The HIV/AIDS Epidemic in Puerto Rico

National Commission on AIDS
WASHINGTON, DC • UNITED STATES OF AMERICA

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The National Commission on Acquired Immune Deficiency Syndrome (AIDS) was established by Public Law 100-607 "for the purpose of promoting the development of a national consensus on policy concerning AIDS and of studying and making recommendations for a consistent national policy" concerning the HIV epidemic. The Commission is a bipartisan body whose members were appointed by the President, the United States Senate, and the United States House of Representatives.

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PREFACE

Members of the National Commission on AIDS visited Puerto Rico on November 27 and 28, 1990, as part of the Commission's overall and continuing strategy of meeting with communities throughout the United States to hear firsthand from persons affected by the epidemic of human immunodeficiency virus (HIV) infection. The visit to Puerto Rico also contributed to the Commission's ongoing efforts to build consensus for a national policy concerning the HIV epidemic by focusing attention on complex policy issues and identifying gaps in care and service delivery.

This report is a result of the Commission's understanding that, from a federal policy perspective, the special status of the Commonwealth of Puerto Rico presents particular challenges. While its residents are U.S. citizens, Puerto Rico is not a state, and because of the nature of "commonwealth status," its residents are not included in many federal initiatives. This report contains the Commission's short- and medium-term recommendations on actions the U.S. government should take to effectively include the people of Puerto Rico in the national response to the HIV epidemic.

This document does not fully address the entire range of issues related to HIV disease in Puerto Rico. As a national advisory body, the Commission seeks to highlight key issues for consideration by the President and Congress in the formulation of HIV/AIDS policy. The state of the epidemic in Puerto Rico is described in this report; however, the many issues that are the exclusive domain of local government, although presented to the Commission during the visit, are not the subject of specific recommendations. Rather, this report addresses how the federal government can work in partnership with the Commonwealth of Puerto Rico to strengthen the response to the epidemic.

Since the Commission's visit to Puerto Rico in November 1990, new programs and significant organizational changes have been put in place to respond to the epidemic. Where information is available, changes have been noted. While these are important steps, the Commission feels that the underlying challenges raised in this report warrant continued and diligent attention and present opportunities for collaboration to create the best response to the epidemic.

David E. Rogers, M.D.
Vice Chairman

June E. Osborn, M.D.
Chairman

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The National Commission on AIDS would like to thank the people of Puerto Rico for their warm reception of the Commission on its visit to the island, particularly the many individuals who willingly spoke to us about the profound suffering they have experienced as a result of the HIV epidemic.

The Commission would like to thank all the witnesses who testified during the two days of hearings and all the individuals who were instrumental in coordinating each of the 14 site visits the Commission conducted in San Juan and throughout the island.

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The Commission would also like to acknowledge the following individuals: Dr. Ineke Cunningham, Professor, University of Puerto Rico; Dr. Johnny Rullan, Executive Director, Central Office of AIDS Affairs and Communicable Diseases; Dr. Teresa Diaz, Epidemiologist, Centers for Disease Control; Donald Babb, President, *Fundacion SIDA de Puerto Rico*; Dr. Sam Matheny, Professor of Clinical Family Medicine, University of Southern California; Dr. Jaime Rivera-Dueno, Executive Director, *Instituto del SIDA de San Juan*; Dr. Carmen Feliciano, Director of Ambulatory Services, *Instituto del SIDA de San Juan*; Nora Vargas, Attorney, Sabana AIDS Litigation Project; Joe Kennedy, Acting Regional Director, Region II Civil Rights Office for the Department of Health and Human Services, New York, New York; William Peyot, Legal Advisor, Office of the Disability Ombudsman for the Commonwealth of Puerto Rico; Dr. Pedro Borras, Director, Department of Health, city of San Juan; Nadia Gardana, Director of Special Projects, Office of AIDS Affairs and Communicable Diseases; Pedro Maldonado, Special Assistant on Health Issues, Office of the Honorable Mabel Velez de Acevedo, President of the Committee on Health and Public Welfare, Puerto Rico House of Representatives; Professor Daisy Gely, Principal Investigator, Puerto Rico AIDS Education and Training Center, Medical Science Campus; Hector Colon, Director, Research Institute, Commonwealth of Puerto Rico Department of Anti-Addiction Services; Tamara Cruz, Director, Development and Human Resources, United Way of Puerto Rico; Zenaida Fernandez, Executive Director, Association of Community Health Centers; Father Francisco Garcia, Director, Providencia Shelter; Sister Maria Teresa Jensen and Luis Maldonado, Ponce, Puerto Rico; and Dr. Jose Toro, Executive Director, *Fundacion SIDA de Puerto Rico*.

