

# Cuba's HIV/AIDS Strategy: An Integrated, Rights-Based Approach

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Any errors are the sole responsibility of the author.

*Cover photo: A National STI/HIV/AIDS Prevention Center health promoter distributes condoms and HIV/AIDS information on World AIDS Day in Havana. ©MEDICC.*

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*"One should do in each moment  
what each moment requires."  
- José Martí*

## **SUMMARY**

Upon diagnosing the first case of HIV in 1985 and subsequent cases in 1986, the Cuban government implemented a national program to monitor and manage the epidemic. Initially based on infectious disease control and containment strategies, and later broadened to include inter-sectorial education, prevention and treatment efforts, this approach has resulted in the island registering a prevalence rate of 0.1% - the lowest in the Americas [WHO 2008]. Cuba's rate of AIDS-related mortality is similarly low at 1.0 per 100,000 population [Ministerio de Salud Pública 2007]. Mother-to-child transmission and infection through the blood and hemoderivatives are also extraordinarily low in Cuba, where the main transmission route (99%) is sexual relations [Ochoa, et al. 2006]. Despite these strides however, the number of new infections has steadily risen since 1996, most precipitously among men who have sex with men (MSM); currently 84% of all men diagnosed with HIV in Cuba are MSM [Programa Nacional ITS/VIH/Sida 2008].

This paper discusses the Cuban approach to HIV, which like the nation's public health system, is founded on the principal that **health is a human right**. In practice, this translates into a continuum of care through universal access to primary, secondary, and tertiary health services, government commitment to equalizing and improving social determinants, and scientific research and development aimed at advancing population health. **Constitutional rights**, including job and housing guarantees and anti-discrimination laws, also play a role. Free, equitable access to care, a robust national biotechnology capability, and an educated citizenry with confidence in the public health system have helped contain the epidemic on the island.

Other components of the Cuban strategy as it has evolved over time include:

- ❖ **sexual education program beginning in grade school** for the entire population;
- ❖ **a targeted, pro-active prevention program** including free and subsidized condom distribution, HIV screening for pregnant women and blood donors, outreach to more vulnerable groups, and confidential hotlines;
- ❖ **aggressive and systematic education program** about the epidemiological, social, psychological, and biological aspects of HIV and AIDS designed for different populations (women, youth, men who have sex with men, transvestites, prisoners, people engaging in transactional sex, etc);
- ❖ **free and anonymous HIV testing** for those requesting it;
- ❖ **free anti-retroviral treatment** for all who need it;
- ❖ **government-provided high nutrition diet for people with HIV and AIDS;**
- ❖ **wide range of counseling services** for persons with HIV and those affected by it, including accompaniment, counseling, support, information, and sharing of experiences;
- ❖ **national support network** for people with HIV or AIDS, their families, friends and co-workers, including dedicated chapters by and for women, transvestites and transsexuals, and men who have sex with men;
- ❖ **systematic safe sex education for targeted groups** including women, transvestites and transsexuals without regard to sexual orientation, and men who have sex with men;
- ❖ **participation of people with HIV or AIDS in program design, implementation, and evaluation** including outreach, prevention, counseling, and capacity building;

- ❖ **training of human resources** in health, including sensitivity and clinical training for doctors, dentists, and other health professionals attending people with HIV; and
- ❖ **coordinating work between sectors** so that all parts of society are helping forge a response to the epidemic.

In short, Cuba's experience has shown that **government will combined with an integrated, rights-based approach** can positively affect outcomes for preventing HIV and provide a healthy, dignified life for people with HIV or AIDS. That such results are possible in a small, low-income country like Cuba represents a learning opportunity for other nations - particularly in the Global South - seeking to forge relevant strategies to address the HIV/AIDS crisis.

## **THE CUBAN EPIDEMIC - PAST & PRESENT**

The origins of Cuba's current HIV/AIDS program date to 1983, when public health authorities on the island became aware of an emerging infectious disease affecting the immunological system of patients in the United States and Europe. Although the etiology of the disease wasn't yet understood, alarms were already ringing in Havana, where treating communicable tropical diseases is one of the classic public health challenges. As a result, the decision was made to apply traditional epidemiological measures to control the disease some in the international press were reprehensibly calling the gay plague. In 1983, Cuba established a National AIDS Commission and the Epidemiological Surveillance System was implemented in hospitals nationwide to monitor clinical markers of the disease including recurring pneumonia (especially that caused by *Pneumocystis carinii*) and Kaposi's sarcoma [Ministerio de Salud Pública 2001].

The **National AIDS Commission** was composed of a multi-disciplinary team mandated to:

- ❖ design a national HIV prevention program for the general population and vulnerable groups;
- ❖ develop efforts for prevention of mother-to-child (vertical) transmission of HIV;

- ❖ design methods and measures to prevent opportunistic infections and new HIV infections;
- ❖ undertake national epidemiological surveillance and control;
- ❖ spearhead scientific research and development in the field; and
- ❖ establish a national sanatorium network to which all people evidencing symptoms of the illness were to be admitted [Pérez et al 2004].

Once it was understood that the disease could be transmitted through blood, Cuba undertook several proactive measures including the destruction of 20,000 potentially infected containers of blood and hemoderivatives stored in blood banks [Lantero et al. 2006], a ban on imported blood and hemoderivatives (eg, Factor VIII, different types of gamma globulin), and the creation of a national product pipeline for these products. These costly, but effective measures proved indispensable in preventing new infections. HIV testing of all blood and blood products became standard nationwide in 1986, effectively eliminating blood transfusions and use of blood products as transmission routes.

<b>Snapshot: Cuba's HIV/AIDS Statistics through December 31, 2007</b>	
Cumulative total of seropositive people detected	9,304
Cumulative % of seropositive people detected in Havana City	54%
Cumulative % of seropositive males	81%
Cumulative % of seropositive males that are MSM	84%
Cumulative total of AIDS cases	3,492
Cumulative total of AIDS-related deaths	1,582
Annual average of HIV tests	1.6 million
Source: Programa Nacional ITS/VIH/Sida, Dirección de Epidemiología, Ministerio de Salud Pública	

Cuba's diagnosis of its first case of HIV in late 1985 proved a watershed event for several reasons. First, unlike other countries, the initial cases of the disease in Cuba did not manifest among men who have sex with other men or injection drug users, but rather among international volunteers returning from Africa. According to Dr Jorge Pérez, former Director of the Sanatorio de Santiago de Las Vegas and current Vice Director of the Pedro Kourí Institute of Tropical Medicine (IPK), "luckily the first person detected in Cuba was an internationalist returning from Africa who was also heterosexual...the first case was not susceptible to discrimination" [Oxfam interview 2007].

At the beginning, therefore, HIV in Cuba was understood as a sexually-transmitted infection that could infect the population regardless of their sexual practices. This allowed the government to fashion an initial response based on the epidemiology of HIV, without having to wrestle with ingrained moral and social prejudices or religious doctrine which have hamstrung HIV/AIDS efforts in other countries. Indeed, the authors of *Human Rights and HIV/AIDS: Now More than Ever* point out that "in many countries...pressure by foreign donors, religious conservatives and other ideological forces has resulted in restrictions on information that emphasizes safer sex and condom use. This has resulted in young people being denied life-saving information about HIV transmission; young women being denied access to reproductive health information and services; and men and women being denied access to condoms and comprehensive HIV information."

Upon confirming the presence of HIV on the island, Cuba implemented a sanatorium policy for people diagnosed with HIV or AIDS, sparking a contentious debate in global health circles. Critics vilified the quarantine strategy as violating the rights of people with HIV [Pérez-Stable 1991], while health experts on the island and elsewhere maintain these closed communities were the most effective mechanism for providing the comprehensive biological, psychological, and social care patients required [Bayer and Healton 1989].

