

# Action for Universal Access 2010: Myths and Realities



## **Civil Society Interactive Hearing at the UN High Level Meeting on AIDS**

Speeches by Civil Society representatives delivered on Tuesday June 10<sup>th</sup>, 2008  
11:00am – 1:00pm  
Conference Room 4 – United Nations, New York

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### **HIV and Human Rights**

Mark Heywood, *South Africa, AIDS Law Project*

*Mr. Heywood was elected National Deputy Chairperson of the South African National AIDS Council, a national body established to advise the government on its HIV/AIDS response. He serves as the Director of the AIDS Law Project, and is a founding member of the Treatment Action Campaign, the AIDS and Rights Alliance of Southern Africa, and the Global Reference Group on HIV/AIDS and Human Rights.*

Friends and comrades. Good morning.

My theme is: Human Rights – do we believe in them and what if we do? My name is Mark Heywood. I am one of the leaders of the Treatment Action Campaign and the Deputy Chairperson of the SA National AIDS Council.

We are all equals in this meeting. We each have a responsibility for human rights. Some of you, particularly from government, have power and resources to better people's lives. Some of you have little power, but come from communities whose rights are violated daily. But whether from government or civil society we must admit that we are failing many, many people. This is because in most parts of the world human rights violations that increase the risk of HIV infection and those that follow after HIV infection are getting worse.

Hundreds of thousands of children still are being born with preventable HIV infection – hardly making them equal. People are dying of preventable illnesses. People are being confined in squalid prisons for drug resistant TB – with no concern for their dignity - in the name of 'public health'. Woman and children are

raped in frightening numbers. Rich people live with HIV -- and poor people die, usually after a period of added pain and indignity.

Regrettably – in China, Zimbabwe and other countries – many who fight for rights – or expose their violations – find themselves the victims of their governments or their self-serving officials. We call on China to free Hu Jia now.

We have to ask: do our governments really believe in human rights?

In the last 20 years nearly one third of UN Members have adopted new Constitutions, many of which explicitly protect human rights. But this legal commitment is meaningless unless these rights are given effect to. This is a duty of governments – not a choice.

And it is the duty of civil society to hold governments up to the standards they have accepted on paper. Poor people cannot afford lip service to human rights from civil society either. When civil society is snared in endless conferences and flattered at “consultations” we become part of the problem. When we gratefully accept the hand-me-downs of government, we leave the poor and vulnerable, defenseless, and eventually very uncivil – as we have seen in the horrific xenophobic violence of South Africa that has displaced 50,000 people.

We say to civil society leaders: work with and assist your governments, but do not trust their promises. There is a direct link between the degree to which human rights are protected and your pressure on government and its institutions.

We have learnt this from experience in South Africa. For example:

Despite our liberation, it took 14 years until a court eventually ordered our national defense force to end the mandatory exclusion of people with HIV from all positions.

In South Africa it takes pressure from community activists to get the police to investigate and the courts to effectively prosecute murder, rape and domestic violence.

In South Africa officials of my government (some probably sitting among you) still persecute doctors for carrying out WHO recommendations on the prevention of mother to child HIV transmission and reducing maternal mortality.

Unfortunately, human rights violations are the global reality, especially when people lack power and organization to fight back.

Therefore civil society must recognize that human rights have to be demanded, fought for, won and then held onto. This can be done through systematic

community organisation, demonstration, legal action, treatment and prevention literacy, human rights education and by demanding to be meaningfully involved at every level of policy-making.

To the democratic governments here today we say: Recognise us as equals. Account to us. The response to HIV will be better for that. When you exclude us from planning or implementation, or dismiss our demands, you betray a solemn pact to govern with stalwart adherence to democratic principles, which are the foundation for respect, protection and fulfillment of human rights. Where governments are not democratic and suppress and torture us we call on the UN to end its policies of quiet diplomacy. This meeting must not make any more false promises.

Human rights will not be realized if they are delivered in e-mailed Declarations from New York.

Finally this High Level Meeting must reconfirm the principle that Universal Access by will not be achieved without human rights. So we call on you to:

Demand an urgent increase in development aid to meet the commitments that have already been promised, particularly by OECD countries; This is not a favour to us, but a human rights duty.

Devise and implement systems that measure and monitor human rights; have the courage to openly denounce countries such as Zimbabwe that violate rights to health; demand investment in justice systems that poor people have access to.

Finally, end the distracting talk of AIDS 'exceptionalism'. Every threat to life and dignity of poor people, be it through a disease or other causes, should generate an exceptional response.

We call on the UN and the WHO not to relegate the response to AIDS to the level of your past failures, such as TB or your mute witness to the demise of our health systems. Instead, raise the response to other challenges to the level we seek to achieve with AIDS.

Good luck and thank you.

## Opening Plenary Speaker

Ratri Suryadarma, Malaysia, Coordination of Action research on AIDS and Mobility Asia (CARAM Asia)

*Ms. Suryadarma is an Indonesian woman openly living with AIDS and is the Program Officer at CARAM Asia, an advocacy and research organization that works to promote and protect the rights and health of Asian migrant workers globally.*

Your Excellencies, President of the General Assembly, Secretary General, Honorable Delegates and my dear fellow community members.

I stand before you as a woman from Asia Pacific, where women's highest risk for HIV infection is through marriage.

For more than twenty five years now, we have known how HIV is transmitted and can be prevented, but some governments still believe that they can protect **their** country from HIV by stopping "non-nationals infected with HIV" from entering their country.

Attitudes and policies such as these will not contribute to reaching the goal of Universal Access; it will however contribute to increased stigma and discrimination of people living with HIV.

Yet, your countries have committed to the goal of Universal Access by 2010. So we are halfway there and I ask, "How strong do you hold that commitment?"

In my region, experts say there is a "concentrated" epidemic. By that they mean HIV is contained within marginalized and vulnerable groups such as drug users, sex workers, gay men, Men Who Have Sex with Men; many of whom are married, transgenders, migrant workers, prisoners and even refugees who are being infected with HIV at a higher rate. Yet they are often denied or have limited access to HIV Prevention, Treatment, Care and Support.

I ask you, "why?" Are we not all human and deserving of the same rights and treatment?

