and quality of life as a couple, but fear of becoming HIV positive or my partner becoming HIV positive suggested that there is continual concern on the part of couples, and that these fears need to be addressed either through prevention education or support services such as support groups and counseling. Couples prevention needs on the workshop range from basic HIV 101 for newer couples to more advanced discussions on harm reduction techniques. Intimacy is a common theme among HIV sero divergent couples. This issue is often tied to the issue of prevention in that we know that as many couples gain intimacy over time the perception of risk decreases, and unprotected sex increases, again Remian provided much of this work as far back as 1995. Sexuality is tied to prevention in more than the obvious ways

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as well, in the newer couples they often site more pleasure seeking motivations for non condom use rather than intimacy, both of these issues were brought up by couples in the sero supportive workshop and healthy discussions ensued. The picture actually here is of a peer facilitated small group session where the individuals, where all of these issues were raised by the individuals, of note in this session we actually divide the couples by serostatus for this so that the facilitator here is positive, so it's a positive environment all around, and in the negative groups we had a negative facilitator.

As far as providing peer-based programs and providing role models and inspiring couples, many couples experience breakthroughs, or what one couple referred to as magic moments; either around communications, understanding their partners emotional needs, or in more practical terms, prevention information they just didn't know. The picture here is of a couple that has been together for several years and had a magic moment during the communications real exercise that we did. Younger couples were also inspired by long time couples, several couples were inspired or encouraged that other couples could maintain a long term healthy relationship and remain sero divergent as well. This type of prevention message is probably more effective than any social marketing campaign that we could develop. Likewise, several long term couples reported that both their relationships and their commitment to prevention were

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reinvigorated by attending the workshop. There were actually two levels of role modeling going on. There was one amongst the couples themselves and another between the positive participants that attended and the HIV positive workshop team. Positive participants in the workshop were impressed that other positive people could produce the workshop. Two members of the actual 2005 sero supportive workshop had been invited into the workshop team as advisors for this year's workshop, and there is room for them to come right on to our team and work with us on all of our other projects as well. Again one of the discussion questions that was discussed in the group was what is the one message that PHAs must communicate to other PHAs with respect to reducing the number of new HIV infections? Well with respect to sero divergent couples one important message is that it is possible to stay healthy, to stay, sorry, it is possible to have a healthy long-term sero divergent relationship, and that supports are available or can be made available by positive people themselves.

Just quickly, I just went over some of our outcomes delivered. We delivered a formal prevention session there; we also established informal prevention dialogue and role modeling. We did a lot of consciousness raising, community building, we established an informal social network, and we got support group potential. This particular group that we did decided not to run the support group this year, but that option

is always there for them and they know that. We also gained advisors on future leadership workshops, so we've done some leadership building as well. Now I'm just going to shamelessly plug my first presentation in the sero supportive workshop where I can discuss the nuts and bolts of the workshop itself, the origins, the development, and implementation and evaluation, thank you very much.

SAN PATTEN: Thanks very much Neil, and now before the room clears we actually do have ten more minutes because the session started late due to the plenary extending into our time, so we've been given the thumbs up to go a little bit longer, so if anybody has a question or a comment that they'd like to make to the panel please go to one of the two microphones, number one or number two. If you keep your questions and comments brief, then we can have as many people participate as possible.

BRUCE TICK: Hi I'm Bruce Tick. I work with the World Health Organization in the Department of Child and Adolescent Health, and I've got a question for Mary Jane. I was wondering first of all what were the outcomes in terms of the evidence-based programs that you were working on, and secondly I was very surprised in your core components to see information and skills, but not services.

MARY JANE ROTHERAM-BORUS: We would have put services, like access to healthcare, as an environmental barrier that you

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have to make sure that you had. We have had multiple programs for children and families, so let me take our family-based intervention. At two years for both the parents and for their children, we had reduced depression, reduced anxiety, fewer sex and drug behaviors both by the adolescents and by their parents. At four years we had relapse on those behaviors, but in fact parents were injecting drug users and they relapsed into substance use less often. At four years adolescents were more likely to stay in school and less likely to initiate sexual risk behaviors. At six years adolescents – oh and they had fewer babies, teenage mothers, teenage pregnancies - at six years the parents were again less likely to relapse into substance use, the adolescents had less conflict in their romantic relationships. Do you want me to go on and on? And their grandchildren had better home environment, were better adjusted, these are babies that weren't around when the intervention was started. Their grandchildren were better adjusted and tended to have higher IQs and home environments. Teenagers were involved in less sex and drugs, and more likely to be assertive with their doctors, and fewer mental health symptoms, over two years.

FEMALE SPEAKER: Could you please explain how they relate to HIV positive people and what is the health outcome in terms of HIV positive people because you are talking about a big community, a big family, as if all of them were HIV

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positive, so if you could be more specific in the evidence based for prevention intervention that have outcomes to HIV positive people.

MARY JANE ROTHERAM-BORUS: Currently today in terms of health outcomes for HIV positive people one of the primary focuses have be on sex and drugs. There has been a study with adults, healthy relationships which is impressive, with the multiple studies with adults there has been, on reducing transmission the maintaining health outcomes are not in terms of AIDS or not AIDS, CD-4 counts, or viral load. They are about behaviors of how you relate to your doctor, adherence to medical regimens, and adherence to ARVs, and there are multiple evidence-based interventions for that.