Once HIV was better understood as a preventable and manageable chronic disease, and education efforts had taken hold, the sanatorium policy was amended in favor of a mix of in-patient and ambulatory care in 1993. People living in the sanatoria, who refuted the reasoning

behind quarantine once scientific advances made it clear that HIV was not a death sentence, were a factor contributing to this policy change. Since then, the number of people attending sanatoria has decreased significantly. By September 2003, 60% of HIV-positive people were cared for in the Ambulatory Care System, while 40% remained in the sanatoria [Pérez et al. 2004]. As of April 2008, there were 220 people living at Havana's Comprehensive Care Center for People with HIV/AIDS (formerly known as the Santiago de Las Vegas Sanatorium) [Author interview 2008]. It's worth noting that most doctors and people with HIV/AIDS feel that ambulatory attention is the ideal system for providing the integral care and support required [Miñoso & Valdés 2006; Malagón et al. 2006]. Cuba currently has 12 sanatoria around the country.

When HIV test kits became available in early 1986, Cuba launched the National Program for the Prevention and Control of HIV/AIDS to limit infection [Ministerio de Salud Pública 1997]. To this end, research was conducted to ascertain the main modes of transmission and diagnostic equipment and other resources were acquired to equip 33 laboratories across the country, including the AIDS Reference and Research Laboratory (LISIDA in Spanish), headquartered in the outskirts of Havana.

Delivering HIV interventions for the people it most affects requires political will, a long-term supply of considerable financial resources, scientific and public-health vision, and dedication from all sectors of society.

- *Nature*, May 15, 2008

Actions taken at this stage included active screening of vulnerable groups considered to be at high risk (including all volunteers returning from international postings, people testing positive for other STIs and the incarcerated); testing pregnant women as part of the series of standardized tests recommended for all expectant mothers; and a rapid scaling up of training human resources to ensure proper staffing and competency levels in the laboratory network. Furthermore, taking into account the lessons learned in the control of other STIs including syphilis and gonorrhoea, contract tracing was implemented as an epidemiological control strategy in 1986. Through the Partners Notification Program, people who had sexual contact with people diagnosed with HIV were contacted by specially trained health professionals to



advise they take an HIV test. Program participation was voluntary and by informed consent, and results were shared with the respective health authorities [Pérez et al. 2004]. Over one-third of Cubans with HIV have been diagnosed through this contact tracing program [Ministerio de Salud Pública 2008].

Efforts launched during this period that would later yield positive results included domestic production of diagnostic kits (UMELISA and Western Blot) beginning in 1995, and generic anti-retroviral drugs beginning in 2003. The latter has had measurable impact on AIDS morbidity in Cuba and mother-to-child transmission of the disease [Castro et al. 2007]. Today, Cuba's HIV testing focuses on the following groups: blood donors; persons with other STIs and their sexual contacts; hospitalized patients exhibiting symptoms of HIV and those receiving services that put them in sustained contact with blood and blood products such as dialysis; persons requesting testing; family doctor-initiated testing; pregnant women and their sexual partners; prison inmates; and people who have had sexual contact with people with HIV. Moreover, the national program guarantees free antiretroviral treatment for all people requiring it.

## Cuba's HIV/AIDS Timeline

- 1983** National AIDS Commission convened
- 1985** First case of HIV in Cuba clinically diagnosed
- 1986** National Program for the Prevention and Control of HIV/AIDS launched  
Working Group for Confronting & Fighting AIDS (GOPELS) established  
Government announces HIV-infection has been detected in the population  
First Cuban dies of AIDS-related complications  
All donated blood is tested for HIV
- 1987** Zidovudine (AZT) recommended as monotherapy for AIDS patients
- 1989** First case of pediatric HIV detected
- 1991** AIDS Prevention Group (GPSIDA) officially established
- 1993** Mandatory sanatorium policy amended to allow alternative known as the Ambulatory Care System
- 1995** Laboratories nationwide using Cuban-manufactured HIV test kits
- 1996** Children with HIV and their mothers begin receiving anti-retroviral treatment  
Cuba joins the International NAMES Project
- 1997** Pregnant women with HIV begin receiving AZT to prevent mother-to-child transmission
- 1998** Day Hospital alternative expands on Ambulatory Care System  
National STI/HIV/AIDS Prevention Center opens  
Support Line (Línea de Apoyo) network for people with HIV/AIDS founded
- 2000** MSM Project (Proyecto HSH) created
- 2001** Cuba begins manufacturing antiretroviral drugs and distributing them free to those needing them  
National STI/HIV/AIDS Strategic Plan 2001-2006 launched
- 2003** Universal Antiretroviral Treatment achieved  
First Global Fund to Fight AIDS, Tuberculosis & Malaria award approved
- 2005** Ministry of Public Health and GOPELS refine Sanatoria Care and Ambulatory Care Systems
- 2006** Second Global Fund to Fight AIDS, Tuberculosis & Malaria award approved
- 2008** Third Global Fund to Fight AIDS, Tuberculosis & Malaria award approved

## **HIV PREVENTION IN CUBA**

A constellation of contextual factors allows Cuba to approach HIV prevention in an integrated and targeted way for both vulnerable groups and the general population. First, since the 1960s, the Cuban public health system has provided free, accessible, and universal medical attention in a nationally coordinated network of primary, secondary, and tertiary specialist services. This continuum of care is guaranteed by the Cuban Constitution and is further reinforced by specific resolutions protecting the rights of persons with HIV to adequate medical care, employment and social security [Ministerio de Salud Pública 1997].

Second, the Cuban philosophy of health is based on the assumption that preventing disease permits a more effective use of resources than treating that disease once it manifests. From meningitis B and other vaccine-preventable diseases to vector-borne illnesses like dengue, Cuba has maintained massive disease prevention programs and campaigns which depend on public participation. These programs and campaigns typically use a bio-psycho-social approach, (rather than focusing only on the epidemiology of the disease), which considers a range of factors making certain groups more vulnerable; this is clear in the case of HIV prevention.

Finally, the Cuban government's political will allows for multi-disciplinary, inter-sectorial programs which are fundamental for achieving and sustaining population health. To this end, a national body was established in 1986 to integrate prevention efforts among three dozen ministries, organizations, and institutes. Today, the Working Group for Confronting & Fighting AIDS (GOPELS in Spanish) coordinates intersectorial work among entities as varied as the Ministry of Health, the Cuban Institute of Radio and Television, and the Federation of University Students, among others. As the country's national AIDS coordinating authority, GOPELS, together with the monitoring and evaluation programs overseen by the National Program for Prevention and Control of HIV/AIDS and the National Strategic Plans for STI/HIV/AIDS (2001-2006 & 2007-2011), are putting into practice the "Three Ones" - key principles for the coordination of a national response to HIV/AIDS established by UNAIDS member countries in 2003.

Importantly, in 1984, the Family Doctor Program was introduced, whereby doctor-and-nurse teams were located in each neighborhood in medical offices created for this purpose so as to determine the health picture for that catchment area and provide services specific to that population. Multi-service community clinics known as polyclinics were also situated in neighborhoods throughout the country to bring care closer to patients. This strong community-oriented primary care network contributed to improving population health overall [Presno & Sansó 2004] so the system as a whole was better prepared to respond to emerging (including HIV) and re-emerging diseases, and also provided a frontline for prevention efforts. Today, the family doctors' offices and community polyclinics play a pivotal role in prevention by providing counseling services, active screening services, promoting safer sex practices, and distributing educational materials, condoms and lubricants, while also serving as primary care providers for people with HIV participating in the ambulatory care system. Taken together, these initiatives profoundly affected how HIV manifested in Cuba in the early years of the epidemic.

Since then Cuba has fostered collaboration with a wide range of international and non-governmental organizations to strengthen the country's response to HIV. Organizations like Médicos del Mundo España, HIVOS Holanda, Doctors without Borders (Holland, Spain), the Global Fund, the World Health and Pan American Health Organizations, and UN agencies UNAIDS, UNDP, UNICEF and UNESCO, work together with Cuban entities to prioritize issues, evaluate the National Strategic Plan, and identify and address shortfalls in the national program. According to the *Grant Scorecard* for Cuba's Phase I grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Cuba performed and managed the grant well, reaching and even exceeding most targets: 154% of counseling target for persons aged 15 to 34; 100% of target for HIV/STI education programs for students; 241% of peer educators training target, mostly MSM; 524% of youth counselors trained target; and 116% of target reached for distribution of condoms to the general public [Global Fund 2005]. As a result, two more rounds of funding to strengthen the multi-sector national response to prevent and address the HIV/AIDS epidemic were approved by the fund, the most recent in 2008 [Ochoa personal communication 2008].