These communities are not only at a higher risk of HIV in Asia, it is the same everywhere. If you allow one group to become infected with HIV, you will never stop the epidemic. Isn't that the lesson we have learned?

In fact the epidemic is moving out of concentrated groups into the general population. Look at the increasing rates of infection among women, children and youth. This is where you can see the effect of falsely believing that HIV will remain isolated among certain groups.

These groups need services that are sensitive to their needs, supported with

adequate finances and resources. Instead, many countries have criminalized behaviors that push people underground and make them afraid to come forward to receive proper prevention and treatment.

As the Honorable UN Secretary General, Mr. Ban Ki Moon, recently noted, and I quote “We must guard against legislation that blocks universal access by criminalizing the lifestyles of vulnerable groups. We have to find ways to reach out to sex workers, men who have sex with men and drug users, ensuring that they have what they need to protect themselves.”

Here, communities, NGOs and people living with HIV can complement and build upon your efforts. You cannot do it alone. We have to work hand in hand together! Here are some recommendations:

Decriminalize behaviors associated with risk of HIV that are targeted at specific groups.

Eliminate mandatory testing of migrant workers and travel restrictions of people living with HIV.

Pass enabling laws that make it easier to get the right prevention method to people who need them, especially clean needles to drug users and condoms to sex workers and their clients.

Stop treating HIV as a separate issue: link the UNGASS on HIV with the UNGASS on drugs; integrate reproductive health, gender and human rights into HIV prevention and address co-infection of Hepatitis C and TB with urgent prevention and treatment responses.

Make treatment affordable and easy to access for all. Explore exercising the TRIPS Flexibility such as compulsory licenses for HIV, Hepatitis C, TB and other essential medicines.

And let us, the Community, sit at the table and make decisions with you.

I am also a Person Living With HIV, and by revealing my HIV status publicly, I am taking a risk of being banned from entering this country and over seventy other countries around the world.

When I found out about my HIV status in 2006, it was thought in my country that only Sex Workers and Drug users got infected. I am neither. But really what does it matter how I got infected?

As a woman living with HIV, I could be accused of bringing HIV into my home, beaten for something I didn't do, stripped of any inheritance rights and thrown out in the streets because of a health condition.

As a woman I need my human rights respected as well as my rights to property and inheritance, I need protection against domestic and sexual violence, I need

to be able to manage and control all matters related to my sexuality and reproductive health. As a Person Living with HIV I need equal access to prevention, treatment, care and support. As a mother I ask this not only for myself but for my daughter and future generations.

In closing, I am committed to the working for the best possible life for people everywhere. While it is not my intention to embarrass anyone or point fingers, I do want to ask, what is more embarrassing and shameful than a tragedy that could have been prevented. We have the tools and knowledge. We need the will.

But more than anything else, we need action!

Keep your promise and renew your commitment of Universal Access by 2010. To not do so would mean to condemn many people living with HIV, like myself, to unnecessary pain, suffering and... even death. I will honor my commitment and so I ask. Will you honor yours?

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### **Sex Workers and HIV**

Gulnara Kurmanova, *Kyrgyzstan, Tais Plus*

*Ms. Kurmanova has been an advocate for the implementation of rights-based approaches in the comprehensive response to HIV and AIDS and the involvement of key populations in the design, implementation and evaluation of AIDS responses. She is involved with the International Committee on the Rights of Sex Workers in Europe, the Network of Sex Work Projects, and the Global Working Group on Sex Work and HIV Policy. Ms. Kurmanova is the alternate representative for Asia for the UNAIDS PCB.*

I will begin with an example of institutional repression and violence that explains why sex workers remain at high risk of HIV and are unable to access health services. Recently one South East Asian country passed an anti-trafficking law that has led to massive human rights violations against sex workers. The law erroneously equates sex work with trafficking. Sex workers have been forcibly detained in so-called “rehabilitation centres” where they have been raped and robbed by police and guards. Thousands of women have lost their livelihoods. HIV positive sex workers have great difficulty in accessing ARV’s – both in and outside the detention centers. Additionally, sex workers are arrested if found with condoms, as evidence of sex work, resulting in sex workers being scared to carry condoms and to access STI services.

As sex workers, we call on countries to address the following:

1. **Decriminalisation.** Sex work is legitimate work and should not be criminalized. It is not a crime. It should not be equated to trafficking or sexual

exploitation. Sex work should be considered a legitimate form of labor and sex workers should be protected under labor laws. People should have right to work as a sex workers.

**2. Human Rights.** The fundamental human rights of sex workers need to be protected. Government policies and AIDS programming continues to undermine these rights. Sex workers' rights to information, privacy and freedom from violence, are violated through compulsory testing, and obligatory status disclosure, rape, and murder.

**3. Stigma and Discrimination.** Even in cases where sex work is formally decriminalized, sex workers are persecuted by the police, medical doctors, and local communities. One of the most obvious manifestations of discrimination is allowing outsiders to make decisions about sex workers' lives, health and work, or to look at sex workers as hopeless victims who need external help and so-called 'rehabilitation' to 'become good girls'.

Moralistic policies and programs are not effective. We need to adopt approaches that actually work. We call on all UN agencies and the international community to develop policies that support sex work as work and that include sex workers in their development and decision-making processes that directly affect them. This would be a good opportunity to empower sex workers and strengthen sex workers groups, unions and networks around the world.

Governments must uphold the human rights of sex workers, prevent all forms of violence, including rape and murder, stop the mandatory testing and denial of ARV's, other medications and health services in general for sex workers.

We also call on UNAIDS and UNFPA to accept the perspective of sex workers in the Guidance Note on Sex Work and HIV and finally agree on the concept and content of this paper in the interest of sex workers and public health. We need an effective tool to protect our lives.

Sex workers are not part of the AIDS problem; we are part of the solution.

Thank you.

## **The Rights of Sexual Minorities**

Leonardo Sanchez, *Dominican Republic, Amigos Siempre Amigos (ASA)*

*Mr. Sanchez is the Executive Director of ASA, the first and only legally registered organization dealing exclusively with the rights of gay men in the Dominican Republic. A renowned researcher, facilitator, and activist for the rights of sexual minorities, Mr. Sanchez has supported the creation and growth of an alliance working to secure sexual rights nationally.*

(Speech delivered in Spanish – Spanish text below)

The Declaration of Human Rights and the Yogyakarta Principles, reminds us that all human beings are created in dignity and rights. Nevertheless one African leader promised to “cut off the heads” of all homosexuals in his country. In the Caribbean, one politician in 2006 stated that homosexuals, “will find no solace”, in the midst of concentrated epidemics in the region. These statements were made in an environment where African countries invested less than 1% of HIV programming targeting MSM populations and where homophobic murders have become a critical issue in the Caribbean.

