



Transcript provided by kaisernetwork.org, a free service of the Kaiser Family Foundation¹
(Tip: Click on the binocular icon to search this document)

**2008 HIV/AIDS Implementers' Meeting
Plenary: Linking People to Resources
Government of Uganda; PEPFAR;
Global Fund to Fight AIDS, Tuberculosis, and Malaria;
UNAIDS; UNICEF; World Bank; and WHO
June 5, 2008**

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

[START RECORDING]

DR. DEBREWOK ZEWODIE: Good morning. My name is Debrewok Zewdie. I am the Director of the Global HIV/AIDS Program of the World Bank. It is a pleasure for me to host this distinguished panel. We have a rich set of people who will be discussing bringing people closer to resources, which is the title of the Plenary.

The way we are going to do the Plenary will be we have two presenters. They would each give us a presentation for about 15 to 18 minutes, and we have four distinguished panelists who would come after the presentations and give us their view of the presentations for a few minutes. And then we would have a dialog on the panel, where we will be asking questions. We will not take questions from the floor for a very specific reason, because the theme is going to be discussed in separate sessions in detail.

With that, let me introduce the first speaker. I am sure you would agree with me that we have had enough bio reading to last us a lifetime, so I am not going to read bios. I am only going to introduce individuals who would speak about their bios as they give their presentations. The first presenter is Dr. Martine Etienne, who is a trained epidemiologist specializing in the development and evaluation of adherence programs nationally, internationally. And she is

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

a distinguished individual, and she is currently the director of the Community Health and HIV/AIDS Treatment Support Program of AIDS Relief, PEPFAR. Etienne?

MARTINE ETIENNE, M.P.H., PH.D.: Good morning. Thank you. So, I am going to talk a bit about engaging in local solutions to link persons to resources. And then I will share a little bit about the AIDS relief experience and some of the things that we have done in our program.

I wanted to ask a few questions so that we could think about as we are discussing this and as we also talk with the panel. Healthcare linkages, is this an outcome or an activity? And why has it become such a central term in HIV care programming? What is it about the current health systems that demands linkage solutions? And how can we successfully program so that this term becomes obsolete?

Access to ART is really just the beginning of providing care and treatment. It is challenging. It is a challenge to quality treatment and durable health outcomes. And how multiple access of care or services are provided will ultimately dictate treatment scalability, treatment outcomes and sustainability of HIV programs. And so obtaining the outcome of linked services requires operating a systematic procedure to be able to process hundreds and thousands of patients through different outlets of health services.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

So we are moving to thinking towards focusing on services. What kind of services do we need to provide? Are healthcare facilities providing integrated patient care services, or are they operating largely independent health programs? There are a myriad of funding sources and agencies, multiple different reporting formats and standards, different accountability of drugs and consumables, and multiple organizations providing different services for one patient. So, ultimately you have one patient needing many different services but being provided from different programs, and you end up having to almost case manage the patient.

And so this is a scenario of what we have seen in our experience. This is Hospital A, and they are provided with funding to provide TB services. They are also provided with PMTCT, PMTCT Plus monies to provide PMTCT services. And then there are care and treatment dollars. And all of these are perhaps coming from different streams. But then there are different organizations and groups that provide care that are outside of that hospital that are also funded through different agencies and organizations. But this patient needs all of these services. And so we are in a situation where we are providing multiple services to achieve one outcome.

For example, what services are necessary for an infant to be born free of HIV and alive at two years of age? There

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

are several: community sensitization, antenatal testing and counseling, secondary prevention and adherence education, infant laboratory diagnostics, home-based care, clean bed nets, clean water. But who takes accountability, or who is responsible for this individual's health outcome? There are a myriad of services that are needed, but how do we make sure this mom and this child get all the services they need, and who is responsible for that?

And so we are looking at more of a comprehensive outpatient service delivery and how that can be achieved, what that model looks like and how can we get there, what services do we want to see provided, how are these services phased in as a facility's capacity grows, and what is the cost for service provided?

