In SHARP Focus at the International AIDS Conference 2006

Editor: Susana T. Fried (susana.fried@gmail.com). Assistant Editor: Marissa Hildebrant (marissahilde@yahoo.com).

Editor's note: In SHARP Focus at the International AIDS Conference (AIDS 2006) is an initiative of the OSI/SHARP (sexual health and rights project). Its purpose it to provide information about key sexual health and rights issues, activities, and debates (paying particular attention to those addressing sex workers, men who have sex with men and lesbian, gay, bisexual and transgender persons – or, in new terminology 'same sex practicing individuals') as these emerge during AIDS 2006. This is the final of five issues, and it seeks to provide a summary of some of the key sexual health and rights debates and outcomes of the conference. For more information, please contact Susana T. Fried at susana.fried@gmail.com, Marissa Hildebrant at marissahilde@yahoo.com or Rachel Thomas, OSI/SHARP at rthomas@sorosny.org.

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1. Editorial: *Morals and Morality*

Catalysts for change

Even in relatively small amounts, a catalyst accelerates change without being consumed in the process. As more than 24,000 activists, health workers, scientists and government representatives from 132 countries participated in the 16th International AIDS Conference, the visibly small but essential presence of catalysts from intersecting worlds- sex workers, transgendered persons, men who have sex with men, lesbians, gays, bisexuals, young people, injecting drug users and people living with HIV and AIDS brought ideas and strategies for innovative processes and positive change. Fueled by commitment failures staged at the recent United Nations General Assembly Special Session Review (UNGASS – May 31 to June 2, 2006), civil society actors tried once again to move beyond the rhetoric to focus on concrete actions and forward-looking solutions. The question remains, how do we address the overwhelming possibility that national action and international donations may not be enough to respond to the global HIV/AIDS crisis? How do we scale up testing and treatment, while also scaling up efforts to secure sexual health and rights?

We might begin by listening to the silences of the conference. In a Rhrealitycheck.org blog, Maria de Bruyn (IPAS) commented that, "while women may be invited to international and national meetings to 'tell their stories,' their insights and contributions to policymaking are often marginalized or not even sought." For example, it seems that the HIV/AIDS community as a whole has yet to address the larger context of sexual and reproductive health issues. Nearly inaudible were discussions of abortion services for pregnant women living with HIV/AIDS (or responses to forced or coercive abortions on HIV+ pregnant women) or female condoms (paraded in a small corner of the conference by the Prevention Now! campaign and the Pleasure Project) or options for women living with HIV/AIDS who want to bear children and remain sexually active. Furthermore, the pharmaceutical companies and scientists present at the conference seemed at times, to be in a different conversation, where access to treatment and prevention strategies, particularly for marginalized communities and developing countries, appear as ancillary considerations rather than central concerns.

There were some who noted the silences of those carrying the weight of this century's disease in the conference. "There are still far too many instances where punitive laws, stigma, gender inequities and lack of access to needed prevention and care services conspire to fuel the HIV pandemic," said conference Co-Chair Dr. Mark Wainberg, director of the McGill University AIDS Center. Indeed, it would be a major oversight to omit Dr. Wainberg's action beyond words, as his support could be observed in his enthusiastic participation in a sex worker demonstration on Wednesday 15 August in front of the media center.

The conference – "south" and "north"

Throughout the formal conference (mostly held in the "south" building), the unwillingness to talk about sex, and more specifically to discuss men who have sex with men, young people's sex and sexuality and the occupational and personal

lives of sex workers, presented itself as a persistent barrier to real prevention of HIV/AIDS transmission in communities throughout the world. Ignorance and intolerance pushed transgender, LGBT, and sex worker activists largely into the segmented conference corners of the Global Village (in the "north" building), which served as the free access space of the conference. Why were their voices and the voices of PLWHA not brought to center-stage? Several reports mentioned that PLWHA arrived in significant numbers at the conference, but as Anindita Ramaswamy so aptly titles her Bangkok Post article, the "AIDS Circus Shuts Out HIV Patients." Even though the conference advertised itself as a forum for the needs and rights of PLWHA, the voices of academics, politicians, and celebrities trumped, "despite the well-known fact that AIDS programs cannot make a difference without the intimate involvement of people living with the disease," Ramaswamy points out.