Such inadequate commitments to resources and human rights illustrate that stigma is helping to drive a global health problem. Sero-prevalence studies around the world have shown a disproportionate impact of HIV on sexual minorities with estimates that range between 7% and 46%. Globally, transgenders’ invisibility, is affected by state-sanctioned ill-treatment and vulnerability to HIV and AIDS through signed international and national legal instruments that does not recognize or refuse to address gender-based identity as an issue.

For women who have sex with women, research has lagged behind information on their vulnerability, because of perceive low risk about sexual practice, creating few opportunities for providing prevention, care and support services. Implementing CEDAW in recognizing the population vulnerability to HIV and AIDS.

In the Asia-Pacific region, HIV resources have climbed from less than \$50m to close to \$200m from the Global Fund, but resources do not necessarily follow priorities for 5 out of 24 countries get the majority of the resources. Such inequalities worsen an already dire public health situation in a context where persistent human rights abuses, severely complicate efforts at universal access. The urgency, is reflected in Hijra communities, where infection rates reaches 50%. Such elevated risk is a reflection of overt or covert marginalization in planning, policy design, program development, and resources mobilization, that is often expressed through silence, denial or explicit exclusion.

We call on governments as representatives of the people, international agencies, and the United Nations system to commit financial resources, technical support, and sustained institutional dialogue in order to develop and empower sexual minority communities to cultivate local leadership, nationally, within regions, and globally. We are call on the UN and the international community to hold itself accountable to equal treatment for sexual minorities and to reflect the Yogyakarta principles that already existing in national laws. The continued violation of our human rights principles is not only a reflection of a double standard in state action, but demonstrates the unwillingness of such states to respect the humanity of all its citizens. If equality and acceptance is the responsibility of leadership for all, then, our nations' leaders cannot be selective in his or her approach to the right to health, safety and security of all its citizens. As citizens of the world, and as a fellowship of nations, we have an obligation to love and protect all of our citizens, regardless of our differences, in the name of our collective well-being that is the foundation of peace.

### Spanish

La Declaración de Derechos Humanos y en particular los Principios de Yogyakarta, nos recuerdan que todo ser humano ha sido creado en igual dignidad y derechos. Sin embargo, recientemente un jefe de estado Africano prometió “decapitar” a todos los homosexuales en su país. En el Caribe, los homicidios homofóbicos se han convertido en un asunto crítico, mientras que los dirigentes políticos promueven insistentemente que las minorías sexuales nunca tendrán derechos, justificando sus posiciones basándose en interpretaciones de doctrinas religiosas. Estos pronunciamientos surgen de un ambiente en donde dos tercios de las naciones prohíben sexo entre dos hombres, y menos del 1% de los recursos que se invierten en VIH es destinado a la población de hombres gay, transgeneros, transexuales y otros hombres que tienen sexo con hombres. Esta distribución inadecuada de recursos violenta el ejercicio de los derechos humanos y solo muestra el cómo el estigma y la discriminación alimenta y promueve una crisis global de salud.

En todo el mundo, lo estudios de seroprevalencia han demostrado un impacto del VIH desproporcionado sobre las minorías sexuales estimándose en un rango de entre 7% y 46%.

Las opciones de sobre vivencia de las transgéneros y transexuales a nivel global son muy limitadas. Las comunidades hijra son conocidas por su habilidosa abogacía para la igualdad de acceso. Sin embargo algunos estudios han detectado tasas de infección de hasta 50% en esta población. Esta alta prevalencia manifiesta una exclusión vergonzosa de las minorías sexuales en discusiones sobre prevención, atención y servicios de apoyo. También refleja la negligencia por parte de las autoridades y tomadores de decisiones de permitir un involucramiento adecuado de estos grupos en la planificación de servicios de salud sexual y reproductiva, y una marginalización en procesos relacionados

tanto al diseño e implementación de programas, como en la movilización de recursos.

El marco legal y epidemiológico, tanto nacional como internacional, fomenta la invisibilidad de esta población, negando o invisibilizando aspectos de identidad de género. El uso de las siglas HSH o en inglés MSM, es otra muestra de esto. A su vez conlleva al maltrato y a la vulnerabilidad al VIH con la bendición de los Estados y los organismos internacionales, constituidos en fuerzas hegemónicas. En cuanto a las mujeres que tienen sexo con mujeres, la carencia de datos silencia las voces de la comunidad que hablan de su vulnerabilidad. Los tomadores de decisiones deben rendir cuenta sobre la vulnerabilidad de estas mujeres frente al VIH e implementar los compromisos frente a la CEDAW.

En Asia, los recursos para dar respuesta al VIH por parte del Fondo Mundial se han incrementado de \$50m hasta casi \$200m, pero, estos recursos no necesariamente siguen las prioridades ya que solo 5 de 24 países en la región de Asia Pacífica reciben la mayoría de estos recursos. Tal disparidad empeora la situación de la salud pública en un contexto de sostenidos abusos hacia las minorías sexuales, dificulta marcadamente el acceso universal y la provisión de servicios a una población que carece de recursos esenciales.

Hacemos un llamado a los gobiernos como representantes de la ciudadanía, a las agencias internacionales y la familia de las Naciones Unidas, de comprometer recursos financieros y técnicos así como de sostener un diálogo institucional para desarrollar y empoderar a las minorías sexuales a cultivar un liderazgo nacional, regional y global. También para que asuman a lo interno un trato de igualdad para las minorías sexuales, y una reflexión sobre la aplicación y promoción de los principios de Yogyakarta. Estos principios resaltan compromisos ya hechos en materia de derechos humanos y ratificados en leyes nacionales.