And so now you may have something that looks like this, where Hospital A is providing comprehensive services, but they are comprehensive outpatient services, and they are funded to provide initially perhaps a few services like community-based support or VCT services or effective, efficient laboratory services. And then they are provided with a bit more funding, perhaps, to provide services like ART, TB treatment, and PMTCT. And then perhaps capacity is continuously built, and they are provided with more funding to service other needs in the community, into survival services, malaria prevention. But

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

these services are decentralized, and using the community to provide these services is going to be important.

And so how can a comprehensive service provider deliver care in the current resource-limited setting? The paradigm again is using the community as an effective strategy, empowering them to support the services, building capacity for the community members to service their community, to take responsibility for their community and for their health.

I want to talk a bit about the AIDS relief experience and some of our challenges and where we are headed working towards a comprehensive service model. For our program, we have tried to use care and treatment resources to fund as many related services as possible and then gradually expanded on these services. The AIDS relief model, the AIDS relief program key cornerstone is using adherence and adherence support as a vital therapeutic intervention. And so we build the program around community programs, around people living with HIV, so they own the program, and supporting adherence interventions through the community, and not just adherent to ART, but adherence to care, adherence to healthy behaviors, adherence to community health.

And we immediately worked with treatment facilities to greatly augment the capacity of any existing community health programs. And we tried to establish community programs if none

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

existed and form partnerships with existing community programs. The key was to develop and class out specific services which were to be provided for the patient at the home community level, trying to figure out what is needed in the community for that patient and how were we going to support that and build the capacity of the community to support the community and its members. And then so there was enormous effort built on building capacity to provide these services at this level.

And what we began doing was increasing training and capacity building for people living with HIV. And these are members of the program, so patients who are part of the program were now being used and implemented in the program to support their community, to support themselves and their community members.

We facilitated in increasing community support groups. And I should just stop here and say how effective and how exciting the support groups are because of the outcome that they are providing for the community. And what is happening in the clinic is it is alleviating some of the burden from the clinic, and now the care is being decentralized into the community, because now support groups are not just support groups, they are supporting the community, patients are supporting each other. They are teaching each other. They are learning from each other. Income-generating activities are

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

started. And community health nurses are able to go out and support these support groups at any point in time to provide care in the field.

And we have also increased community mobilization activities that targeted religious leaders, traditional healers, community officials and other community members, so that the entire community is a stakeholder in the betterment of the community's health. And so the mobilization of the community members into care and treatment was a success through church-based testing, home-based testing. The community and its members and patients in the field were doing the treatment preparation for patients, and their family members were being part of that. And so the care is continuous in the community. It is a cycle that just never ends. It is continuous and it is a support system that provides for continuity of care.

So just a few things that we have learned and that we are still working towards this idea of providing comprehensive services. The ability to provide the comprehensive services is the integration, and successful programs can be achieved best by supporting and building capacity of all community stakeholders within the program and decentralizing as much of the services as possible into the community. It supports the empowerment, ownership and responsibility for the care of its members. The programs are now moving towards decentralization

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

into the community. The patients own the program. They run the support groups. They run the education. They run the mobilization efforts.

And a few things that we have tried to also implement is sort of a graduation system of patients who are now stakeholders and part of the program, so at some point patients become employed by the clinics. Not all patients are able to. We are not, of course, able to employ all patients. But there is some sense of empowerment and ownership of the program, and the program is now owned by the patients. And so we believe these strategies should be considered priority for programs seeking optimal health success.

So where we are headed is continuously building on the community to bring services, for example, bringing VCT services to the community through mobile community testing and home-based testing; increasing the ability to prepare patients for ARV therapy in the community by other patients; finding moms, for example, in need of antenatal care; distributing Water Guard for clean water and bed nets to prevent malaria; again, not just only focusing on HIV, but comprehensive services; providing TB DOT care; providing home-based care; increasing prevention strategy; and championing healthy behaviors as well as promoting risk reduction.