Repeating terminologies like "scaling up the response" and "evidence based prevention" (or the more recent alternative "evidence informed") drove discussions in many sessions, which offered up new views on old practices, like male circumcision as a form of HIV prevention. In a personal live journal blog, Wolf asks, "At a time when many men in North America are discussing reconstructive surgery of foreskins, and there is a decrease in male circumcision among the general population, are adult men in North America going to go to a mohel*?" Other strategies seem to have a more painless face. Despite the fifteen-year history of under-funding and lack of research, microbicides and other new prevention technologies received a welcome mat at the conference. However, sex worker advocates expressed their apprehension about the implications for sex workers who might use microbicides but have clients who refuse to use condoms. Reflecting on women's rights issues at the conference, writers from AWID Resource Net Friday File, Shareen Gokal & Shamillah Wilson, addressed the ways in which we overlook "how to bridge the incredible inequality that women suffer, how to empower women, and what does prevention and care mean in contexts where women are facing severe violations of all their rights let alone the right to negotiate safe sex or access treatment."

"ABC" under a microscope

Regardless of discrepancies in sexual negotiating power, the push for increased condom distribution was strong, particularly within critical discourses of the United States' "ABC' strategy (Abstinence, Being Faithful, Condom Use), where the "C" is systematically lacking in funding allocations. For example, a fact sheet on Uganda published in August 2005 by the Center for Health and Gender Equity (USA) documents that the Office of the U.S. Global AIDS Coordinator decided "the total number of condoms that may be procured through U.S. funding is limited to the number that will cover only those in 'high risk' groups as calculated according to narrowly defined parameters and are to be distributed in only limited areas, rather than supplementing the supply available to the general population for HIV prevention." Once again replying to targeted injustice, United Nations (UN) special envoy on AIDS for Africa, Stephen Lewis denounced President George Bush's $15 billion Emergency Plan for HIV/AIDS (PEPFAR), bemoaning its "ideologically driven policies [for] undermining African countries' efforts to combat the disease." With 40 million people worldwide living with HIV/AIDS, the pandemic is not only targeting black people in Africa, but also those in the United States and especially in black same-sex practicing contexts (severely underrepresented at the conference and likely to further impede treatment and prevention efforts). A message sent on the AF-AIDS list-serv for the *African Civil Society Coalition* read "Nothing will be delivered unless African targets are met . . . the conference theme 'Time To Deliver' may turn out to be an empty slogan, unless specific African targets set for universal access for HIV and AIDS prevention and treatment by 2010 are met." In several conference sessions, Beatrice Were, Ugandan activist living with HIV/AIDS, reiterated that PEPFAR funds too often support religious organizations that disparage condom use and other contraceptive methods such as microbicides and diaphragms. With this strategy, many activists query, how could PEPFAR possibly expect to achieve its aim to prevent seven million new infections? "Where rape and abductions are common, A and B become meaningless. The very approaches of ABC undermine the negotiating ability and human rights of women and unleash stigma and discrimination," said Were, adding that NGOs funded by PEPFAR asked Nigerian sex workers to abstain from sex. (Session on Sexual and Reproductive Health and Rights and HIV/AIDS, 16 August 2006).

Beatrice Were's concerns were echoed by others, including Bill and Melinda Gates. Bill Gates commented that "Abstinence is often not an option for poor women and girls who have no choice but to marry at an early age. Being faithful will not protect a woman whose partner is not faithful. And using condoms is not a decision that a woman can make by herself; it depends on a man. We need to put the power to prevent HIV in the hands of women. This is true whether the woman is a faithful married mother of small children or a sex worker trying to scrape out a living in a slum. No matter where she lives or what she does, a woman should never need her partner's permission to save her own life" (Bill and Melinda Gates, opening session, at www.kaisernetwork.org).

* A mohel conducts the circumcision in newborn boys as part of the Jewish ritual of male circumcision.

Sex work on the agenda

Melinda Gates followed her husband at the opening ceremony calling on governments to meet with sex workers in order to better devise effective HIV/AIDS prevention, care, treatment and support strategies. Former US President Bill Clinton commented on current U.S. policies, remarking that "PEPFAR, on balance, has done a terrific amount of good." However, Clinton was also quoted saying, "I think that abstinence-only is an error. . . I don't see how you can go into a country with a lot of sex workers and not deal with sex workers." (at www.kaisernetwork.org). Clinton paralleled the unique HIV/AIDS discourse of morals and mortality by surmising that even with disapproval about prostitution, the money should be there to save lives.