La violación sostenida de estos principios de derechos humanos no solamente evidencia el doble discurso en cuanto la acción de los Estados, sino también demuestra la falta de voluntad de ciertos Estados en el respeto la condición humana de todos sus ciudadanos y ciudadanas. Si la igualdad y la aceptación significan la responsabilidad de un liderazgo común, los dirigentes de nuestras naciones no pueden ser selectivos en su abordaje de derechos especialmente cuando se trata de la salud y la seguridad para la ciudadanía.

Como ciudadanas del mundo y como una confederación de naciones, tenemos la obligación de amar y proteger a todas sin importar nuestras diferencias, en el nombre del bien estar colectivo, que es la piedra angular de la paz.

## People who use Drugs

Albert Zaripov, *Russia, International Treatment Preparedness Coalition (ITPC)*

*Since 2002, Mr. Zaripov has been an HIV counselor at Vera, an organization providing support for relatives of people who use drugs. An advocate for access to HIV treatment, Mr. Zaripov is also member of ITPC and the Russian Union of People with HIV.*

(Speech delivered in Russian - Russian text below)

My name is Alik Zaripov and I am from Russia.

I am not going to quote statistics or criticize the drug treatment system in my country. This won't help my friends who use drugs, nor will it help those who have died because of drugs. I simply want to tell you my story.

I began to use drugs in 1996. My friends started using drugs at the same time as me; there were 12 of us altogether.

I was stopped by the police many times because of injection marks on my arms. I didn't trust the state institutions—how could I? I was “a drug addict”! There was one harm reduction project in the entire city and even then, it was on other side of the city and I had no way of getting there.

Five years after I first started to inject drugs—in 2001—I tested positive for HIV; I began to actively seek help in order to stop using drugs. I turned to doctors who gave me useless advice. They would say to me: “You want help? Then you need to get registered as a drug user.” “Get registered?” I thought to myself, “so that my personal information could be available to everyone? No way. I definitely need help, but I don't need anymore problems in my life!”

Neither I, nor my family had the money for drug treatment. But I got lucky. Thanks to the organization where I work, I was able to go through detoxification and rehabilitation free of charge.

I had been sober for about a year and my life was beginning to take shape—I began to set goals, wanted to begin my studies at the university, start a family, and get a driver's license. It was then that I suddenly found out that I had been registered as a drug user in the database.

Do you know what my first thought was? “My past will always follow me like a shadow. How can I become part of this society, when I have already been labeled as a ‘drug addict’ and my future employers will be able to access this information?” I decided that all of my attempts at a normal life were useless—I figured I might as well start using drugs again, because I would never achieve anything in life.

But I didn't relapse that day and, as I later understood, that saved me. I am certain had I used that day, I would now be either in prison, in the hospital, or dead.

This is my story. There were 12 of us altogether, but I was the only one who quit drugs. Three died of drug overdoses. Seven continue to use to this day. All of them have gone through every single drug treatment program available in our city. Their parents have long turned away from them. Some of them, like me, are living with HIV. All of them have Hepatitis C. Two have children, but they continue to use and they can't quit!

This story is about me and my 11 friends. But such stories are numerous throughout the world. Millions of people who use drugs are suffering, unable to access basic healthcare services. Millions of people are persecuted by the police. Hundreds of thousands are imprisoned, their only crime being that they use drugs. Hundreds of thousands of people who use drugs die each year of drug overdoses, tuberculosis and HIV-related infections.

I am certain that many of their problems could be effectively addressed through harm reduction programs and opiate substitution therapy. Yet, despite the evidence pointing to the effectiveness of harm reduction in reducing the risk of HIV infection, despite the fact that methadone and buprenorphine are included on WHO's list of essential medicines, needle exchange programs and opiate substitution therapy remain unavailable for the overwhelming majority of the people who need them. And for drug users who are HIV positive, access to ARVs remains limited. We are told that, as patients, we are too complicated, while no assistance is offered to solve the many other problems we face. Treatment of HIV is not just about distribution of medications!

So what is the world waiting for? What is the United Nations waiting for? Universal access means including all people in need! Maybe the issue is the fact that it's the law enforcement and not the healthcare agencies that deal with injecting drug users?

Maybe it's time to change the process by which the global drug policy is shaped? I think that we, the people who are living with HIV, people who use drugs and other representatives of civil society have to be actively engaged in this process. Our active participation is needed so that global drug policies take into account the issues of health and human rights, so that harm reduction, substitution therapy, treatment, and rehabilitation are finally prioritized.

The price of our inaction—the lost lives of our friends.

## Russian

Здравствуйте, уважаемые коллеги!

Меня зовут Алик Зарипов, и я из России.

Я не буду приводить цифры или критиковать систему лечения в моей стране. Это не поможет моим друзьям, которые употребляют наркотики, как не поможет и тем, кто погиб от наркотиков. Я просто хочу рассказать свою историю.

Я начал употреблять в 1996 году. Одновременно со мной начали употреблять и все мои друзья - нас было 12 человек.

Меня много раз задерживала полиция за проколы на руках от инъекций. У меня не было доверия государственным учреждениям, ведь я "наркоман"! У нас в городе был один проект снижения вреда, но он находился на другом конце города, и у меня не было возможности туда ездить.

Через 5 лет после начала употребления - в 2001 году - я узнал, что у меня ВИЧ, и я начал активно искать помощь в прекращении употребления наркотиков. Я обращался за помощью к врачам и получал бесполезные советы. Мне говорили: «Ты хочешь помощи-- вставай на наркологический учёт». «Какой учёт? - думал я, - чтобы данные обо мне были доступны для всех?! Нет, простите, мне, конечно, нужна помощь, но я не хочу усложнять себе жизнь!».

Денег ни у меня, ни у моих близких не было. Но мне повезло. Благодаря моей организации, мне удалось пройти курс детоксикации и реабилитации бесплатно.

Я перестал употреблять наркотики, и в течение года моя жизнь стала налаживаться. Я начал ставить перед собой трезвые цели: я хотел поступить в институт, создать семью, получить водительские права. Но неожиданно я узнал, что я стою на учёте и информация обо мне как о «наркомане» уже включена в базу данных.

Знаете, какая у меня была первая мысль? Моё прошлое меня теперь никогда не отпустит. Как можно адаптироваться в обществе, если я «наркоман» и данные обо мне могут получить мои будущие работодатели? Я решил, что всё бессмысленно – можно смело идти и снова употреблять наркотики: всё равно мне ничего не добиться в этой жизни.