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The HIV/AIDS Epidemic in Puerto Rico

The relationship between the United States and the Spanish-Caribbean island of Puerto Rico dates from 1898, when, at the conclusion of the Spanish-American War, Spain ceded the island to the United States. Although Puerto Rico itself is not a state, its island-born residents have been citizens since 1917. Political, economic, and social ties inextricably link the welfare of Puerto Ricans to the island's relationship with the United States. Despite the profound impact of the HIV/AIDS epidemic in Puerto Rico and the repercussions for Puerto Rican communities on the mainland, this nation's response to the HIV epidemic has not yet adequately taken into account the unique problems arising from the commonwealth status of Puerto Rico.

The Commission recommends:

1. **That the issues confronted by the people of the Commonwealth of Puerto Rico be fully taken into consideration when establishing national policy and programs related to HIV infection and AIDS.**
2. **That the federal government and the Commonwealth of Puerto Rico urgently explore innovative approaches to partnerships, so that appropriate programs to respond to the HIV epidemic can be put in place with and for Puerto Ricans.**

In just a decade, AIDS has become the leading cause of death in Puerto Rico for men between the ages of 25 and 44 years and for women between the ages of 25 and 34 years (Puerto Rico Department of Health, 1989). In this island population community of 3.5 million people, four people are diagnosed with AIDS and three others die of AIDS-related complications every day (Rullan, 1990). In 1992, in San Juan, the capital of Puerto Rico, nearly one in every 20 adults between the ages of 25 and 44 seen at the San Juan Municipal Hospital for non-AIDS-related illnesses have been found to be HIV-infected (J. Rivera-Dueno, Instituto de SIDA de San Juan, San Juan, Puerto Rico, personal communication, February 1992).

The response to the HIV epidemic in Puerto Rico would be best understood within the overall context of the island's health status and health programs; however, the health status of the island's inhabitants and their access to health services are not adequately documented. The Hispanic Health and Nutrition Examination Survey (HHNES), which assessed the health and nutritional status of the Hispanic communities in the United States, did not include any samples of Commonwealth residents (GAO, 1992). In addition, the National Health and Nutrition Examination Survey (NHANES), the National Medical Expenditure Survey (NMES), and the National Health Interview Survey (NHIS) have never surveyed residents of Puerto Rico. Similarly, there is no reliable information on access to services.

The Commission recommends:

3. **That Congress authorize the U.S. Department of Health and Human Services to conduct, in collaboration with the Commonwealth of Puerto Rico, a comprehensive study of the overall health status and services of people living in Puerto Rico. This study should also**

review the organization and delivery of health care in Puerto Rico and assess the federal role in assisting the people of Puerto Rico in addressing their most pressing health issues, particularly HIV disease. Consideration should also be given to including Puerto Rico in health surveys that cover the rest of the United States, such as NHANES, NMES, and NHIS, in such a manner that data on island residents can also be analyzed independently.

Puerto Rico is linked with the continental United States not only politically, economically, and socially, but also through extensive migration between Puerto Rico and Puerto Rican communities on the U.S. mainland. This migration occurs mainly for employment, educational, and family reasons. Moreover, a new migration pattern seems to be evolving as a result of the HIV epidemic: some people with AIDS travel to seek health care on the mainland, and others return to Puerto Rico in search of the kind of compassion they can only find among their loved ones (Lambert, 1990). There is an urgent need for coordination of HIV prevention and health care services between these communities to ensure continuity of care and appropriate patient and family follow-up and referrals. The tremendous challenge of AIDS in Puerto Rico can never be successfully dealt with unless corresponding attention is given to Puerto Rican populations on the mainland and the implications of this ongoing migration are fully and clearly understood (Diaz, 1990).