Regrets and other protests

President Clinton expressed his regret in not supporting needle-exchange programs while he was in office, citing evidence that these programs do not lead to increased drug usage. On the third day of the conference, a dozen members of the South African lobby group TAC (Treatment Action Campaign) stood up together, chanting slogans and holding signs reading "Media: Activist not 'Hollywood' Conference." On Friday, 44 TAC activists were arrested while protesting against health minister Manto Tshabalala-Msimang's policies, which champion traditional treatments like garlic, lemons and beetroots instead of anti-retroviral drugs. Indeed, despite the sidelining of particular communities, some were sure to make their mark on the conference. Seventy employees under Delta Chelsea Management (Canada), workers in the group Hotel Workers Rising, were suspended indefinitely for wearing a button with a red ribbon to show support for the IAC, besides agreeing not to go on strike until the conference ended. Their buttons read, "lifting one another above the poverty line."

"More people registered to attend this conference than there are doctors in the whole of Eastern and Central Africa."

With so many institutional obstacles, it's hard to believe the Financial Times statement (14 August 2006) that "nearly every participant makes a living in this industry." Roger England writes that 21 per cent of all health aid funds in 2004 went to HIV/AIDS, adding that this is the only disease to have its own United Nations agency. But England appears not to fully account for how funds are quarantined and mismanaged in HIV/AIDS initiatives, so that as a result, not every "participant" actually makes a living wage. The conference awarded $20,000 in US dollars to community groups and grassroots activists from Ukraine, Bangladesh, Thailand, Zambia and Zimbabwe, who were honored at the conference with the *Red Ribbon Award* for their model local HIV/AIDS initiatives: providing access to care, treatment and support for PLWHA; addressing stigma and discrimination related to HIV/AIDS; addressing gender inequalities that fuel the HIV/AIDS epidemic; promoting HIV/AIDS prevention programs; and providing support to children orphaned by AIDS and other vulnerable children. At the closing session, Anders Nordstrom, acting director-general of the World Health Organization, noted that "more people registered to attend this conference than there are doctors in the whole of Eastern and Central Africa." Perhaps the conference's global youth network was the most productive, generating some 418 time-specific commitments from government representatives, United Nations officials, leaders, activists and caring adults. For example, Nasimul Hussain, Coordinator of the Ministry of Health (Guyana) wrote on the Global Village's youth commitment board, now made available at youth.aids2006.org, "I will train 300 youth peer educators and will also encourage 150 young people to get tested for HIV by August 2007."

Toward Mexico City

On Friday, as the networking zones in the Global Village disassembled their tapestry-decorated spaces, distributed the remnants of fliers and condoms, folded up posters and packaged artwork, the physical distinctions between the more than 400 organizations blurred. Regardless of the departure sentiment, footprints were left in Toronto that when followed to Mexico may help grow these seeds of change. Mexico itself has a history with much promise, notably advancing sexual and reproductive health and rights since the 1970s progressive family planning policy. William Smith, vice president for public policy at SIECUS, stated, "With Mexico as the host of the International AIDS Conference in 2008, SIECUS is thrilled to have an opportunity to highlight the great work undertaken in Mexico to tackle sexual and reproductive health and rights issues, including HIV prevention." In 1994, Mexico was the second country in the world to implement national strategies as outlined in the International Conference on Population and Development (ICPD) Programme of Action (POA), and the first in Latin America. But even with the anti-stigma and discrimination campaign lauded by Dr. Peter Piot, Mexico's battle against HIV/AIDS still collides with an ever-increasing rate of new infections. In a country with a strong indigenous population, MSM population, and other marginalized communities, it is essential that the voices left silent in Toronto rise with attention and respect in Mexico.

2. Reports from gender based violence, LGBT, MSM and sex workers streams

Gender-based violence and HIV/AIDS at AIDS 2006, by Cynthia Rothschild, Center for Women's Global Leadership (USA)

One of the notable aspects of AIDS 2006 was the attention given to gender issues and women's equality/inequality as critical aspects of understanding and addressing the spread of HIV and AIDS. During the conference, a number of sessions explored the nexus of gender-based violence (GBV) and HIV/AIDS. Many discussions focused on violence against women and noted the specific and interrelated human rights violations women experience due to pervasive gender inequality and the HIV pandemic. A broad call was made for greater attention to be paid to the link between gender-based violence and HIV/AIDS by governments, the UN system, activists, and service providers, including health care providers engaged in sexual and reproductive health care.