## Condoms in Cuba

Condom use has increased in Cuba in recent years, with higher quality products at low (less than US\$0.01 per) or no cost enjoying wider and more reliable distribution. National findings show the percentage of Cuban adults ages 15 to 49 using condoms during casual sex increased from 47% to 69% between 2001 and 2006 [Ministerio de Salud Pública 2008]. In 2004, over 90 million condoms were sold [Lantero et al 2006]. In addition to grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria which helped distribute or socially market condoms [Global Fund 2005], market research, quality control and sensitivity training for salespeople have played a role. Condoms are available at the following:

- ❖ Cafeterias and bars
- ❖ Pharmacies
- ❖ Hospitals
- ❖ Polyclinics
- ❖ Family doctors' offices
- ❖ AIDS Prevention Centers
- ❖ Centers for Health Promotion & Education
- ❖ Counseling Services

Today, the entity responsible for the education and prevention component of Cuba's STI/HIV/AIDS program is the National STI/HIV/AIDS Prevention Center. Working with other national organizations like the Federation of Cuban Women, the National Center for Sex Education (CENESEX in Spanish), groups like the AIDS Prevention Group (GPSIDA in Spanish), various ministries, student unions, etc, it undertakes a broad spectrum of educational, training, investigative, and consultation activities. Support services - to people with HIV/AIDS, their family and friends, vulnerable groups, people wishing to get tested or those simply looking for more information about the disease - are also core activities. Additionally, the National Prevention Center serves as Cuba's technical partner to the Global Fund to Fight AIDS, Tuberculosis and Malaria.

### **National STI/HIV/AIDS Prevention Center**

With support from Doctors without Borders (Holland) the Ministry of Public Health co-founded the educational component of the STI/HIV/AIDS prevention and control program, the National STI/HIV/AIDS Prevention Center (CNPITS-VIH/SIDA), in 1998 to work towards lowering STI and HIV/AIDS incidence in Cuba. The Center systematically designs, implements, and evaluates the country's STI/HIV/AIDS educational and prevention strategy. The CNPITS-VIH/SIDA uses a community-based, participatory approach, actively incorporating people with

HIV, youth, women, men who maintain sexual relations with men (MSM), people involved in transactional sex, and other vulnerable groups into its educational, consultation, research, training, and evaluation activities. These are carried out by work teams on the local, regional, and national level and include:

- ❖ **Counseling services** - Provided either in person, known as Face-to-Face (Cara-Cara) with 304 offices nationwide, or through Help Line (LíneaAyuda), an anonymous and confidential telephone helpline with 15 nodes throughout the country.
- ❖ **Training** - Sensitivity training and continuing education for health professionals; formation of youth advocates and counselors for the Face-to-Face and Help Line services; safe sex education by and for vulnerable groups.
- ❖ **Development of educational programs, projects and materials** - With active participation by target community (eg, youth, women, MSM, health professionals, etc).
- ❖ **Methodological assessment, support, evaluation, and follow up** - For prevention activities carried out on the community, municipal, and regional levels.
- ❖ **Promotion of volunteerism** - Linking the community and different sectors of society through volunteer prevention training, counseling, monitoring, and evaluation.
- ❖ **Distribution of free condoms and lubricants**
- ❖ **Support Line (Línea de Apoyo), national support network for people with HIV** - With 98 Mutual Support Teams throughout the country comprised of people infected and affected by HIV.

Over the last ten years, CNPITS-VIH/SIDA has developed specific projects responding to the psycho-social aspects particular to Cuba's HIV picture. The relevance and efficacy of well-established projects like *HSH* and *Carrito por la vida* (a mobile counseling and condom

distribution center staffed by and for youths), and more recent endeavors including *Salud y Belleza* (Health & Beauty; hairdressers trained as health promoters in HIV prevention) and *Afroaché* (training health promoters among practitioners of Cuban religions of African origin) result from members of different vulnerable groups actively participating in the design and implementation of educational and prevention initiatives and materials. Books written by doctors for doctors treating people with HIV in the Ambulatory Care System, training manuals designed by people with HIV for people with HIV, and publications for families written in collaboration with family members of people with HIV are examples of this participatory, peer group approach. Other CNPITS-VIH/SIDA publications including *Nutrition & AIDS* and *Legal Issues & AIDS in Cuba* tackle issues fundamental for a healthy, dignified life.

Since its inception, the Center has developed programs by and for people with HIV or AIDS to ensure they participate in shaping the decisions that affect their quality of life. To this end, in 1998, the Center established the Support Line for People with HIV - a national support network for people with HIV and AIDS - as part of its core activities. The Support Line's 98 Mutual Support Teams located in provinces and municipalities throughout the country form a coordinated network of people with HIV working to raise awareness within the HIV+ community, health sector, families, and society in general to remove the HIV stigma; train people with HIV as counselors and health promoters for people infected and affected by HIV; heighten visibility of people with HIV and AIDS within Cuban society; and strengthen collaborative relationships with both Cuban and international institutions working on issues affecting the lives of people with HIV or AIDS. Education and training initiatives, active participation in policy and program design, and providing mutual support for the HIV+ community are cornerstones of Línea de Apoyo.

### **AIDS Prevention Group (GPSIDA)**

GPSIDA was officially established in 1991 by people with HIV/AIDS and others interested in sharing information and experiences about the disease. As early as 1988, an advocacy group for people with HIV had coalesced within Havana's Sanatorio de Santiago de Las Vegas, from where they published Cuba's first informational brochures about HIV prevention. From these modest beginnings and episodic publications, GPSIDA has grown into a national network with

16 chapters and 350 members (115 of whom are people with HIV), trained over 20,000 health promoters, counselors and volunteers, developed a publishing capacity (brochures, monthly bulletins and newsletters, scientific literature, etc) and launched projects specifically for Cuba's most vulnerable groups including women, MSM, and the incarcerated. These activities are designed to achieve the following objectives:

- ❖ Contribute to helping people develop positive attitudes and behavior towards people with HIV/AIDS
- ❖ Contribute to training and providing psycho-social support for people with HIV/AIDS
- ❖ Contribute to the population's understanding of HIV/AIDS and to the modification of attitudes and behaviors in order to reduce the risk of infection; an important piece of this is working with people already diagnosed with HIV to prevent new infections
- ❖ Continue developing organizational and preventative work in regional and national GPSIDA groups

## **WOMEN & HIV**

Women have been the focus of a variety of prevention and treatment efforts since the beginning of Cuba's HIV epidemic. Indeed, one of the initial steps taken when the first case of HIV was diagnosed in a volunteer returning from Africa was to test his wife (also found to be HIV positive). Shortly thereafter, in 1986, a national strategy for controlling mother-to-child HIV transmission was implemented, whereby early detection is achieved by testing all pregnant women for HIV during the first trimester. For those testing positive, specialist counseling services are provided during which the parents decide between continuing or terminating the pregnancy. In the former case, the mother can carry the baby to term without medication or start antiretroviral (ARV) treatment (indicated during pregnancy in the 14th week unless the mother is already taking ARVs and labor and for the newborn through 18 months of age). Evidence shows that voluntary abortion by HIV positive women has dropped in Cuba since the introduction of antiretroviral therapy [Castro et al. 2007]. Other measures include birth by



caesarean section, and providing breast milk substitutes, nutritional supplements and scrupulous follow up. According to pediatric AIDS specialist Dr Ida González et al., "Cuba's health system provides free counseling and prevention coverage to all women diagnosed with HIV, one reason why so few infants have been infected by their mothers" [González et al. 2006]. Since 1986 through the end of 2007, 3.8 million pregnant women have been tested for HIV and 369 births to women with HIV have resulted in 31 cases of mother-to-child transmission. [Ministerio de Salud Pública 2008].