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

And so these things, we believe, will increase better clinical outcomes, translating to lower cost of care, because more people are being identified in the community through mobilization, through education. And so that now begins to get people into care sooner. And then lower rates of patients being lost to follow-up, translating to lower costs due to fewer treatment failures and fewer complications, fewer hospitalizations and fewer patients progressing to costly second line therapy.

We are headed in a direction where children like Ugeniva [misspelled?] in this picture will grow up in an environment where HIV education is freely spoken about, prevention is freely talked about and championing healthy behaviors and using community members, using patients from clinics, using Ugeniva's mother to support a mother who is in her community to seek care, leading to more successful outcomes and more successful and healthier community behaviors and healthier lives.

Thank you.

DR. DEBREWOK ZEWIDIE: Thank you, Etienne. Following on the same theme, the next speaker is Cyriakue Ako. He is the Executive Director of the Ivorian Network of People Living With HIV/AIDS. Cyria?

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

CYRIAKUE AKO: Good morning. I will talk about linking people to resources, the perspective of people living with HIV and AIDS. Let me start my talk with a story. This story is a case story. It happened in Cote-d'Ivoire. It happened in Abuasu [misspelled?].

Jay was very sick. He went to a traditional healer. The traditional healer sent him for HIV testing. Jay was found to be positive. The testing center sent Jay to receive treatment. Soon he felt better, but he also felt alone. He met the community counselor, who introduced him to a support group. Jay met people like himself. He started learning about HIV disease and treatment. He learned about life skills, advocacy and so on. He became an active volunteer with a local PLH organization which is a member of RIP+, the network of people living with HIV in Cote-d'Ivoire. RIP+ is currently implementing a New Partners Initiative project.

This story, the Jay story, illustrates what we all want to happen. Over time, we see Jay as a sick person, a patient, a beneficiary, then an actor within a community, then an autonomous, competent, empowered activist with an active funding network. Could Jay's story be true? Could it be true all the time? How to make this story come true?

My presentation will focus on these key points, these few points. What resources do people need, how do we link

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

people to these resources, what we have learned and how we can do it better? We have categorized the resources in this set. This might not be exhaustive, but we think this is the priorities one: access to prevention services; construct a responsive and informed environment; access to testing; access to care and treatment; provide community care and support; empower people as autonomous and competent agents; and be strong and capable organization with financial resources.

Let us move to slides to understand our great work to link people to these resources. How do we do that? How do we have this person overcome these big obstacles on the way to his wellbeing? What are these obstacles? How do we remove them?

The first resource we have identified was universal access to prevention, what we do. [Inaudible], we promote visibility of people living with HIV and AIDS, and we promote also positive leadership through this set of activities. We also promote positive prevention by advocating for its integration in all prevention, care and support programs at the national level. We develop tools, training, implement and preventing and information tools, in collaboration with other national stakeholders.

For a responsive informed environment, what we do, we work at three levels. At the community level we try to link traditional healers to health system by training them and

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

empowering them. We also train [inaudible] leaders and link them to people living with HIV network. In the private sector, work to strengthen fabric public-private partnership, and we also help inside the work facilities, reduce stigma and increase compassion. With private sector, the main achievement is to help community counselors to work closely at the health facilities as part of the caring providers. We also advocate for the creation of a boarding of community counselor at the national level.

As far as universal access to testing and treatment is concerning, we advocate for access, universal access to testing. I'll just give one figure. In Cote-d'Ivoire, the last survey that was made showed that only 6 percent of the population has been tested. We have a very big challenge to have all the population to access the testing to be tested. So, what are we doing? We organize and promote a national testing day, and we also advocate for free treatment and care.

We work to ensure disclosure and visibility of people living with HIV and AIDS by creating and strengthening positive people living with HIV association. We also use our own experience to promote available services. Living proof, who better can talk about how services are effective if it is not those who take these services? We, as people living with HIV, we are well placed to promote these services. We also promote

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

support groups through [inaudible], assigning support groups all over the country, and we work to assure adherence to treatment.