Some participants lamented the fact that little official programming at the conference addressed gender-based violence as a topic in itself. Before the IAC began, sexual and reproductive rights and women's human rights communities noted that abstracts had been rejected on GBV and HIV, and that this gap must be filled. Partly as a result of the lack of official programming, activists stepped in to create (what turned out to be well-attended) satellite and other sessions within the Global Village. Again and again, participants brought out the connection between sexuality, reproductive rights and ways violence threatens people's capacities to enjoy their human rights --- and threatens people's decision-making about their bodies, sex, families and reproduction.

Other intersections were also highlighted. For example, in many countries women cannot legally own or inherit property which places them at risk when their husbands die. In some circumstances women have their children taken away by their husband's family members, or the women themselves are taken as the property of the husband's brothers. Marriage can be a significant risk factor for HIV transmission for many women, because of unprotected sex and rape by their husbands. Gay men, same sex practicing men and transgender women and men are also at risk of HIV-related violence, as homophobia, sexism and AIDS-phobia motivate perpetrators of violence, who are often not punished for crimes they commit. A few speakers noted that violence directed at lesbians was invisible within most discussions about gender-based violence and HIV.

Women, in particular, face risks related to testing (especially without informed choice or consent) and disclosure of positive results. Concern was expressed about routine and "scaling up" of HIV testing without attention paid to the rights-oriented "side effects" of health interventions that do not take into account risks of violence and other negative consequences. In areas hardest hit by HIV/AIDS, "well-intentioned" institutions are set up very rapidly to address urgent needs related to HIV – so rapidly that they sometimes lack the capacity to react adequately to sexual and reproductive health needs, including those related to GBV. The capacity of these providers must be strengthened to address violence, especially as they are trained to deliver sexual and reproductive health services.

The LGBT Networking Zone, by Kim Vance, ARC International (Canada)

The LGBT Networking Zone provided an invaluable opportunity for dialogue, networking, information sharing and building community. It was particularly important for there to be a unique and independent space from the Gay & MSM Networking Zone, while still working in cooperation with this zone, along with the Sex Worker's Zone and other regional and thematic networking spaces. The LGBT Zone was particularly successful in highlighting transgender issues and lesbian and bi-women's sexuality in the context of HIV/AIDS – issues that many felt had no other space of consistent visibility.

It was also important to have the kind of diverse coordinating partnership that existed between a local organization like the 519 Centre in Toronto, which provided logistical support and activities like community dinners and theatre performances;, an international organization like ARC International, which showed video programming on issues like the Brasilian Resolution and highlighted the best practices within LGBT organizations in the global South; and a human rights organization like Amnesty International, which brought attention to violations against LGBT persons and HIV/AIDS human rights defenders.

The networking zone offered a diverse program, while allowing for impromptu dialogues like one organized in Portuguese on the theme of negotiating safer sex within committed same-sex partnerships. A message board allowed people to network – such as those posted by several youth projects wanting to connect with each other, and a plea from a gay man in Cambodia seeking to organize with others from his country.

The MSM Stream by the Editors

The MSM stream at this year's conference included a session with UNAIDS, a two-day pre-conference event, and a space in the Global Village. The stream of panels and sessions was diverse, including, for example a presentation by Dr. Carlos Caceres of Cayetano Heredia University in Peru who discussed how being a sexual minority implies a certain relationship to the system and that the hegemonic model of MSM is not necessarily inclusive of other sexual diversities, particularly men in the South. The wide-ranging sessions took up issues of language, concepts, strategies and research.

A number of advocates and researchers who focus on men who have sex with men raised questions during the IAC about the use of the term "MSM." An epidemiological concept designed to focus on the sexual practice of a man who has sex with another man (including transgenders and transvestites), the term is intended to be "value-neutral" and does not presume an identity attached to this behavior. Drawn from the public health lexicon, MSM stresses attention to sexual behavior (as opposed to sexual identities), while attempting to avoid imposing or importing meaning attached to this sexual behavior. As Gary Dowsett and colleagues have written in a recent report, A Review of Knowledge about the Sexual Networks and Behaviours of Men who have Sex with Men in Asia "A key finding [in this 4 country study] is the very lack of coherence in that term ['men who have sex with men" or "MSM"] and the dangers in assumptions that are often made in many studies about easily accessed or familiar populations being *the* or the *main* MSM grouping…. Also, even where certain MSM populations have received significant research and programme attention (e.g. the "kothis" of India or Bangladesh), there is nothing in the literature reviewed that would support considering these populations as the key MSM grouping" (Dowsett, G.W., Grierson, J. W., and McNally, S.P., *A Review of Knowledge about the Sexual Networks and Behaviours of Men who have Sex with Men in Asia.* Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia. Monograph Series Number 59. 2006).