SAN PATTEN: Okay let's take a question from microphones one and two, we'll take them both at the same time, and then we will have the panel respond to them.

MALE SPEAKER: My name is Rakim Azabuba[misspelled?] from South Africa, I'm a generalist and I am also a person living with HIV, and I just want to express a bit of problem, because as someone who has experienced discrimination both at the racial level and also at the HIV status level I find it unacceptable that, I mean all of the speakers who, the panelists, and almost everyone else who has spoken, we seem to wish to discriminate against others, I mean everything that we talk about is restricted to people living with HIV and I find

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that unacceptable. I think that it is important that there are people living with HIV who, most of us have experienced or are afraid of being victimized or discriminated against. I think we are the ones that should be setting a precedent in terms of acceptance of others who may be different from us, thank you.

SAN PATTEN: Thank you, microphone two.

MALE SPEAKER: I'll be brief because he just stole my point. My name is William Fleming and I just wanted to note that earlier we heard a point about trying to overcome the difference between positive and negative, and practically speaking that is not easy to do and there are lots of reasons why bringing people with AIDS to the forefront is important, so I don't want to start an argument. I just want to raise that in the presentations I saw a few opportunities where we didn't actually recognize that many caregivers, you could probably say most caregivers, are not positive and yet we did not talk about them as both an asset and a very vulnerable group. I also want to thank you for the presentation for involving the last presentation both for its focus on the divergent couples which I think is important, I mean you can extrapolate that to the world, and our interplay with one another as negative and positive; but also for the practical focus on sex and the way that most of us do get infected, and bringing that to the forefront. So I would encourage all of you in anything that you want to reflect on about how to stop the kind of

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positive/negative separation that we all further in our presentations and in our work unfortunately.

SAN PATTEN: Would any panelists—

MARY JANE ROTHERAM-BORUS: Actually I would just like to say that I think this is a huge and very important point, and I know the way that we translate it is we think, as actually Neil said, people have focused on populations, gay men, IDU. I know our center now only, predominantly focuses on families or communities, and that then in the context of a large extended family there is positives there is negatives, this is a family challenge to have a high quality life everyday for all of them.

SAN PATTEN: Neil or Believe, do you want to respond?

BELIEVE DHLIWAYO: Yeah just maybe a reaction to what my brother from [inaudible] was saying. I think we need to be more accommodative. I think over the years what we have seen; there has been a lot of talk down approach which has been such that people living with HIV and AIDS have not been given a place to express issues arising with them as people who really are bidden with the disease. As much as they would love to be accommodative, but the level of interaction has been so much restrictive and what we are trying to say is that peer-based approach would be such that these individuals are given the space that they can freely express issues that are rising with them, and with capacity being built, it is such that they will learn to be as accommodating as possible. I'm sure what we see,

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most people living with HIV being passionate about issues that are emerging from because the geba[misspelled?] principle is not being taken into cognizance effectively and that's a huge piece of PHAs and they are passionate about that, it is such, we tend sort of to be like more, we are not accommodative to people who are negative or of program planners, but it is for a very long time that there has been that huge gap and we are trying as much as possible to involve the program planners. We need to be involved as well, we need our journalists to be there with us, and we need to discuss these issues collaboratively rather than having people planning and discussing them on our behalf.

SAN PATTEN: Neil did you want to add anything?

NEIL SELTH: No.

SAN PATTEN: Okay one last comment and then we will have to wrap up.

MALE SPEAKER: Hi I thank you all for your wonderful presentations and I was observing in the small group process, and some of what happened in the room today, a sense that I'm feeling some of the history repeating itself as it generally tends to do; and your comments about how slowly things are changing, Mary Jane, I think are very clear and evident over the history of this. I think that one of my hopes is that as we proceed that we don't do another broad brush stroke, it has taken us very long time for some people to catch on that the

role of people who are HIV positive in prevention is probably the best, most important thing that we could do, and we have been way to slow getting there. I hope that now we don't just draw that stroke too broadly and say okay positives are in prevention, that's what we need and that's enough. I think we always have to remember the collaborative needs between the expertise in behavior change, the social workers and psychologists, and the behavioral scientists who can help those who are HIV positive become better efficient agents of change by teaching about whether it's behavior change, the stages of change, theories, the other theories around there that talk about how to make your programs comprehensive because otherwise I think we again proceed very slowly. Now we've got the message, people who are HIV positive are critically important in this process, but at that same time we need to come together with the behavioral scientists, the social workers, the psychologists, the families, and work as a better team I think. So I just hope we don't, because I saw that some of the answers from some of the groups were get people together, you know, get peer support. Yes, but I want it to be sort of high quality peer support that's empowered and informed through the behavioral science so that we don't treat the whole group as being at the same stage of change. Some are in pre-contemplation, some are ready to change, and on down the line so that it's not just a support group, but a group that helps

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people identify who they are and where they are in their own attempt to change, and so that we can then help them then get to the next stage, thank you.

SAN PATTEN: Thanks very much, so I think we're going to have to wrap up, and I just want to really thank the panel Neil, Believe, and Mary Jane, as well as Isobel; and thank you to all of you have stuck around the last few minutes.

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