В тот день я не употребил наркотик, и, как я понял потом, это меня спасло. Я уверен: если бы мне всё-таки удалось употребить в тот день, то сейчас я был бы либо в больнице, либо в тюрьме, либо меня уже не было!

Это моя история. Из 12 моих друзей бросил употреблять только я. Трое умерли от передозировки уличными наркотиками. Семь употребляют и сегодня. Все они неоднократно проходили все существующие программы лечения в нашем городе. От всех уже давно отказались их близкие. У некоторых из них, как и у меня, диагностирована ВИЧ-инфекция. Все больны гепатитом. У двоих родились дети, но они продолжают употреблять и они не могут бросить!

Это личная история – моя и моих друзей. Но таких историй множество по всему миру.

Миллионы людей, употребляющих наркотики, страдают, не имея доступа к базовым услугам в области здравоохранения. Миллионы людей преследуются полицией. Сотни тысяч людей сидят в тюрьме только за то, что они употребляют наркотики. Сотни тысяч наркопотребителей ежегодно умирают от передозировок наркотиками, от туберкулеза, заболеваний, связанных с ВИЧ.

Я уверен, что им могли бы помочь справиться со многими проблемами программы снижения вреда и заместительной терапии. Но, к сожалению, несмотря на доказанную эффективность программ снижения вреда в уменьшении риска распространения ВИЧ, несмотря на то, что метадон и бупренорфин входят в перечень жизненно важных препаратов ВОЗ, программы обмена шприцев и ЗТ остаются недоступными подавляющему большинству людей, принимающих наркотики. А для ВИЧ-инфицированных потребителей наркотиков ограничен доступ и к АРВ-терапии. Нам говорят, что мы сложные пациенты, но ничего не делают, чтобы помочь нам решить другие проблемы. Ведь лечение ВИЧ заключается не только в раздаче таблеток.

Так чего же ждет мир? Чего ждет Организация Объединенных Наций? Ведь всеобщий доступ означает доступность лечения для всех людей, которые в нем нуждаются.

Может быть дело в том, что проблемами наркозависимых занимаются правоохранные органы вместо системы здравоохранения?

Может, настало время начать менять процесс формирования глобальной наркополитики? Я считаю, что нам, людям, живущим с ВИЧ, людям

употребляющим наркотики, и другим представителям гражданского общества необходимо активно участвовать в этих процессах.

Это необходимо для того, чтобы глобальная наркополитика учитывала вопросы здравоохранения и прав человека и чтобы программы снижения вреда от употребления наркотиков, заместительной терапии, лечения и реабилитации наконец заняли в ней приоритетное место.

Цена нашему бездействию--жизни наших друзей.

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### **Women and Girls**

Winnie Sseruma, *London, UK, Christian Aid*

*Originally from Uganda, Ms. Sseruma serves as the HIV Mainstreaming Coordinator at Christian Aid. Until 2006, Ms. Sseruma chaired the African HIV Policy Network, the only organization in Europe that represents the sexual health and HIV needs of Africans in UK policy forums. Ms. Sseruma is a researcher and regularly writes on issues facing Africans living in the Diaspora, especially the impact of HIV on African communities.*

I am a British National of Ugandan ethnicity. Christian Aid, my employer, has a presence in 50 of some of the poorest countries in the world.

Women and girls comprise more than 60 percent of those living with HIV, but also face the additional burden of care. The disproportionate impact of HIV on women is fueled mainly by socio-economic inequalities, discrimination, lack of decision-making power in relationships and violence. Young girls are even more vulnerable due to these structural issues and are now the most affected population.

HIV positive women in particular, face further discrimination which prevents them from accessing HIV services and being able to act on prevention and treatment information. As a woman living with HIV for the last 20 years, I have experienced pro-longed illness and could not get treatment, have faced HIV related stigma and have felt invisible in meetings where decisions were being made about HIV positive people.

My experiences resonate with millions of women and I would like urge you to take the following actions:

- a) To take concrete actions to promote the meaningful participation and leadership of women and girls in the global response to HIV and AIDS.

- b) To bring HIV positive women into key decision making positions in planning and implementing HIV programmes and services.
- c) To enforce the legal and policy frameworks that provide effective protection for women, against domestic and sexual violence and promote gender equality, inheritance and property rights and access to financial credit and employment.
- d) To fund programmes that support the integration of sexual and reproductive health services, maternal and HIV services.
- e) Governments should provide comprehensive sexual education to women and girls, including condom negotiation strategies, and access to male and female condoms.
- f) Older women carers need support to fulfill their critical role care giving responsibility they have assumed for Orphaned and Vulnerable Children and people living with HIV.
- g) We have to do more to address HIV related stigma and discrimination.

Women and girls make up the majority of migrants and yet the health needs of this population have not been adequately been addressed. Instead restrictive policies are being implemented and migration as an issue has become a political football. we need to reverse this situation by implementing policies that address the needs of migrants.

There is an urgency to continue to invest in prevention technologies, better treatment for opportunistic infections like TB which impacts on the lives of the my women every year and makes them vulnerable to HIV.

Lastly, please remember, HIV is a virus, not a moral issue. It is an illness, not a crime. Abolish laws that criminalise HIV transmission and for all those countries that have short and long term travel restrictions, please exercise some common sense and remove them.

## Children and HIV

Sylvia de Rugama, *The Netherlands*

*Ms. De Rugama, a Mexican national, has been living with HIV since 1993, and has openly lived with HIV since 1997. She was granted asylum in 2005 in the Netherlands, where she co-founded the only organization for HIV-positive migrant women and their children.*

Good morning. My name is Sylvia De Rugama Prado. I am Mexican-born, but have Dutch nationality and live in The Netherlands.

Some years ago, my presence on this stage would have been unlikely. I am fortunate enough to be alive and well after 19 years of living with HIV.

I am a migrant, a sister, a daughter, and a wife to be. Sadly, I am not a mother and definitely not a teenage girl anymore.

But, I do know first hand through my work with women and can understand why a young girl from Africa went looking for a better life. Most of all I know the high price that she paid to follow her dreams.

This young woman came to Europe running from poverty, violence, disease and injustice. I met her when she had made it all the way to Amsterdam and our paths came together.

