



1237 Ralph David Abernathy Blvd. SW  
Atlanta, Georgia 30310-1731  
Tel: 404.756.2680  
Fax: 404.756.2684  
Email: [info@SisterSong.net](mailto:info@SisterSong.net)  
Website: [www.SisterSong.net](http://www.SisterSong.net)

## **LAS OLVIDADAS/THE FORGOTTEN ONES: Latinas and the HIV/AIDS Epidemic**

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While Latinos account for 14% of the U.S. population, they account for 20% of new AIDS cases and 18% of the cumulative AIDS cases in the United States. HIV/AIDS has had a devastating impact on Latino communities and is responsible for the death of more than 92,000 Latinos in the United States through 2003. The Centers for Disease Control estimates that more than 80,000 Latinos are currently infected with AIDS, signaling that the HIV/AIDS epidemic will continue to devastate Latino families and communities well into the future.<sup>1</sup>

Latinas have been especially hard hit. The rate of infection among Latinas as a proportion of all Latino AIDS cases has climbed from 15% in 1990 to 23% in 2002.<sup>2</sup> This change represents a 53% increase in the number of Latinas with AIDS since 1990. Latinas now account for 21% of all AIDS deaths among women,<sup>3</sup> with AIDS becoming one of the leading causes of death for Latinas between the ages of 25-44.<sup>4</sup>

Despite these facts, Latinas remain virtually ignored by health policy makers and are one of the most underserved HIV-affected populations. For instance, in New York, the epicenter of the HIV/AIDS crisis, there are only a handful of Latina-centered HIV programs to meet the needs of thousands of Latinas who are HIV positive or at risk of HIV.<sup>5</sup>

Not surprisingly, HIV/AIDS continues to disproportionately impact Latinas, their families and communities. Latinas are more likely to be unaware of their positive HIV status, to learn of their HIV diagnosis at later stages of disease progression, and face numerous obstacles in accessing health care services. They are also more likely to experience considerable discrimination and patient-provider communication barriers that affect the quality of care they receive.

Latinas are most certainly "*Las Olvidadas*" — *the Forgotten Ones*. The price of such neglect has been the unacceptable loss of many Latina lives that have left Latino families and communities fractured and vulnerable. This report is a Call to Action! The report and action agenda provides an analysis of key

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<sup>1</sup> Centers for Disease Control and Prevention (CDC), "Combating HIV/AIDS: Protecting the Health of Latino Communities," CDC Website 2000, 1 Oct. 2004 <<http://www.cdc.gov/hiv/pubs/brochure/latino-report.pdf>>.

<sup>2</sup> Sonia Ruiz, Jennifer Kates and Claire Oseran, *HIV/AIDS Policy Fact Sheet: Latinas and HIV/AIDS* (Washington, DC: KFF, 2003) Publication No. 6007.

<sup>3</sup> Cynthia Guaba, "Latinas, The New Face of AIDS: Su Salud, The First Part of a Two Part Series," *The Dominican Times* Mar./Apr.2004, 20-1.

<sup>4</sup> Guaba 20.

<sup>5</sup> Guaba 20.

factors fueling the HIV/AIDS epidemic among Latinas and offers policy recommendations and action strategies to address Latinas' priority needs. The analysis and recommendations provided are framed from a social justice perspective that takes into account the intersection of race, ethnicity, class, gender and immigration status, among other factors. The report concentrates on the experiences of Latinas in New York, the state with the highest AIDS case rate and the largest concentration of Latinos living with AIDS. However, similar trends are occurring across the country and the action agenda is designed so that it can be easily adapted to the needs and circumstances of other states, as well as national advocacy efforts.

### **Creating an Engine for Latina Activism and Leadership**

The Latina HIV/AIDS crisis will only worsen without aggressive action from key legislators, public health officials and institutions, the media and community-based organizations. Latina advocates must be front and center in articulating Latina-centered strategies and solutions and successfully advocating for their adoption. Towards this aim, the following steps must be undertaken:

**1. Building Capacity:** The Need for a Latina HIV/AIDS Advocacy Coalition Efforts to address the HIV/AIDS crisis among Latinas will require that we galvanize our best thinkers, community leaders, health care providers and strategists under a single, unified and powerful advocacy umbrella consisting of a Latina HIV/AIDS Advocacy Coalition. By bringing together health experts, health providers, researchers, advocates, civic leaders, consumers and health policy makers, the Latina HIV/AIDS Advocacy Coalition can garner the necessary expertise and strategic insight necessary to articulate cutting edge strategies and solutions to address the rising tide of HIV/AIDS among Latinas. An investment in the development of a permanent infrastructure will enable the Latina HIV/AIDS Advocacy Coalition to regularly pool the advocacy resources of its organizational partners, establish early credibility and enhance its negotiating position and leveraging power in support of its goal.

### **2. Development of a Latina AIDS Agenda and Advocacy Campaign**

One of the coalition's initial steps must be to build broad-based consensus concerning the top priorities for strategic action that will most effectively address the prevention barriers and health access problems faced by Latinas. Towards that aim, sponsorship of a Latina AIDS Summit (the "Summit") to develop agreement on priority needs and strategies would generate a shared vision and advance coordinated action. The Summit would serve to galvanize and facilitate dialogue among diverse sectors of the Latino community in order to work cooperatively to establish an agenda for action and map out a Latina AIDS Advocacy Campaign with measurable goals and objectives to achieve strategic impact.

### **3. Investing in Public Education and Strategic Communications**

For the most part, Latino/as and non-Latinos alike remain unaware of the serious HIV prevention barriers and health access problems affecting Latinas. As a result, Latinas public health needs are frequently and more readily overlooked by public officials. A wide-scale public education and strategic media campaign must be developed that educates the general public about the HIV prevention and health care needs of Latinas. The campaign would also serve as a strategic vehicle by which to hold elected officials accountable for adopting sound public health policies and promoting increased HIV/AIDS funding and services for Latinos. Since many laudable advocacy campaigns have been lost not on their merits but based on public perceptions, it is imperative that the Latina HIV/AIDS Advocacy Coalition develop the capacity to continually assess and influence public opinion. Conducting periodic assessments is an important step in developing a program of communication and action that promotes the public's understanding of the issues and generates appropriate levels of support.

### **4. Promoting Grassroots Organizing and Leadership Development**

Most importantly, the Latina HIV/AIDS Advocacy Coalition must also be able to build a vocal, sophisticated and diverse constituency base with the capacity to mobilize quickly and efficiently and to continually inform policy positions through regular dialogue and active participation in a wide range of advocacy activities. This effort could entail focusing on developing Latina leadership through the

development of local community advocacy networks, peer leadership programs, sponsorship of community meetings and HIV/AIDS advocacy “teach-ins”, as well as providing technical assistance to local groups engaged in AIDS policy and advocacy activities.

In summary, the Hispanic Federation and the LUCES coalition believe it is crucial that Latino communities across the nation take bold, proactive steps to demand that increased health funding and services be directed to Latinas. The strategies described above represent a first step in this effort. We hope the report will serve as one of several vehicles by which to generate discussion and strategic action to address the HIV prevention and service needs of Latinas in our communities. The Hispanic Federation published this report. In order to read the entire report, please visit [www.hispanicfederation.org](http://www.hispanicfederation.org).