Cuba's success in keeping mother-to-child transmission low cannot be attributed solely to best practices and ARVs for pregnant women with HIV however. Rather, it must be understood in the context of Cuba's public health system, which has provided free and accessible universal care for nearly five decades. Cuba's National Program for Maternal-Child Health (PAMI in Spanish) was among the first national programs founded under the universal system and provides integrated, comprehensive care to women beginning at reproductive age through pregnancy and childbirth, and to children from when their born through their teens. An average of 12 medical consultations during pregnancy, in-hospital births attended by skilled medical personnel, the skin-to-skin method for premature babies, and other standards of care have meant Cuba has achieved child health indicators comparable to most developed countries: infant mortality is 5.3 per 1,000 live births; 99.9% of births occur in hospital; mortality for children under 5 years old is 7.1 per 1,000 live births, and mortality due to congenital malformations in infants under 1 year old is 1.3 per 1,000 live births. It is this continuum of care, coupled with the measures implemented as part of the National Program for the Prevention and Control of HIV/AIDS that led UNAIDS to call Cuba's prevention of mother-to-child transmission program one of the world's most effective [UNAIDS 2006].

#### **Experience: Daysi Llanares, Help Line Volunteer**

*Daysi Llanares has been volunteering for Havana's anonymous STI-HIV/AIDS hotline, Help Line (LíneaAyuda), for a year and a half. For two years, she has been a volunteer at an anonymous HIV testing and counseling site in Old Havana - one of the municipalities with the highest prevalence rate in the country - where she also coordinates the National STI/HIV/AIDS Prevention Center's Women & HIV project.*

**Question: What kind of calls do you take on LíneAyuda?**

**Daysi:** Our most frequently asked question is 'where can I go to get an anonymous HIV test?' That's followed by general questions about HIV and other sexually transmitted infections like the human papillomavirus, genital warts, gonorrhea...

**Question: Where *do* people go for anonymous tests?**

**Daysi:** There's a whole network of anonymous testing sites. I work at the Tomás Romay Polyclinic in Old Havana, where people can come and get tested without giving any personal information. They come in, get tested and receive their results in 5 days. I'm the counselor who gives them their results. Last month we did 198 tests and more people are coming in all the time.

**Question: What motivates you to do this kind of volunteer work?**

**Daysi:** HIV is a terrible, terrible thing. I feel totally effected by it, even though I'm not positive and no one in my family is either. I'm a nurse by training and feel I have to do something to help. I do it with so much love. Only God knows the love I put into my work.

**Question: Can you describe one of your most memorable experiences?**

**Daysi:** It was recently. It was so powerful and difficult, I'll never forget it: a 15-year old girl came in to get tested. She was dressed in her school uniform and reminded me so much of my own daughter. Her first test came back positive. Her mother was totally destroyed; it was dramatic, as you might imagine. I decided I wouldn't be able to give her the results if she was confirmed positive. I just couldn't. We did another test to confirm the results and the girl was negative in the end, but I was really shaken by that young girl and her mother.

**Question: What has your experience been working with women and HIV prevention?**

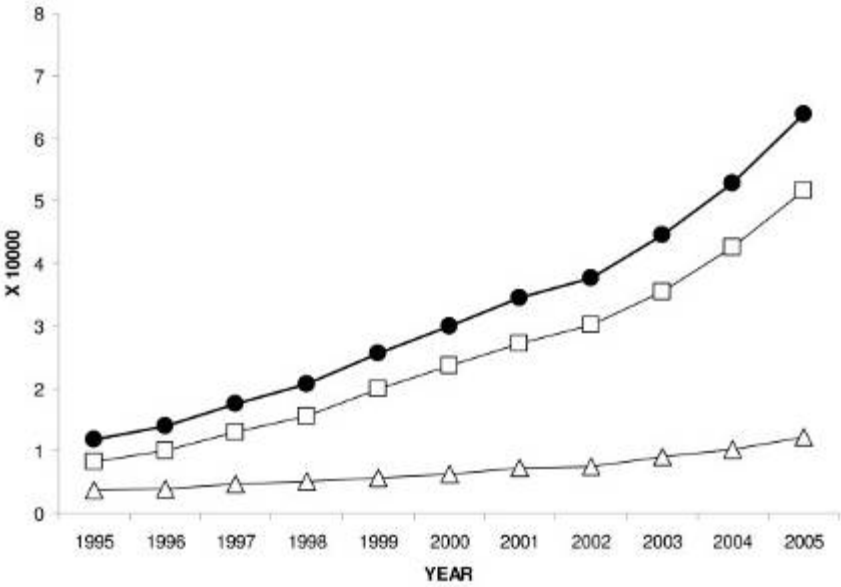
**Daysi:** I like working with women and prevention - young women especially. It's very gratifying for me to help these girls understand the risks they're taking and how they can prevent infection. Then their mothers come to tell me how they've changed, how they're being responsible with their decisions and actions. That makes me so happy.

**Question: But it must be hard giving people their test results, no?**

**Daysi:** It's not easy. From the beginning you have to prepare people that they may be positive. For me it's harder to give results to women than men and in my experience, women have more difficulties accepting the diagnosis than men. HIV affects women differently, socially for instance they may be more marginalized. Also if they don't have kids, this could affect their childbearing decisions and if they *do* have kids, the question becomes: how do I tell them? Men usually don't tell their children.

The effect of the global pandemic on women is especially acute in the Caribbean, where 43% of adults with HIV are female (up from 37% in 2001) - second only to sub-Saharan Africa [UNAIDS 2007]. Although in Cuba the overwhelming majority of people with HIV are men, women have represented a steadily growing segment of the HIV+ population since 1996 (see Figure 1) and today constitute 19% of seropositive Cubans on the island [Castro et al. 2007]. This is a serious concern for health policy makers and practitioners who have implemented initiatives to preempt the 'feminization of HIV' in Cuba, given that both biology and gender combine to make women more vulnerable to HIV. Biologically, women are at higher risk since semen is more infectious than vaginal fluids and it remains in the vaginal and rectal tracts longer than vaginal fluids do on the penis; thin vaginal mucous in younger and older women is more permeable to HIV; and many STIs are asymptomatic in women and therefore go undetected, putting them at higher risk for HIV [Centro Nacional de Prevención de las ITS-VIH/SIDA 2004].

**Figure 1: Uncorrected HIV prevalence among 15- to 49-year-olds**



Key: Circles: total adult population; Triangles: women; Squares: men.

Source: de Arazoza et al. The HIV/AIDS Epidemic in Cuba: description and tentative explanation of its low HIV prevalence BMC Infectious Diseases. 2007.

As a social construct, gender heightens women's vulnerability to HIV since they may feel unable to negotiate condom use or talk openly about sex with their male partners for fear of losing economic or emotional support. Research conducted between 2000 and 2005 by de Arazoza et al. found 71% of HIV+ women in the study were likely infected by men who also had sex with men. In response, specific projects like the National Prevention Center's *Salud y Belleza* (Health & Beauty) and *Mujer y SIDA* (Women & AIDS) conduct targeted outreach, hold training workshops, capacitate health promoters, and publish informational materials. The Federation of Cuban Women (FMC in Spanish), a community-based organization of national scope with 3.8 million members (85% of Cuban women over 14 years old), works closely with the National Program for the Prevention and Control of HIV/AIDS and its affiliated projects to positively affect women's health. To this end the FMC trains health promoters and social workers about working within the community and with people with HIV; runs HIV educational courses for women and their families; and holds workshops, debates, and other activities with women of higher vulnerability.

### **MSM: CUBA'S MOST VULNERABLE**

Over 80% of Cubans infected with HIV are men. Of those, 84% are men who maintain sexual relations with other men [Programa Nacional ITS/VIH/Sida 2008]. This statistical verity has driven Cuban health officials, educators, and advocates to develop programs, undertake research, and seek innovative ways to reach Cuba's most vulnerable group.

A 2001 exploratory study about sexual behavior among men who have sex with men conducted in Havana shed light on the problem: of 264 men studied (over 96% of whom self-identified as MSM), more than 52% had sexual relations without a condom in the last year, while nearly 28% did not know their HIV status [Chacón et al. 2004]. Such risky sexual behavior is promulgated in part by a low perception of risk, as well as sexist stereotypes about masculinity and widespread homophobia in Cuban society, so men having sex with men often do so clandestinely and in a rushed or semi-public setting which are unfavorable for negotiating condom use. Furthermore, Cuban MSM are less likely than their heterosexual counterparts to enjoy family support where they can discuss and resolve problems related to their relationships, health or both. Taken together, these factors can affect self esteem, and

produce depression or feelings of resignation, isolation or guilt, making this community more difficult to reach with the traditional prevention and early detection strategies that have shown results in other sectors of Cuban society.