While searching for a better life she got HIV and now is pregnant with her first child.

She has been running for her life and in doing so, she left the devastation of AIDS behind her. She did not expect it to follow her to a new land, where she believed her dreams would come true. HIV was not going to be in the baby she was longing to hold in her arms.

She and her unborn child are among the fortunate ones who are able to access the services and treatment she and her baby needs to be healthy. Her baby will be born HIV free and most probably she will have a second child. Through her eyes and smile and the way she nourishes her child, you can see that her life is no longer interrupted by living with HIV. But this is not the reality for most women living with HIV. No matter where these mothers are living, they and their unborn children must be able to access the same treatment that she has received and yet we are far falling far short of delivering these services.

In Africa, we have dedicated caretakers, running out of options and being forced to crush and dissolve adult HIV medication in water to be able to give it to children. Are we living in the same world? Are we doing so well treatment wise in some parts of the world that we forget the ones who do not have the same access to treatment? How can that be?

In many developing countries children living with HIV will die before their second birthday. For HIV positive mothers and their unborn children not to have access to comprehensive treatment is unthinkable, it is unacceptable, it is a crime in progress.

Lost to the world will be hundreds of thousands of creative, gifted, often brilliant spirits. We are in a world with an urgent need of true solidarity and commitment. In the west, while surviving HIV, we are leaving behind the most vulnerable, the most innocent victims of this Pandemic. We have an obligation to provide these children with care and protection. They deserve a better tomorrow and we must fulfill the promises made to them to deliver access to care, welfare, health and security.

If it is really the intention and there is a commitment to provide affected children and their families with care and support, universal access is critical.

Our young girls and boys, they are never too young for education and prevention from harm but they will always be too young to die.

In closing, I urge the global community to listen to the voices of children and deliver on the rights of all women and children affected by HIV.

- All mothers living with HIV MUST have access to comprehensive treatment
- Children living with HIV MUST have access to testing and pediatric treatment
- Children orphaned and made vulnerable by HIV MUST receive wholistic care and support.

If we do not ACT NOW to achieve universal access for children – history will judge us!

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### **Young People Living with HIV**

Stephanie Raper, *Australia, People Living with HIV Speakers Bureau*

*Ms. Stephanie Raper is 16 years-old, and a well-known advocate for the rights of children and adolescents living with HIV. She is a member of People Living with HIV/AIDS Speakers Bureau in Victoria, and has been speaking publicly about her status and her experiences since she was a girl.*

My name is Stephanie Raper; I was born HIV positive in Australia 16 years ago. Growing up HIV positive in the so called lucky country is tough, but at least I've had the chance to grow up, sadly many children born with HIV around the world do not.

For the past nine years I have been attending a camp for over 100 HIV positive children and their families. Most of these children have lost one or both parents to AIDS and many a sibling. Some are in the foster system; others live with relatives that don't want them. Some families' fear of social isolation prevents them telling their children of their status until they are teenagers. These teenagers become confused, untrusting and believe their future is limited. Most children born HIV positive in Australia are conditioned at a young age "never to tell", and lose hope and self-esteem.

We are spread far and wide over thousands of miles, but the bond between us is very strong and for a few days every year we come together in a place we are truly free to be ourselves. The secrets we tell in our normal lives, hiding the terrible side effects caused by our medicine and the social shame surrounding HIV is all forgotten. We can be honest, we are treated the same as everyone else. Mealtimes at camp are full of happy, smiling children proudly displaying their colorful medicine, instead of being a source of frustration and embarrassment; we take our tablets like a badge of honor.

There are many reasons why I am able to speak to you today. My mum has survived, my dad has been the provider, they fought to gain access to medicines and services, taught me to advocate for myself, and most importantly are always honest with me. I am extremely fortunate compared to most.

At high school, my family asked permission for me to attend Camp, but when it became clear that it was AIDS camp, the principal demanded that either I tell the whole school community of my HIV status, or leave immediately. I regret not standing up for myself now, but at the time I was so shocked by this reaction, that I left, started at a new school and resolved never to disclose my status at school again.

But the discrimination continues, as I recently discovered I need a blood test to study at university, and that travel restrictions apply in many countries around the world, which will effect my education. I will overcome these obstacles, but most HIV+ children will not.

Being empowered enables me to believe I will finish my degree in Psychology, marry my HIV+ positive boyfriend and eventually have HIV negative children. This is made possible by the fantastic advances in medicines that can eliminate mother-baby transmission. Nine out of ten young HIV+ women do not have access to these medicines. Until we address this tragedy more babies continue to be born with HIV unnecessarily.

While our stories are different, positive youth across the globe share common ground which goes beyond cultures and borders. The social stigma of HIV is an unacceptable barrier to empowering HIV+ youth. It impacts on our ability and

willingness to access education, the workforce and health systems. Children with HIV deserve the same rights and opportunities as everyone else. You must ensure young people living with HIV have their voices heard.

Thank you for listening to my story.

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### **Access to Treatment**

Loon Gangte Henminiun, *India, Delhi Network of Positive People and Collaborative Fund for HIV Treatment Preparedness*

*Since finding out he was living with HIV in 1997, Mr. Henminiun began working as an outreach workers and HIV counselor. In 1999, he co-founded the Delhi Network of Positive People (DNP+), where he currently serves as President. Loon also serves as the Regional Coordinator-South Asia for the Collaborative Fund for HIV Treatment Preparedness, which provides funding to community groups working on treatment access.*

Good morning, ladies and gentleman,

My name is Loon Gangte, I am a person living with HIV, from India.

Thank you for this opportunity to raise 7 important points related to UA to treatment by 2010.

1. First of all, I want to say that my heart is with all PLHIV who died without accessing ART, since we met in 2006.

I also want to express my delight that today 3 million people living with HIV are on ART, this is significant achievement.

However, this means that 7 million people are still waiting for their treatment. We need to accelerate our coverage of comprehensive treatment urgently and we have only 2 years left to do this.

World leaders need to look at the massive regional inequities. While some regions have reached 70% coverage of ART, others are still at 7% only.

2. To achieve UA by 2010, I call on the leaders for affordable and accessible 2<sup>nd</sup> line ARV and also to improve 1<sup>st</sup> line, which is urgently needed.