The Commission recommends:

4. **That efforts be made at all levels of government and the private sector to identify and address the impact of the HIV epidemic on the Puerto Rican communities in the United States. Pilot projects, including case management coordination, linking HIV efforts on the U.S. mainland with those in Puerto Rico, should be developed where migration patterns warrant.**

At present the cap on Medicaid funds allocated to Puerto Rico impedes equitable access of persons with HIV disease in Puerto Rico to services that this program covers–for adults ***and*** children–on the mainland. No new funds were requested in the President's budget proposal for fiscal year 1993.

The Commission again recommends:

5. **That Congress and the Administration work together to raise the Medicaid cap on funds directed to the Commonwealth of Puerto Rico to ensure equal and adequate access to care and treatment.**

Over the last decade, Puerto Rico has not generally fared well in competition for federal assistance for HIV-related services. Although Puerto Rico ranks ahead of 45 states in numbers of AIDS cases, it ranks 20th in funding for AIDS-related programs per capita and ranks 55th among the 57 states and territories in the total funding per reported case (National AIDS Program Office, 1990). Technical, linguistic, and cultural differences contribute to the difficulties in competing effectively for funds and services.

The Commission recommends:

6. **That the U.S. Department of Health and Human Services, in collaboration with the government of the Commonwealth of Puerto Rico, seek ways to strengthen the technical, administrative, and coordinating capabilities of the Puerto Rico Department of Health.**

Similar support should also be provided directly to other health, social service and housing agencies, and community-based organizations in Puerto Rico. Technical assistance provided in these areas should be on-site and ongoing.

Clinical research is needed in Puerto Rico to ensure that local care providers can be alerted to the manifestations of HIV disease that are likely to occur in the island's population. The Commission also believes that access to experimental treatments is an essential component of health care services for all people with HIV disease. Persons living with HIV disease in Puerto Rico have fewer treatment options than are generally available to those on the U.S. mainland, because there are few clinical trials on the island and significant barriers to expanded access programs.

The Commission recommends:

7. **That approaches to expanding clinical research, as well as increasing access to experimental therapies (via clinical trials or expanded access programs) be explored by all involved in the HIV epidemic in Puerto Rico, including the federal, commonwealth, and municipal governments, as well as the private sector.**

The Commission was profoundly disturbed by the testimony at its hearings in Puerto Rico describing the stigmatization and discrimination faced by HIV-infected individuals seeking housing, employment, and health care (Vargas, 1990). Puerto Rico has been slow to develop an advocacy infrastructure adept at handling issues concerning civil rights, but there is growing awareness of discrimination problems and the protections provided by such laws as the Americans with Disabilities Act.

The Commission recommends:

8. **That special efforts be undertaken in Puerto Rico to educate the community and advocates for persons infected with HIV about the provisions of and rationale for anti-discrimination laws, such as the Americans with Disabilities Act, and to build adequate mechanisms to facilitate the enforcement of these laws. These efforts should be undertaken jointly by the federal government and the government of the Commonwealth of Puerto Rico. The Commonwealth government may wish to consider the possibility of establishing an HIV/AIDS anti-discrimination office similar to those found in cities such as Los Angeles and San Francisco.**

Few communities in the United States, with the exception of cities such as New York, Newark, and Jersey City, have been as hard hit as Puerto Rico by the twin epidemics of substance use and HIV infection (CDC, 1992a). Seventy-four percent of the total number of AIDS cases reported in Puerto Rico are directly linked to injection drug use (Puerto Rico Department of Health, 1992a). Resources are urgently needed to expand effective drug treatment programs. It is also imperative that federal assistance given to Puerto Rico to fight the drug epidemic include strategies to fight the twin epidemics of HIV and substance use. Therefore, aggressive outreach efforts should be established to educate all those who are unable to stop using drugs about bleach and clean needle/syringe programs to prevent HIV transmission.