During the MSM satellite (held 10-11 August 2006) Shivananda Khan of the Naz Foundation International raised questions about the use of the term "MSMW", as it was being used to encompass the fact that men who have sex with men also have sex with women. In conversations with the editors, Shivananda noted that he is concerned with the constant addition of new letters to acronyms, arguing that this "alphabet soup" does not help clarify the multiplicity of genders and sexual practices, particularly as they play out in terms of HIV/AIDS vulnerability.

It becomes even more complicated when one considers the full spectrum of genders and sexualities. For example, transgender women are sometimes included in MSM statistics, but this may mask the specificity of the epidemic among transgender women. Moreover, as Melissa Ditmore (NSWP) commented, it also indicates "insensitivity to the implications of labeling as "MSM" people who spend their lives trying to be recognized as women!" Ditmore and Andrew Hunter (Asia Pacific Network of Sex Workers/APNSW) called attention to the impact of statistical weighting assigned by the scholarship award program meant to correct for gender balance. While supporting greater gender balance, they also noted that one unintended consequence was that male sex workers were not very prominent - affirmative action for women and transgenders had the pernicious impact of eclipsing male sex workers, including male sex workers who are experiencing skyrocketing rates of HIV in Asia (as documented by the FHI-CDC clinic that turns away sex workers).

The Stiletto Lounge – sex workers' networking zone, with Anna Louise Crago, STELLA (Canada)

They marched, they performed safer sex skits, they smiled patiently when asked detailed questions about their work - the sex workers of this conference may have been small in number but were unparalleled in terms of their community organizing and advocacy skills. Despite claims that this conference saw less representation of sex workers than in Bangkok two years earlier, sex workers arranged several main conference sessions addressing the need for worker rights, the problematic conflation of sex work and human trafficking, US HIV/AIDS policy, safer sex and pleasure, criminalization of HIV and more. However, the presence of male sex workers and transgender sex workers from developing countries was minimal, and many, such as Cheryl Overs, Network of Sex Work Projects (NWSP), commented about some of the potentially negative unintended consequences of new lexicons and priorities. For example, she noted that redefining sex work as a "women's issue" may push male and transgender sex workers to the periphery of the dialogue. Others expressed their concern that sex workers were mostly relegated to being a side-show in the Global Village, because most abstracts were rejected by conference organizers.

Sex workers and their allies staged a demonstration during the opening ceremonies. Organized jointly by the Global Network of Sex Work Projects, the Asia-Pacific Network of Sex Workers, SANGRAM and others, sex workers called for "Rights not Raids" to protest the Gates' Foundation's grant to IJM (International Justice Mission). IJM, according to sex workers' rights groups, including Empower in Thailand, has undertaken raids of brothels in which sex workers are working by choice. The human rights abuses that result from these raids have been documented by some of the sex worker groups present.

On Wednesday, the sex workers' human rights march was arguably the largest demonstration of the week with more than 200 people calling for an end to violence and discrimination against sex workers, workers rights, and access to HIV prevention, treatment and care. Moreover, sex worker participation and leadership were deemed essential in developing the programs and policies that affect their lives. Creativity was amply displayed at the APNSW Star-Whores Show in the Global Village--the PEPFAR-critique and musical revue. And finally, there were a flurry of workshops and activities inside and outside the Stiletto Lounge. Some highlights included a presentation by Awa Dambele from the organization Danaya So, an association of over 2000 sex workers across 5 cities in Mali. Also on the schedule was a workshop by Human Rights Watch about how to document, report, and publicize abuses of sex workers' rights, which was much appreciated by those in attendance.

3. Analysis: A question of initiation? Who decides and why does it matter – new debates about testing

A new concept has become a flashpoint for conversation and contention during AIDS 2006 – *provider initiated testing*. This emerging concept, introduced publicly a few years ago by the WHO and UNAIDS is intended to indicate an expansion of the testing spectrum, and rests somewhere in between forced and/or mandatory testing and voluntary testing (and counseling). The question of the potential negative and positive impact of provider initiated testing arises in the context of calls for a massive scale-up in testing. Among the nuances of the debate is the question of whether testing will be *routine* or whether it will be *routinely offered.*