The response to this challenge is based on two strategies:

- ❖ training MSMs as health promoters and counselors to support, educate and inform other MSMs, taking advantage of 'cultural competencies' in bio-psycho-social prevention and treatment efforts
- ❖ being pro-active by carrying out prevention activities where MSMs cruise and connect instead of waiting for them to seek help, support or information

For its part, the National STI/HIV/AIDS Prevention Center has the national *MSM Project* (Proyecto HSH), that designs educational materials, convenes video debates and organizes MSM-dedicated film festivals. Additionally, GPSIDA directs several MSM projects on a local level. Condom use and quality, coming out of the closet, homosexuals in Cuba, and correlated topics have been explored in recent MSM-specific newsletters and manuals published by these projects. Together, these initiatives realize important outreach and education work with the MSM community and have trained over 7,000 volunteer MSM health promoters nationwide.

### **Experience: MSM Project Volunteers**

*Pioneers in Cuba's HIV prevention program, volunteers Raúl Regueiro and Fidel Segura from Havana and Omar Parada from the eastern province of Granma have been health promoters with the National STI/HIV/AIDS Prevention Center since 1998. They helped found the MSM Project in 2001 and today dedicate themselves to educating and counseling members of Cuba's male gay and bisexual community about how to prevent HIV/AIDS.*

**Question: Describe your work. What does a MSM health promoter do?**

**Fidel:** We work nights and weekends - when other people are resting, we're at work, going to where the gay community goes to have fun and relax.

**Raúl:** We talk to people, answer their questions, clarify doubts. And of course, hand out condoms and lubricant and show people how to use them. Sometimes we get surprising questions like 'what does a person with HIV look like?' Another big part of our work is training - right now we're

conducting the health promoter training workshop with 32 participants. The video debates are also very popular.

**Omar:** We dedicate a lot of time to answering questions about sexuality and sexual practices, what constitutes risky behavior, how HIV is transmitted. We also organize activities like the Masculine Diversity Film Series which has had a big impact, especially in my province.

**Question: What's the atmosphere in Granma towards MSM? I imagine it's quite different from Havana.**

**Omar:** The smaller the place, the more obvious it is when someone is different. There's bias and machismo, but it's on an individual rather than institutional level. The MSM Project has a lot of government support, which helps. There are also a lot of bisexuals in Granma: they're in the closet during the day, but not at night.

**Question: When you say you work in 'gay gathering spots' what does that mean? Gay bars and the like?**

**Raúl:** Cuba has its own particularities and is writing its own history...you can't compare it to other places. We don't have gay bars per se, but we've created our own spaces. Especially the MSM Project, which hosts all sorts of recreational activities, galas, workshops.

**Fidel:** We take advantage of those spaces created by the community to do promotional and educational work. The Malecón for example, is one of those spaces that on nights and weekends transforms into a gay gathering place.

**Question: This volunteer work can be very draining psychologically. How do you prevent burnout?**

**Omar:** By avoiding repetition and varying the type of activities you're doing - switching up between a training workshop or gala, hosting a salon or health promoter class - helps. Actual counseling is the most draining.

**Raúl:** We figure a promoter can work for 2 years. That's why we're constantly training more volunteers. We also organize outings and regional and national meetings so that volunteers can get to know each other, bond as a group, and relax and have fun.

**Question: As gay men, have you experienced discrimination?**

**Fidel:** I feel like being part of the MSM Project helps - it has a lot of prestige and being a health promoter tends to lessen discrimination.

**Omar:** Sometimes it's invisible, though, silent or subliminal discrimination, which can be worse. The way people look at you or getting hassled by the police...

**Raúl:** It's not visceral, but it's there. Sometimes people want to impose themselves or their power on you...

Some of the most aggressive outreach, educational, and legislative initiatives around homosexual, bisexual, transsexual, and transgender issues in Cuba have been spearheaded by the National Center for Sex Education (CENESEX; [www.cenesex.sld.cu](http://www.cenesex.sld.cu)). "We need to do everything possible in Cuba to legitimize and ensure respect for sexual orientation," says Mariela Castro, Director of CENESEX [Reed 2006]. To this end, a draft law to amend the family code to recognize civil unions and extend inheritance and related rights to same sex couples was presented to the Cuban Parliament in 2007 and is expected to be enacted soon. The same progressive legislative approach was taken with regards to transgender people, who will soon be able to change official identification documents without undergoing gender reassignment surgery and lesbians, who will be eligible for reproductive assistance.

On the community level, CENESEX runs sensitivity workshops with police, hosts regular gay, bisexual, transvestite and transgender support groups and offers a variety of sexual counseling services. CENESEX is also at the forefront of Cuba's education initiative regarding sexual orientation and gender identity - a coordinated mass media strategy that is bringing these issues to Cuban airwaves, newspapers, and magazines for the first time in an integrated way. In 2008 alone, Cuba prepared to launch a 10-part radio series on sexual diversity, featured a gay character and another with HIV in the soap opera *Dust in the Wind* (*Polvo en el Viento*) and convened the Cuban Symposium for International Day against Homophobia in Havana and six other provinces - a heavily promoted and attended event combining education, culture, and prevention that was the largest observation of sexual diversity in Cuban history. Organized by CENESEX with participation by many other organizations and state institutions, the event enjoyed broad government support, including the presence of Ricardo Alarcón, President of the Cuban National Assembly.

Providing mainstream sexual diversity education while empowering gay, bi, and transgendered people to share experiences, learn their rights and how to exercise them, holds promise for reversing prejudicial perceptions about sexual orientation and gender identity. In this way, traditional Cuban culture has the possibility of catching up with rights-based legislation already in place. In terms of prevention, "we cannot separate ourselves from the social, political, and historical reality of men having sex with other men," says Mariela Castro. "We have to work

towards removing stigma, supporting these men and developing a prevention strategy beyond 'use a condom' [Castro 2008].

### **Snapshot: Components of Cuba's HIV/AIDS Approach**

Cuba's HIV/AIDS strategy contains epidemiological, educational, and prevention components fundamental to controlling the spread of the infection, while helping provide a safe, healthy, and dignified life for people with HIV or AIDS, including:

- ❖ free and universal health care, including all diagnostic tests, medications, specialized services and, for terminal patients, hospice care
- ❖ HIV/AIDS is a national priority for government and policy makers
- ❖ national coordinating body for inter-sectorial initiatives
- ❖ legislation protecting rights of people with HIV, including job security
- ❖ prevention efforts and continuum of care have bio-psycho-social focus
- ❖ early detection through widespread testing, including contact tracing
- ❖ antiretroviral treatment free for all needing it
- ❖ active participation by people with HIV/AIDS in developing prevention and treatment processes
- ❖ attention and treatment of opportunistic infections
- ❖ prevention, prevention and more prevention
- ❖ education, education and more education

## **TREATMENT PROGRAMS & PROTOCOLS**

From the start, Cuba's HIV/AIDS strategy has combined prevention and early detection with treatment. Since 1986, immune-bolstering medications have been recommended for people with HIV and a year later, Zidovudine (AZT) was recommended for all those developing AIDS. Children with HIV and their mothers began receiving Highly Active Antiretroviral Treatment (HAART) in 1996 and in 1997, HIV positive pregnant women and their children began receiving AZT and breast milk substitutes. Until 2001, when Cuba began manufacturing and distributing antiretrovirals, these medications were donated. In 2003, universal ART coverage reached all patients meeting clinical criteria for AIDS using Cuban-produced generic antiretrovirals. ARV treatments not produced in Cuba are acquired with support from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Today, these protocols represent the standard of care for persons with AIDS in Cuba.



## Generic Antiretrovirals Produced in Cuba

### Nucleoside reverse transcriptase inhibitors

- ❖ Zidovudine (AZT)
- ❖ Didanosine (DDI)
- ❖ Stavudine (D4T)
- ❖ Lamivudine (3TC)
- ❖ Zalcitabine (DDC)

### Non-nucleoside reverse transcriptase inhibitors

- ❖ Nevirapine (NVP)

### Protease inhibitors

- ❖ Indinavir (IDV)

Source: Pautas Cubanas para el tratamiento y manejo de los pacientes VIH/SIDA sometidos a Terapéutica Antiretroviral. Instituto de Medicina Tropical Pedro Kourí. 2003.