3. It is evident that the current Patent system doesn't enhance R&D for the neglected diseases affecting the poor countries and poor people. So the world needs to find alternative system/solution.

Seven years after the DOHA declaration, it is unacceptable that poor countries are forced to sign FTA or punished for exercising the TRIPS flexibilities. Profit should no longer be put before human lives!

4. It is high time to move on from ancient century old to modern and effective drugs & diagnostic for this curable disease called TB, which continues to be the leading killer of PLHIV.

5. Until and unless treatment for HCV is made available and accessible for the drug user community, UA will never be a reality.

6. Prevention of Parents to Child programme should be comprehensive so that it takes care of the child health as much as the mother and must go beyond delivery.

No more single pills Nevarapine.

7. Let's stop pitting AIDS against other diseases, and against strengthening health systems.

We need to fight for health care for all including ARV, TB, HCV, HBV and all the others.

Finally, I would like to challenge the world leaders that the era of declaration must end; and begin the era of action with concrete plan and budgetary allocation to achieve UA by 2010 and save millions of lives.

Thank you.

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### **HIV-related Travels Restrictions, Mobility and Migration**

Gracia Violeta Ross Quiroga, *Bolivia, Bolivian People Living with HIV Network*

*Ms. Ross Quiroga is an HIV positive activist from Bolivia and an expert on sexual and reproductive health and rights. She is member of many national, regional and international networks of people living with HIV, and was a founding member of the Global Coalition on Women and AIDS, where she currently serves on the leadership council. Ms. Ross Quiroga is the current NGO Delegate for Latin America and the Caribbean for the UNAIDS PCB and an NGO delegate for the Global Fund to Fight AIDS, Tuberculosis and Malaria.*

Good morning. My name is Violeta, I am from Bolivia. I thank God and you all for the opportunity to address this audience in this country, despite the fact that I am openly living with HIV for the last 8 years.

While visiting this country, I can be trusted not to transmit HIV or to become a burden on the public health budget of this country. This is what every country with travel restrictions must realize. It is wrong and unfair to assume that I or any other person will transmit HIV. I am a responsible person and I am here to contribute to the fight against this epidemic, just like all my colleagues living with HIV present at this meeting.

But like me, many people living with HIV are likely to face the prejudice that assumes we are not responsible and with it coercive measures such as mandatory testing, having visas canceled or denied, or even being deported from the countries we visit. This is an outrage in 2008 with all we know about HIV.

Regardless of the political commitment and the progress in responding to the AIDS epidemic, the reality of HIV related travel restrictions for entry and residence continue to exist in at least half countries represented in this forum.

HIV related travel restrictions:

- Create and perpetuate the myth that the risk of AIDS is outside our borders.
- Violate fundamental human dignity and human rights
- Fuel stigma and discrimination against those of us living with HIV
- Deny the greater involvement of people living with HIV in the response to the epidemic as well as in the mobility of the world
- Create the idea that people living with HIV are the enemies in this epidemic, not the virus itself
- Go against the commitments already made in 2001 and 2006 and the goals of Universal Access by 2010, and
- Send contradictory and hypocritical messages, because on the one hand we have commitments made but in the other hand we have borders closed

Therefore, in the name of more than 30 million people living with HIV, we recommend:

- That member states abolish ALL HIV related travel & residency restrictions and report regularly on progress made.
- That member states implement programs for migrant and mobile populations with a human rights approach, in which HIV status should not be a precondition to access work or a reason for deportation
- That member states enact and enforce legislations that eliminate all forms of discrimination against people living with HIV and AIDS.

- That member states adopt a resolution that no high level meeting should ever again be held in any country with travel restrictions for people living with HIV.
- That member states to the commitments already made in 2001 and to the goals of Universal Access of 2006.

HIV related travel restrictions are discriminatory...even migratory birds have laws and treaties that protect them while moving across borders, but not people living with HIV... This has to change. But in order to achieve EQUALITY and JUSTICE for people living with HIV, we need to see real POLITICAL WILL and political commitment.

This IS possible. Today more than 70 countries do not have any kind of restrictions for people living with HIV. They report no problems and they are providing the kind of political leadership this world needs. We ask all countries with HIV travel restrictions to follow their example. Show real commitment to lead on HIV by joining them.

Thank you.

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### **Workplace Responses**

Gary Cohen, *United States, Becton, Dickson and Company*

*As Executive Vice President of Becton, Dickinson and Company, Mr. Cohen is an advocate and expert in children's health, HIV/AIDS and health system strengthening. He serves on the boards for Perrigo Company and the US Fund for UNICEF, among others, and is a member of the private sector delegation to the Global Fund to Fight AIDS, Tuberculosis and Malaria.*

My name is Gary Cohen. I am Executive Vice President of Becton, Dickinson and Company, known as 'BD', a global medical device and diagnostics company with 28,000 employees in 50 countries. Thank you for the opportunity to provide these comments.

As a leader in a company extensively involved in HIV/AIDS and TB, let me first mention how important it is for the entire business sector to be included as an equal partner in the global response to these diseases. We need to ensure that public private partnerships are created, funded and monitored effectively.

Companies have access to workforces, families and communities throughout the world, which can enable health plans and policies to be implemented that are complimentary to the efforts of government and non-government organizations. Many companies have already implemented non-discrimination policies specifying that HIV status cannot be utilized as a basis of employment, promotion and retention. This is the fundamental starting point for corporate involvement in HIV and AIDS. Further, these policies often stipulate provision of

specific health care services including prevention, VCT and anti-retroviral treatment. These benefits are often extended to families, and some companies have expanded their outreach to surrounding communities. There is still much more progress to be made, particularly among employers in the informal sector. Public private partnerships are critical in linking employees, their dependents and community members to health services, and ensuring the services received are of a high standard.

Beyond workforce policies, the application of core competencies represents an even broader opportunity for business sector engagement. One method is to create access to appropriate technology. An example is public/private collaboration to advance diagnostic technology for TB, including tests for drug resistant strains, to address HIV and TB co-infection.

Another important intervention is to provide technical assistance that strengthens local capacities. Some companies have deployed trainers in developing countries in partnership with country health ministries and international agencies. An example is training to improve laboratory worker skills to perform diagnostic tests for HIV/AIDS and TB. This has been deployed in 58 countries.