According to the BBC,

> *Experts are calling for a massive increase in routine testing for HIV to try to combat the spread of the virus. Figures show that over 90% of people carrying HIV do not know they have it. Dr Kevin De Cock, of the World Health Organization, said empowering doctors to test patients could have a significant effect. However, other delegates at the 16th international conference on HIV and AIDS in Toronto expressed concerns over civil liberties. (BBC News, 15 August 2006, accessed at http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/4793413.stm)*

Describing what has come to be called *provider initiated testing with an opt-out option*, USA Today (14 August 2006) reported on draft recommendations issued by the US Centers for Disease Control and Prevention, "calling for routine HIV testing without specific consent in all doctors' offices, clinics and hospital unless patients explicitly refuse or "opt out."" (Final recommendations will be published September 22.) The devil is likely in the details: while virtually no one contests the value of provider initiated testing in theory, the details of practice matter. For example, failure to ensure specific consent puts an individual's human rights at risk, according to a number of HIV/AIDS advocates. Moreover, advocates insist that provider initiation of testing be done in a non-coercive manner – along with ensuring confidentiality and conducting pre- and post-test counseling. Noted Mark Heywood (AIDS Law Project, South Africa) in a session on HIV Testing in the Era of Treatment Scale Up (14 August 2006), 'counseling is not a luxury, it is a medical intervention.'

USA Today also noted that the World Health Organization and the United Nations Programme on HIV/AIDS are pushing for widespread testing. Quoting Kevin De Cock, head of WHO's AIDS program, USA Today reported "'It's estimated that no more than 10% of people around the world know whether they have an infectious disease for which effective treatments are available." He adds that "treatment programs can't expand without more testing, but the results must remain confidential and appropriate counseling must be provided." (USA Today, 14 August 2006).

An article on 15 August in The Times, (at www.timesonline.co.uk) reported that Dr. Jim Yong Kim "called for a reappraisal of the role of human rights in the context of rapidly improving treatment options, which have transformed AIDS from a death sentence to a chronic disease." Dr. Kim, formerly of the WHO and now director of Harvard's Francois Xavier Bagnoud Centre for Health and Human Rights, told The Times, "There are people who are still saying that protecting a person's right not to know [if they are HIV-positive] is the most important thing. But the particular human right is the right to die prematurely not knowing your HIV status. That just doesn't make any sense to me. The conversation has to change because we now have different tools." Human rights advocates contest this view, and emphasize the importance of context, or, as Joanne Csete of the Canadian HIV/AIDS Legal Network put it, "Women do not get abandoned by their communities, or beaten up by their partners for having other diseases," (BBC News, 15 August 2006, at www.news.bbc.co.uk). Even officials at some of the agencies promoting *provider initiated opt-out testing* acknowledge some of the challenges. According to an article in AFP (Agence France Presse) on 15 August 2006, "officials acknowledge that some people who might suspect they are infected are unwilling to take AIDS tests, fearing discrimination, stigma and an erosion of their own basic rights in often developing societies."

Amnesty International joined in sounding an alarm noting, "The pressure to scale up testing risks bypassing long established principles of informed consent, counselling and confidentiality. Although many service providers support voluntary counselling and testing, a number of influential policy makers and health professionals, including government representatives and clinicians, promote approaches which risk depriving individuals of the right to make their own informed choice. HIV testing needs to be expanded to achieve universal access to treatment, care and support for all persons and to contribute to more effective prevention strategies. Scaling up of HIV testing cannot mean that people's rights to confidentiality, counselling and informed consent are dismissed. Choices on testing must remain with the individual" (Amnesty International Public Statement, AI Index: POL 30/037/2006 (Public) News Service No. 217, 18 August 2006).

During a press conference held on August 16 at the IAC, human rights advocates (including Mary Robinson, Former President of Ireland; Executive Director of Realizing Rights: The Ethical Globalization Initiative; Beri Hull, Global Advocacy Officer, International Community of Women with Living with HIV/AIDS; Joseph Amon, Director, HIV/AIDS Division, Human Rights Watch; and Anand Grover, Project Director, HIV/AIDS Unit, Lawyers Collective, Mumbai, India) called for protections in the scale-up of testing at the country level, including simultaneous efforts to address stigma and discrimination, provide an environment supporting fully informed choice and consent, provide pre- and post-test counseling, ensure confidentiality, protect individuals from possible retribution suffered upon disclosure of a positive test, and provide HIV-positive people with access to adequate support, care and treatment.