Administered according to national guidelines, including meticulous follow up via the Cuban computer software SIDATRAT (Automated System for Comprehensive Medical Care for People with HIV/AIDS) which records each patient's diagnostic history, viral load, CD4 count, opportunistic infections, adverse reactions and other information, universal antiretroviral therapy has shown positive results. Aragonés reports that between 2001 when ART was introduced and 2004, opportunistic infections dropped by 76% [Aragonés 2005]. Even more dramatic is the decrease in annual AIDS-related mortality: from 24.3% in 2000 to 6.25% in 2007 [Ministerio de Salud Pública 2008]. Meeting such treatment needs are the most urgent action for extending and improving the quality of life for people with AIDS [Global Fund 2004]. Additionally, the Cuban government provides high protein rations for everyone with HIV/AIDS to ensure proper nutrition, reinforced through projects like *Nutrición y Sida* (Nutrition & AIDS) run by the National STI/HIV/AIDS Prevention Center.

Once a person is diagnosed with HIV following a minimum of two ELISA and two Western Blot tests, "under strict conditions of confidentiality and respect, a team of specialists (epidemiologists, nurses, family doctors) and HIV positive people locate the person to inform them that they are seropositive, offer solidarity, help and the necessary information, and to orient them to the various types of assistance that exist, including Sanatorium and Ambulatory Care [Ministerio de Salud Pública 2001]. Treatment is identical for both variants, though it's

worth noting that in 2005, Sanatorial and Ambulatory Care were revised by the Ministry of Public Health and approved by GOPELS. This provided two alternatives for Sanatorium Care: temporary residency in the sanatorium followed by a full spectrum of services on the local level and long term residency in the sanatorium. For its part, Ambulatory Care means not residing in a sanatorium, but rather receiving information, treatment, and support on the local level by health professionals specially-trained in HIV/AIDS, and the prevention centers and sanatoria located around the country [Lantero, personal communication 2008].

Learning to take care of one's health is fundamental whatever the chronic disease. According to Cuba's public health approach, whenever a communicable disease is detected, regardless of its epidemiology, the patient has the added social responsibility of protecting the health of others. These two concepts - protecting one's health and the health of others - form the basis of the health education every person diagnosed with HIV receives in the eight week interactive course entitled Learning to Live with HIV (*Aprendiendo a Vivir con VIH*). Participants continue to receive 100% of their salary for the duration of the course. The course includes general information about HIV; how the disease progresses; safe-sex practices; self-care, self esteem and assertiveness training; ARV adherence; nutrition; and rights and responsibilities of those with HIV. Participants are also encouraged to share experiences and information with other people with HIV as part of Mutual Support Teams (EAM in Spanish). The purpose of Learning to Live with HIV is to help people understand and assimilate their HIV positive status so as to affect practices that positively impact their health and the health of others.

### **Experience: Mariela Mendoza, 21 Years Living with HIV**

*Mariela Mendoza, a nurse, married with children and resident of Havana's Comprehensive Care Center for People with HIV/AIDS, contracted the virus while volunteering in Ethiopia as part of Cuba's international health cooperation program. She is asymptomatic after 21 years of living with HIV. We spoke with Mariela at her home on the Center's grounds.*

**Question: Tell me a little bit of your story.**

**Mariela:** I was volunteering in Ethiopia as a nurse from 1986 through 1988. While we were over there we learned that HIV had been detected in Cuba. From that point on, all returning volunteers were tested for the virus, myself included. I was negative...I went back to work in a psychiatric hospital and continued my life until another volunteer opportunity came around, 8 months later. They detected the virus during the routine check up all volunteers do before going abroad.

**Question: That must have been a terrible shock.**

**Mariela:** It meant death. I associated it with death and felt every emotion: pain, sadness, desperation. It took me two years of psychiatric treatment before I could start over and get back to work. Working helps keep my mind off things and I feel useful. It's an important part of my treatment.

**Question: What do you do? What does a typical day here look like for you?**

**Mariela:** I'm an inter-hospital care nurse, meaning I accompany people with HIV to their specialist appointments, lab tests and such. Being a nurse helps a lot when you're living with this condition. Sometimes when I'm with a terminal patient, I see myself, my future. That's when I go from 'Mariela living-with-HIV' to 'Mariela the nurse': alleviating pain, being an affectionate caregiver. I've also seen discrimination in my work - that's when I launch into educator and advocate mode, informing people about HIV, the rights of people with HIV.

**Question: How has HIV in Cuba changed since you were first diagnosed?**

**Mariela:** It was so different before. Even the men cried when they found out they were positive and back then everyone was separated from their spouses, children, parents. It's been a long time since I've seen someone come here in tears. Prevention is totally different now too. I didn't know what a condom was before I got here and I'm a nurse! Treatment is better. Today people with HIV can live in their communities, where they have access to medical attention with doctors and dentists who know about HIV and how to treat patients in a caring, dignified way.

**Question: How has the sanatorium, now the Centro, changed since you first arrived?**

**Mariela:** When I got here it was still a secret, obligatory place. But I never felt isolated or imprisoned or humiliated. Even though we're far from our families, we're like a family here. Also, the concept of the sanatorium has changed - now it's like a recuperative center, where you go when something extraordinary happens, like a kidney infection or some horrible flu and you need specialist monitoring and treatment. Welfare cases are different - they'll live here if they have nowhere else to go.

**Question: That's not your situation. Why did you decide to stay?**

**Mariela:** My reason for being is protecting my health, closely followed by working with other people with HIV - it makes me feel human. That's why I stayed. Also, there are all kinds of germs out there. At least here I'm somewhat protected.

**Question: How can Cuba's HIV/AIDS program be improved?**

**Mariela:** More prevention, more training and information. Sometimes people in the health field are the least informed. It's also very important that we talk about men who have sex with men. We're moving towards this as a society and GPSIDA and others have done an amazing job along these lines.

**Question: What would you say to someone diagnosed today with HIV?**

**Mariela:** Take care of your health. Use a condom. AIDS has no face, age, sex or race. Try to live. Look at me, 21 years and I'm still alive and happy.

Upon completing the course, participants are evaluated by a multidisciplinary team of specialists according to detailed national and bioethics guidelines to assess whether they're committed to their health and the health of others (see Figure 2); elements of the evaluation include their psychological status and outlook; their employment, housing, and family situations; and their CD4 and viral load counts. A comprehensive interview whereby the person with HIV weighs in on the decision is also conducted. On the basis of these evaluations and interview, patients are either remitted to ambulatory care or not [Álvarez 2004].

### **Figure 2: Elements of Protecting One's Health & the Health of Others**

Requisites for the Ambulatory Care System include protecting individual health by:

- ❖ Following the recommended diet
- ❖ Following medical instructions (adhering to medication regimens, keeping doctors appointments, and completing follow-up exams)
- ❖ Maintaining good personal and environmental hygiene
- ❖ Not consuming alcoholic beverages habitually

And protecting the health of others by:

- ❖ Using a condom during sexual relations
- ❖ Maintaining a stable and single partner
- ❖ Letting your partner know, before engaging in sexual relations, of your seropositive status
- ❖ Any other requirement considered important by your family doctor

Source: Programa Nacional de Prevención y Control del VIH/SIDA. Ministerio de Salud Pública. 1997.

"Our objective is to prepare people with HIV for their new life and all the factors related to HIV prevention and their health, so that they can return to their communities and regular lives as soon as possible and as prepared as possible," says Dr Rigoberto López, Director of Havana's Comprehensive Care Center for People with HIV/AIDS. But it's not always easy, he admits. "We're not magicians; HIV is a multifaceted entity affecting the psyche and biology of a person, and also has social implications. For this reason we have to work step by step and concentrate on the most urgent problems" [Author interview 2008].