Philanthropic funding represents a further opportunity for business sector involvement in core issues impacting HIV/AIDS. One example is funding and technical support to provide HIV prevention and treatment services to health workers who are themselves at high risks of disease transmission in the work environment, which further constrains the ability to achieve the goal of universal access.

Companies can also deploy volunteer programs that provides their most precious resource; their people, by sending volunteer teams to strengthen health services access for people living in rural districts and villages in poorly resourced countries.

When the skills and resources of companies are fully harnessed, the business sector can have significant impact in helping address the world's most pressing issues, such as HIV/AIDS and TB. I've provided actual examples of business contributions from the health care industry. Similarly, companies in other industries have demonstrated very positive contributions in areas such as financing, IT, media, communications, and surveillance systems. As a business leader, and a member of civil society, it is a privilege to be able to contribute in this manner, but also to stress that it is incumbent on us to do more. 2010 is around the corner and we need to harness every asset at our disposal to achieve these ideals.

## **Workplace Responses**

Romano Ojiambo-Ochieng, *Uganda, Amalgamated Transport and General Workers' Union (ATGWU)*

*Mr. Ojiambo-Ochieng is the General Secretary of ATGWU, which organizes and represents workers in the transport, oil, chemical and private security industries. As a national and regional trade union leader and HIV/AIDS activist, He works to highlight the realities of HIV in the workplace, and the importance of trade union participation in workplace HIV programs.*

As I speak to you now, millions of workers are in their workplaces, working with a virus called HIV and faced with stigma and discrimination and other related problems, simply because they are HIV positive. By the time we are through with this meeting, hundreds of them will have died due to AIDS.

HIV/AIDS is a workplace issue, linked to the broader issues of economic growth and sustainable development. It affects both the individual workers, including migrant workers, and the enterprises that employ them. It undermines the capacity of the economy to sustain decent jobs and adequate living standards for all.

The workplace offers distinct opportunities and advantages as a key delivery point for HIV prevention, treatment programmes for workers and their dependants. The position of labour unions in the workplace makes them ideally placed to help workers who are reluctant to test for fear of discrimination, as well as the millions of workers diagnosed with HIV and who, because of stigma, ignorance, fear of dismissal or deportation, have no idea how to deal with their situation. From our experience, with unions involved, workers are better protected, and receive the support they need.

Despite the 2001 UNGASS Declaration of Commitment on HIV/AIDS, the 2006 UN Political Declaration and the fact that HIV/AIDS has been with us for nearly 30 years, the potential of workplaces as a vital entry point for HIV/AIDS programmes continues to be overlooked. Workplaces have not been targeted by most national programmes and labour unions still do not receive recognition as civil society organisations that are key players in workplace interventions.

We, therefore, recommend:

- Increased public and private investment for workplace initiatives through educational programmes, prevention, care, support and treatment;
- Increased investment for training of labour union activists and occupational health and safety personnel to effectively implement workplace initiatives;
- The adoption of occupational health and safety measures and non-discriminatory practices in keeping with the ILO Code of practice on HIV/AIDS.

- Representation of labour unions and employers on national HIV/AIDS consultative and policy-making bodies, with a view to strengthening workplace approaches to combating HIV/AIDS.

Let us all work together to make our workplaces safe and healthy.

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### **Civil Society involvement and AIDS Accountability**

Allesandra Nilo, Brazil, Gestos

*Ms. Nilo is the Executive Director of Gestos, a nongovernmental organization working on gender relations, communications, AIDS and human rights. Gestos works primarily with low-income communities and professionals in the health care, education and legal fields to monitor the creation and implementation of public policies through national and international advocacy efforts. (CSH)*

Thank you, Mrs/Mr. Chair

Notwithstanding the efforts of some governments and other key stakeholders, none of the UNGASS-AIDS 2001 goals were achieved in 2003 or in 2005, and it is likely, at the current rate of progress and insufficient funds made available, it is sure that Universal Access will not be reached by 2010 either. It is time to talk frankly about this.

UNGASS-AIDS reinforces the necessity for having governments, organized civil society, and people living with HIV/AIDS in designing, implementing, and evaluating the national AIDS programs in the countries. Civil society is still providing services that should be the government's responsibility. However, we are considered annoying when we start monitoring the AIDS response.

We acknowledge that there is a positive examples of civil society participation in some countries. But the continued exclusion or tokenistic involvement of the community sector in many other countries puts into question the validity of the 2008 country progress reports. This exclusion is especially true for groups of women, youth, and marginalized populations that governments here still do not want to recognize. To be clear, I am talking about men who have sex with men, lesbians, sex workers, people who use drugs, and transgender people,.

Given this, the difficulty of holding governments accountable is a fact. There is a clear conflict of interest, because those who implement can not be the only ones monitoring and evaluating their responses. We can see this in relation to corruption, which remains a grave problem in many non-democratic and democratic countries alike (as also in developed and developing countries), impacting on the AIDS response, but this is not referenced in the reports.

It has become clear that many governments, whether from developing or developed countries, have failed to report the reality on the ground to this Assembly. In fact over 40 countries failed to even report. And so what? What will happen to them for not reporting properly – where is the accountability?

This High Level Meeting must direct us toward a new and integrated monitoring and accountability system, with effective participation of civil society at all levels, not only for rubber stamping government reports. Technical assistance or any other important strategy will not work without strong mechanisms of social and democratic control.

A real partnership between governments, donors, and the affected populations requires a balance of power in making decisions – including decision on funding allocation. And UNAIDS and other relevant UN organizations, must have a stronger position in the countries to defend and support this inclusive mechanism.

We are facing a crisis that challenges the political project of Universal Access by 2010 because there is a development model that creates priorities for problems, instead of creating integrated solutions for problems. It is a false competition. AIDS can not and should not fight for space with health system strengthening, climate change, or energy and food supply crisis. All of these problems must be addressed in a coordinated, integrated and consistent way.

This is why we need to review the strategic thinking and create a clear and stronger mechanism of mutual accountability – with different levels of participation for making both the strategies and the money work. Proper accountability, not as I said just a rubber stamping, is required at all levels. The meaningful civil society participation in the monitoring process is required now. There is no other realistic choice.

Thank you!