This view was supported by Amnesty International who sought to ensure attention to social marginalization – highlighting the most likely targets of human right violations set in motion by testing that is not voluntary, nor conducted on the basis of informed consent with pre- and post-test counseling. **"**Sex workers, injecting drug users, prisoners and men who have sex with men continue to face exclusion, discrimination and criminalisation, and lack of access to the conditions that allow people to protect themselves from HIV infection. More needs to be done to ensure that all people have full access to the preventive tools and treatment that are currently available. Orphaned children need government commitment to guarantee their education, security and access to health services."

4. *Sharing my opinions: provider initiated testing, universal access and beyond.* An interview with Sofia Gruskin, Executive Director, Program on International Health and Human Rights, Harvard University School of Public Health, Boston, Massachusetts, USA

Editors (Ed): Could you give us a bit of history about the current testing debate?
Sofia Gruskin (SG): HIV testing has been an issue since the start of the pandemic. Some of the complexities were clear from early on - more than 15 years ago – when the focus was on testing the blood supply not people. So people thought that the only way to learn your status was to give blood. It was out of this history, and the stigma and discrimination that existed from the very start that made people afraid to come forward, that voluntary counseling and testing emerged as the strategy of choice. It was evident early on that if testing wasn't voluntary, you would drive people underground – especially those who were already marginalized, like sex workers, same sex practicing and transgender individuals, injecting drug users – who, because they did not know their sero-status might unknowingly spread the virus. So, in this case human rights protection, in the form of voluntary testing with pre- and post-test counseling and informed consent, functioned in the service of public health. Despite this public health strategy, a number of governments started to impose mandatory testing outside the health context – for example imposing testing on students entering the country, on immigrants or even tourists – to ensure that people coming across their borders were *clean*.

Much has changed in recent years. Today, with the advent of rapid testing (and new testing technologies) people can get their results in one visit, rather than needing to return days or weeks later. And, because of ever expanding access to ARVs and other forms of treatment, there are more reasons to know your status. Add to this the fact that there has been low uptake and demand for VCT in places where it is available and where VCT sites have been effective they have not been sufficiently replicated. In fact, the number of people who are HIV infected and who know their status is still shockingly low. Pre-test counseling as traditionally done is also expensive – prohibitively expensive in resource poor settings in terms of the cost of staff time, of counseling time, of processing of test results – all of which taken together has prevented many people from getting access to testing.

Ed: What about the policy history?
SG: At a political level, perhaps most important was the WHO's 3X5 initiative. In order to meet the goal of getting 3 million people in treatment by 2005, it was clear that many more people would have to be tested. Indeed, more people would have to be tested than the entire number tested since the advent of the epidemic. In this sense, technical changes,

political changes, and treatment changes have happened in concordance, resulting in a push for a massive scale up in testing. Everyone agrees that things need to change.

Ed: So why are so many people framing the question of how and if to scale up testing around human rights?
SG: Four years ago – right before the Barcelona IAC – Kevin De Cock (then heading up the CDC's Africa program) published an article in The Lancet, putting much of the blame for the inadequate success in AIDS efforts on *human rights exceptionalism* - noting that human rights activists had inappropriately placed a focus on human rights – in this case meaning attention to privacy and confidentiality – which interfered with the ability of public health practitioners to address the disease effectively. While his understanding of human rights at the time was misguided, it moved the debate on testing towards one where people juxtaposed a "public health approach" versus a "human rights approach" even as there was, and continues to be, little clarity as to what people mean when either term is asserted in relation to the other.

Ed: What is the change in testing policy that is being proposed?
SG: Most importantly, changes in the global guidance around testing are intended to take advantage of the fact that people's entry to health services can be used as an entry point for testing. By 2003, discussions about moving towards scaling up of *provider initiated* testing were emerging. The idea behind *provider initiated* and *routine offer of testing* was intended to focus on the clinical setting and to allow health care providers to take advantage of a person's presence in a health setting. Many in the health and human rights community recognized the importance of scaling up testing and the benefit of provider initiation and offer but were concerned that any efforts to scale up must recognize that the purpose of testing is not for testing's sake and that testing must be done in such a way that it ensures a person stays connected to services. All of this requires a number of factors be in place, including not only that a person knows they can refuse a test but that a health care setting would ensure that people have access to treatment and services – in other words, they are able to stay connected to the health system. In addition, an enabling legal environment, and efforts to reduce stigma and discrimination within the health setting and society as a whole are required not only because they are necessary in rights terms but for effective implementation.