One continually pressing problem is resource scarcity. Compounding the customary challenges faced by developing economies the world over, Cuba was plunged into a severe economic crisis in the 1990's known as the Special Period from which it still has yet to fully

recover. Precipitated by the fall of the Socialist Bloc, Cuba abruptly lost 85% of its trade; reserves for medicines, equipment and supplies contracted by 70%; and daily caloric intake dropped by 33% [Reed and Frank 1997]. The decades-long trade and financial embargo the United States has imposed on Cuba compounded this downturn.

The embargo effectively prohibits Cuba from buying United States' technology, medication, and replacement parts, whether purchased directly or from a company in a third country, and proscribes scientific exchange between US and Cuban specialists. Responding to HIV and AIDS, due to the diagnostic technology, treatment protocols (with US companies and their subsidiaries holding many of the patents), and specialized knowledge required, has suffered particularly under this extraterritorial policy. Dr Jorge Pérez, Vice Director of IPK, the national reference center for attention to and treatment for opportunistic infections, recalls when "I went to go buy the first machine to measure CD4 and when I went to ask about it, they told me 'this machine is North American technology and we have explicit orders not to even explain to you how it works; you are Cubans and you have no right to this technology'" [Oxfam interview 2007]. As resistance to available antiretrovirals increases, these types of procurement obstacles could present difficulties to guaranteeing effective interventions for persons with AIDS in Cuba.

## **CHALLENGES MOVING FORWARD**

**Difficulties engendered by the US embargo and other economic realities will continue to present challenges to Cuba's HIV/AIDS program and the public health system as a whole.** While the political will to continue growing and improving the program remains firmly intact, identifying and stimulating efficiencies within the existing structure to improve care and make better use of scarce resources are key features moving forward. Decentralizing HIV/AIDS services, combined with a re-organization of Cuba's primary care system, is an ongoing process designed to achieve such efficiencies and a better standard of care. "Today we're not just challenged to provide universal care at all levels," says Dr Cristina Luna, National Director of Ambulatory Care, "but also better quality care, better organized and integrated services. People expect much more of us now" than in the 1960s when universal

care was introduced [Reed 2008]. Assuring accessibility to second-line antiretroviral regimens for those needing them is another pressing challenge in Cuba's effort to provide effective treatment and a better standard of care.

**Underreporting of HIV/AIDS remains a challenge** in the region [PAHO 2007] and Cuba is no exception. Despite active screenings, aggressive outreach, free and accessible testing, and contact tracing, some people remain beyond the reach of the country's medical and social framework. In a study conducted between 2003 and 2004, 63 people debuted as clinical AIDS patients, meaning they had not been tested or diagnosed for HIV until they presented with clinical manifestations of AIDS. This group represents 4.2% of all people with HIV/AIDS in Cuba [Oropesa et al. 2007]. Another study showed that inadequate knowledge of classification procedures among primary care doctors in one Havana neighborhood was a factor contributing to underreporting [Bolaños et al. 2006].

Along with underreporting, **Cuba's rising HIV incidence** is another troubling trend, made more so because it will be more complicated and costly to maintain universal ART coverage as more people contract HIV. Transactional sex and sexual activity among the young and elderly are factors contributing to Cuba's climbing infection rates. The last is particularly disquieting: Cubans between the age of 20 and 24 have the highest rate of infection per 100,000 inhabitants and rates among those 60 and over are also on the rise [Cortés et al. 2006]. Evidence of HIV in the elderly was borne out by the clinical AIDS debut study by Oropesa et al. which found that people over age 50 - mostly male - were 17 times more likely to present as clinical AIDS patients at the time of their HIV diagnosis.

Although civil, administrative, labor and other laws exist to protect people with HIV against **discrimination, the (often silent) stigma attached to HIV, continues to be a problem.** Some people with HIV have encountered difficulties upon returning to work, for instance [Rodríguez et al. 2005] or more frequently "by health system personnel...particularly in doctors' offices," including lapses in confidentiality. This leads some people with HIV to obfuscate their seropositive status in health care settings. There are indications that such discrimination was more pronounced in the early years of the epidemic, but is ebbing as HIV/AIDS-specific

education and training for health professionals take hold [Miñoso & Valdés 2006] and since ARVs have transformed AIDS into a chronic illness [Castro, Khawja, González-Núñez 2007]. Sensitivity and clinical training in the health sector should continue apace to further this progress. The community-based system, with everything from dispensing of dietary supplements to weekly visits from the family doctor occurring right in the neighborhood, has implications for the privacy of persons with HIV/AIDS and can be another source of discrimination.

The stigmatization of homosexuals, bisexuals, and transgendered people in Cuba is pervasive (including in health care settings), increasing the likelihood of discrimination - regardless of a person's serostatus. Ongoing education through the publication of informational materials, broadcasting of movies, and radio and television programs, and active participation by members of these communities are essential for converting sexual diversity into the norm in machista Cuba. With such high prevalence rates among MSM, this is one of the country's most urgent HIV prevention needs, despite society's resistance to openly talk about homosexuality. As Mariela Castro of CENESEX points out, "the freedom of sexual choice and gender identity (are) exercises in equality and social justice" - equality and social justice being two pillars of the Cuban revolutionary program [Rodríguez 2008]. A third pillar is the basic human right to live free from discrimination, an area in which Cuban society has made great strides with regards to women and racism, but not sexual orientation.

"...there is a deeply-rooted moral prejudice which is hard to change. It's so deeply rooted, parents tell you they would rather have a son who's a thief than a queer."

- Interviewee in Torres et al. 2006

**Defusing taboos to increase the effectiveness of prevention efforts** is an area in which education - both at home, in the schools and within society at large - must be at the forefront. Research conducted by Castro and Aragonés found that "the majority of women of different ages with AIDS received no type of information from their families about sexuality when they were children or adolescents, in large measure because it was considered inappropriate for family conversation" [Castro y Aragonés 2006]. Some parents are resistant to sexual

education in schools that includes discussion of sexual diversity or condom use; television programs and public service announcements on these topics have also been criticized by certain sectors of civil society. Mariela Castro thinks more, not less, education is the solution: "We have to work more and better in the schools. We've worked with the Ministry of Education, but I'm still not satisfied that we've made enough progress. We need to deepen understanding among teachers and other school staff. We need to carry more on educational TV and so on" [Reed 2006].

**Individual behavior is another issue which continues to frustrate HIV/AIDS initiatives globally and in Cuba.** Risky sexual behavior including having multiple sexual partners and having sex without a condom are two important factors in the Cuban context. Earlier sexual debut, especially among girls, is another troubling trend [Gómez & Fariñas 2006]. Nonadherence to antiretroviral protocols due to unpleasant side effects, interaction with other medications, the number of pills to take and when, dietary restrictions, adverse effects during pregnancy, a non-supportive home or work environment, or the desire to take a medication vacation exemplifies how individual behavior can hamstring treatment efforts [Spire et al. 2002]. More training for health professionals, people with AIDS, their families, and others, about ARV adherence can help in this area.

## **IS THE CUBAN MODEL REPLICABLE?**

Every country has its unique history, culture and conditions and while Cuba's HIV/AIDS strategy cannot be lifted wholesale into another context, the experience offers valuable lessons - especially for other resource scarce settings where the greatest burden of the disease is felt: of the 60 million people with HIV, 95% are in low-income countries [Global Fund 2008]. In practice, this crisis is multiplied due to crumbling health systems marked by an absence of epidemiological surveillance, reliable health statistics, medical personnel, and even basic infrastructure. Cuba's experience has shown that sharing the burden between international aid agencies, non-governmental organizations, civil society, and above all the stakeholders themselves, people with HIV/AIDS, to forge more creative, better funded and closer integrated solutions, can positively affect outcomes. Some of the most important components of these solutions which are relevant for other settings include:



**Provide community-based primary care.** This has relevance for public health systems from Alaska to Zimbabwe since it emphasizes health promotion and disease prevention in order to improve health status over time. Furthermore, a strong primary care system bolsters statistic gathering systems fundamental for epidemiological control and to combat underreporting of HIV. To be effective, comprehensive, community-based care requires understanding health not just as the absence of disease, but as a series of related bio-psycho-social factors that promote and sustain well being *and* health. While extraordinarily cost effective when amortized, this approach requires governmental commitment to equalizing and improving social determinants (equitable access to education, housing, potable water, etc) and the necessary human resources for health to provide the services required. Training health promoters from the local community in prevention and health and hygiene is an economical first step in this direction.