For community care and support, what are we doing? Psychological and social support, economical support, by promoting income-generating activity through what we call now the business plan with social impact. This helps to sustain the organizations and to provide sustainable resources to help people to reach their needs. We also seek and link organization and our people with funding sources.

We also work for legal support. We support people living with HIV with legal issues, and we constantly advocate for a legal framework to protect people living with HIV in the country. And to have all these things work within that, we need to set up and promote an effective referral [inaudible]. This is a schematic of our referral and [inaudible] system. This is through what Jay came and had his life saved.

So, if we have linked the individual with these services – testing, treatment, community support, effective referral system and so on, will I be tempted to think that we have succeeded, that we are finished? But if we stop there, I believe we overlook critical needs. How many people are involving to do the work? How many people are really accessing the services? Why many people are still hiding themselves?

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

Why many people are still in the passive beneficiary stage?

Our desire is to have every people living with HIV on the board as an active, wellbeing agent, for themselves, for the community and at the organizational level.

So, what are the obstacles? This slide shows what we call the [inaudible] blocking phase. This phase needs to be constantly be addressed to help people living with HIV to greater access services. These phases are five. They are few, but they are the most challenge that limits access to services – gender issue, vulnerability, auto-stigmatization, discrimination and stigmatization. How could people access services if they are stigmatized, if they auto-stigmatize themselves? How people can access services if they are arrested when just they ask for their right?

I read in the newspaper today that three gay people were arrested at this conference in [inaudible] because what I think they just came for their right to fight for better access to services, but with [inaudible] I do not think that they will access to these services.

RIP+ response to address this are included into its approach called [inaudible] process. [Inaudible] means together we are powerful in a local language, and [inaudible] is also the name of the first organization, or the first peer organization that was formed by this approach in the west of

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

Cote-d'Ivoire. [Inaudible] works at three levels, at the individual level, the organizational level and the environmental level.

At the individual level we build self-esteem, acceptance, knowledge and skills. At the organization level we provide capacity building, capacity at the organizational level, capacity at the technical level, and we mentor organizations. At the environmental level we address stigma through Ambassador of Hope mission advocacy and involving media. And that process leads to validation to the individual, autonomy and positive leadership.

To end with the needs, let us move to this slide, linking empowered individual with empowered organization. Let us take the example of RIP. RIP was founded in 1997 with the first four People Living with HIV organizations in Cote-d'Ivoire. It has grown to 49 organizations today. And it has received resources, funds, from several donors, including [inaudible], the government, the [inaudible] New Partners Initiative and so on. RIP worked to build organizational capacity, assist these affiliate organizations, provide subgrants, mentor them and monitor and evaluate their work.

What have we learned over years of work? It is generally admitted that every new infection involves a person living with HIV and AIDS. So, for prevention, [inaudible]

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**2008 HIV/AIDS Implementers' Meeting
Government of Uganda; PEPFAR; Global Fund to Fight AIDS,
Tuberculosis, and Malaria; UNAIDS; UNICEF; World Bank; and WHO
6/5/08**

change among [inaudible] has its greatest impact on the academic. We also learned that visibility of [inaudible] can gravely reduce stigmatization. Enhancing the capacity of people living with HIV for [inaudible] their peers is fundamental.

To get beyond the emergencies intervention approach, we need to take a step back and [inaudible] the specific experience and needs of the individual and link this individual with tailored resources. It is also important to focus on qualitative indicators such as hope, reduction of anxieties. Most of the programs just look at quantitative indicators, how many people have been tested, but we do not really look at what these people have become after being tested. We need to [inaudible] capacity of the individual towards their autonomy.

Few challenges, but very important challenges. Access to universal and free services remains a very big challenge. Have legislation that specifically protects people living with HIV at a country level and at the international level. And empower people living with HIV from a beneficiary stage to active partners. I will conclude to say that Jay's story is true, and it is not just happening in Abuasu. Thank you.

[END RECORDING]

¹ kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.