In fact, WHO/UNAIDS put out a statement in 2004 which focused on provider-initiated testing but recognized that the promotion and protection of human rights is critical to an effective response. However, the overall statement is the result of political compromise, and it does not provide explicit guidance. Instead, it makes reference to routine offer and uses the language of "opt-in" and "opt-out but does not give specificity to these terms. The result has been tremendous confusion among health care practitioners and policy makers alike.

Ed: What have been the testing policies within countries and how have they changed?
SG: In the past few years a number of countries have put into place policies specifying *routine testing*, but fail to specify *provider initiated* and *routine offer*. In essence this leaves it to governments, health care practitioners, and others to decide what *routine* means. The result has been that a variety of practices have emerged: for some providers, *routine* means that when you come in with a broken arm, for example, the practitioner offers to do an HIV test. S/he asks if you want the test and asks you to fill out consent form. There's not much pre-test counseling, but there is informed consent and post-test counseling is assured. On the other hand, in other health care settings, you come in with a broken arm, for example, the practitioners tell you that they will perform a battery of tests without giving any detail about which tests and to what end. There is no informed consent and at the end, you will be told your sero-status.

Ed: So what are the implications of this?
SG: In order for human rights to be promoted and protected, the language of *provider initiated* has to be coupled with *routine offer*. It is not one or the other. The semantics make a big difference --*provider initiated routine testing* has a very different meaning from the *routine provider initiated offer* of testing. Moreover, it needs to be emphasized that the concern for human rights protection is not ancillary to an effective AIDS response, but central to it. This artificial pitting of public health and human rights against one another has to be stopped.

Ed: What are some of the implications for marginalized groups and for sexual health and rights concerns?
SG: Well, let's talk for a minute about where most folks get tested. We need to distinguish between middle-class men getting treatment in doctor's offices from poor pregnant women at ante-natal clinics. While policy does not distinguish between the two (nor should it), it is significant to think through how the health care encounter is likely to play itself out, especially when women in low income communities access sexual and reproductive health services right before labor or during delivery. In this context, what can informed consent really mean? What kind of substantive counseling can take place?

Ed: Is this a question of quantity versus quality?
SG: Not really. Let's be clear - if you want to increase the numbers of people on treatment, you need to test more people. The next question then becomes, when treatment is limited who gets access and what rights protections need to be in place to ensure that even if people get access that this access will be sustained over time? For many women, the most likely location where they will not only be tested but receive treatment the first time is in ante-natal clinics. In this context, consistency in how the numbers of people counted as being on treatment matters: if a woman receives treatment only in the context of pregnancy and childbirth what protections are in place to assure she can continue to access treatment once she has delivered? After delivery, access to treatment may no longer be guaranteed at the ante-natal clinic and even if treatment is available it must be accessed at another site. However, not only is data not generally being collected to see whether women continue to get treatment over time but little work has been done to determine the rights protections that must be in place to ensure that this can happen.

Ed: What about traditionally marginalized groups?
SG: There are several really critical issues – especially with regard to sex workers and men who have sex with men and drug users. First, if the purpose of testing is to increase access to (limited) treatment, you inevitably bump up against the need to set priorities about who gets limited treatment. Even if this is based on medical status as measured by CD4 count it assumes that everyone can come forward to the system in the same way. Sex workers, drug users and men who have sex with men are unlikely to be considered as priority populations when treatment is limited AND they are not the ones who will be receiving testing benignly. Moreover, since policies are vague and open, they can be used to support indiscriminate testing on the street and in other settings, because this can be seen as *just routine*. Even if the policy doesn't intend it, it can become coercive.

Ed: What is your overall evaluation of this IAC? How would you compare it to other IACs, especially from the perspective of the visibility of women's human rights and gender issues, the visibility of issues specifically relating to sex workers, same sex practicing people and those identifying as lesbian, gay, bisexual and transgender?
SG: I am delighted to see these issues so prominent. However, there is a distinction between the official scientific conference and the sessions held as satellites or as part of the Global Village. Within the scientific conference, most of the abstracts and panels on sexual health and rights and other related issues were rejected and there was little attention to this range of issues. However, these issues are front and center in the conference as a whole. So one thing we need to decide is whether this will result in our only speaking to others who care about these issues or what really matters is for us to have this space even if not officially – in which case this is a fine way to proceed as we look forward to Mexico City.

Contact:
Sexual Health and Rights Project
Open Society Institute
400 W. 59th St.
New York, NY 10019

Phone: 212-548-0600
Website: www.soros.org/initiatives/health/focus/sharp

Sue Simon, Project Director, ssimon@sorosny.org
Rachel Thomas, Project Associate, rthomas@sorosny.org