#### **Rights for People with HIV/AIDS**

- ❖ The right to nondiscrimination on the basis of HIV status
- ❖ The right to treatment as part of essential health care
- ❖ The right of people with HIV and AIDS to participate in the development of AIDS policies and programs

Source: Human Rights and HIV/AIDS: Now More Than Ever. Open Society Institute. 2007.

**Active participation by stakeholders and vulnerable groups in policy design and implementation.** This is fundamental to controlling HIV/AIDS in any context. Prevention efforts especially, have been shown to be more effective when developed and implemented by members of the community they're intended to reach, known as peer education. This is essential in places where injection drug use, transactional sex, and homophobia are contributing to the spread of the disease, particularly Latin America and the Caribbean. Women are especially vulnerable to HIV, with incidence on the rise globally: according to UNAIDS, 48% of people with HIV are women with an average of 1 million new infections annually [UNAIDS 2007]. Women, too, should be active participants in the design and implementation of prevention programs and messages. Incorporating a gender focus in these initiatives needs to be standard practice.

**Table 1: Regional HIV/AIDS Comparison**

Country	Adult HIV prevalence rate (per 100,000)	AIDS mortality rate, 2005 (per 100,000)	Antiretroviral therapy coverage (%)	Contraceptive prevalence (%)
Argentina	456	11	71	65
Bahamas	2,807	<200	---	---
Barbados	1,236	<200	67	---
Bolivia	120	<10	18	58
Brazil	454	8	78	---
Canada	222	<10	---	---
Colombia	509	18	34	78
Costa Rica	235	<10	>95	---
<b>Cuba</b>	<b>52</b>	<b>&lt;10</b>	<b>&gt;95</b>	<b>73</b>
Dominican Republic	1,036	75	24	70
El Salvador	770	36	46	67
Guatemala	825	21	31	43
Haiti	3,377	188	26	32
Honduras	1,392	51	41	65
Jamaica	1,371	49	33	69
Mexico	244	6	54	71
Nicaragua	215	<10	26	69
Paraguay	338	<10	25	73
Peru	480	20	42	71
Trinidad & Tobago	2,538	146	53	38
United States	508	5	---	73
Uruguay	362	<50	55	77
Venezuela	598	23	---	---

Source: WHO. World Health Statistics. 2008. Ginebra. 2008.

**Limit the amount of conditional aid.** Financial aid for HIV prevention and treatment with no or few strings attached is optimal since it allows programs to be tailored to local culture, conditions and needs. Needle exchange programs, condom distribution, safe sex education for men who have sex with men and other initiatives should be free from religious or moralistic approaches to controlling infectious disease. Cooperation with international and private sector organizations providing unconditional aid should be favored over bilateral government agreements and charitable causes which place restrictions on how to fashion a national response to HIV/AIDS.

**Provide universal antiretroviral treatment for those requiring it.** Evidence-based findings show access to antiretroviral treatment is the best way to limit AIDS mortality. Increased access to antiretrovirals cut in half the percentage of AIDS-related deaths in the Bahamas between 1996 and 2005 (from 18% to 9% and that was with only 61% of patients requiring therapy receiving it); in Trinidad & Tobago deaths attributable to AIDS dropped by 53% between 2002 and 2006 after antiretroviral treatment was introduced; and in Barbados, AIDS-related deaths dropped by 85% between 2002 and 2006 after free treatment was begun [UNAIDS 2008].

Although 3 million people in the developing world needing antiretroviral treatment received it in 2007, (a 42% increase over the previous year), there are still millions of people with AIDS around the world who are not receiving these life-prolonging medicines [Lynch 2008]. At the current rate, the 'All by 2010' goal - a target established in 2005 by UN signatories to work towards providing universal ARV access to the 10-16 million people needing it by 2010 - will fall short by at least 50% [Avert 2008]. This abandonment of people in desperate need of life-stabilizing and prolonging medicines is unconscionable, especially since ARVs, including some second-line treatments, are currently available at the lowest prices in the pandemic's history due to the production of generic equivalents. Nevertheless, onerous barriers to ARV access remain and people continue to die. Lack of political will, multi-national pharmaceutical companies that place profit margin over health, and patent and intellectual property rights' protection for medicines forced on developing countries by the US and others through the WTO Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS), all share responsibility. The fact is, when governments prioritize access to these medicines (eg Cuba, Brazil), AIDS-attributable mortality drops [Pérez et al. 2004, Marins 2003].

Yet, ARVs alone will not solve the problem since many developing countries - especially in sub-Saharan Africa, where 76% of all deaths due to AIDS occurred in 2007 [UNAIDS 2007] - don't even have the health infrastructure to correctly administer the medications should they be made available. Indeed, most of the 6,800 persons who become infected and over 5,700 who die every day from HIV and AIDS is due to inadequate access to HIV prevention and treatment services [UNAIDS 2007]. National responses to the pandemic must include not only universal

access to ARVs, but also universal, equitable access to health services to ensure the proper dosage, follow-up, and care required.

**Design and implement a comprehensive education and prevention strategy.**

Misinformation, sexual taboos, gender inequalities, discrimination, and stigmatization can only be overcome by an ongoing, multidisciplinary educational process. Creating a volunteer movement to work on education and prevention initiatives is cost effective and helps stakeholders take ownership of the issue. Sensitivity training for health professionals, as well as continuing education about scientific, epidemiologic, treatment, and other advances in HIV/AIDS research, are essential for addressing discrimination within health systems. Education should also extend to helping people with HIV/AIDS to learn their rights, while empowering them to exercise those rights.

**Prevent mother-to-child and blood product transmission of HIV.** Active screening of all pregnant women and blood donors and products is a relatively low cost, highly effective early detection mechanism. They are also among the most politically palatable public health measures that can be enacted to control HIV infection. Coupling detection with antiretroviral treatment, safe birthing practices, and breast milk substitutes where practical has shown to be highly effective in limiting mother-to-child transmission in Cuba and elsewhere.

**Protect the rights of people with HIV/AIDS.** The right to work and housing, to live a dignified life free from discrimination and violence, to access medicine and care that can save or improve quality of life, and to participate in decisions and policies are basic rights, including for people with HIV or AIDS, that should be top priorities of governments everywhere.

## CONCLUSIONS

There are no cookie cutter solutions or easy answers to the global HIV/AIDS crisis. Nevertheless, the Cuban experience has shown that a rights-based approach addressing the epidemiologic, biological, social, and psychological underpinnings of the pandemic serves to improve health outcomes, as well as provide a more dignified life for people with HIV/AIDS. Equitable access to care, multi-disciplinary and inter-sectorial problem solving, an aggressive education and prevention program, and pro-active participation by stakeholders and vulnerable groups in decision making are key to the strategy. This is most effective when local conditions including most common infection routes and increased disease burden due to epidemiological factors including location, sexual orientation or gender, inform HIV/AIDS control and treatment programs.

Making antiretroviral medicines available to those needing them has proven to be the most effective way to decrease AIDS-attributable morbidity, increase the quality of life for people with HIV/AIDS, and control mother-to-child transmission. Furthermore, wider availability of cheaper generic antiretrovirals is lowering access barriers to these treatments globally and negates the amoral cost effective argument against providing them. Equitable access to these life saving medicines should be a right for everyone needing them, rather than a privilege for those who can afford them.

Though Cuba has shown a slow, but steady rise in HIV incidence and challenges such as homophobia, machismo, destructive individual behavior, and economic scarcity remain, the government's commitment to an integrated and comprehensive HIV/AIDS program is laudable. Protecting the program's budget, addressing difficult, polemic issues like homosexuality and discrimination in Cuban society, involving people with HIV/AIDS in decisions affecting their lives, enforcing protective legislation, and enabling inter-sectorial cooperation, shows the government's political will to tackling HIV/AIDS in Cuba.

More importantly, Cubans living with HIV/AIDS on the island embody the spirit, fortitude and intelligence required to confront this global health crisis. From them, and their colleagues everywhere, the world has the most to learn.

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