The Commission recommends:

9. **That the Department of Anti-Addiction Services, the Puerto Rico Department of Health, nongovernmental organizations, and the federal government work together to create a strong, coordinated response to the twin epidemics of substance use and HIV. This response should include the expansion of treatment programs and establishment of bleach and clean needle/syringe programs.**

The existing high levels of HIV infection in Puerto Rico and the fact that many individuals appear not to have adopted measures that would reduce their risk of infection suggest that not only should existing prevention programs be continued, but additional efforts should be instituted as a matter of urgency. These are warranted because of the unique situation prevailing in Puerto Rico, the magnitude of the epidemic, and the situation with regard to stigmatization and discrimination.

The Commission recommends:

10. **That the Public Health Service, the Commonwealth of Puerto Rico, and community-based organizations continue, coordinate, and intensify existing prevention efforts. Additionally, these entities should develop ways to establish and expand prevention initiatives specifically targeted at adolescents; incarcerated populations; men who have sex with men; substance users; and women.**

CHAPTER I

Puerto Rico and Its Links to Puerto Rican Communities on the U.S. Mainland

A Caribbean island 110 miles long and 35 miles wide, Puerto Rico has a population of about 3.5 million. Located 1,032 miles southeast of the tip of Florida, Puerto Rico's relationship with the United States dates from 1898 when, at the end of the Spanish-American War, Spain ceded Puerto Rico to the United States. In 1917, Puerto Ricans became citizens of the United States, a status that facilitated the movement of people between the island and the U.S. mainland and obliged the men to serve in the U.S. armed forces, yet did not grant the right to vote in presidential elections or the right to full congressional representation.

Commonwealth–Federal Relations

In 1952, the island became a commonwealth when its constitution received approval by both the United States Congress and the people of Puerto Rico. As a result of Puerto Rico's new commonwealth status, the federal government ended its involvement in all local matters, granting full local executive, legislative, and judicial authority to the government of Puerto Rico.

Because U.S. citizens in Puerto Rico do not have the right to vote in Presidential elections or full congressional representation, they are not subject to federal income tax. Although Puerto Rico is not a state, political, economic, and social ties inextricably link the welfare of Puerto Ricans to the island's relationship with the United States.

The legal nature of *Estado Libre Asociado* or "The Free Associated State," as the Commonwealth was named, created a complex relationship with the federal government. For some purposes the federal government treats Puerto Rico like a state, for others it does not (GAO, 1990). These inconsistencies create serious problems in Puerto Rico's attempts to gain assistance in its health efforts. For example, international agencies such as the World Health Organization (WHO) and the Pan American Health Organization (PAHO) are reluctant to target specific programs for Puerto Rico because it is part of the United States. Yet Puerto Rico may not be receiving needed services from the United States. For example, states are automatically considered in all federal policies or programs such as data gathering and allocation of resources, but Puerto Rico is not.

Health and Social Service Programs

The HIV/AIDS epidemic is increasing the effects of the disparities in federal policies toward the residents of Puerto Rico. Medicaid, the combined federal–state program that finances 40% of care for people with HIV disease in the continental United States, serves to illustrate the inequities that exist. Current federal laws cap the total Medicaid funding allocated to Puerto Rico for health care services at $79 million, thus severely limiting island residents' participation in the largest health care financing

program in the country. In addition, Assistance to Families with Dependent Children (AFDC), which provides medical assistance and social benefits to indigent families, including those affected by HIV disease, is capped in Puerto Rico at $83 million (GAO, 1990). Supplemental Security Income, which provides welfare assistance and assures access to Medicaid for indigent individuals, does not benefit residents of Puerto Rico.

Policy Considerations

Because of the present relationship with the United States, the concerns of Puerto Rico are often overlooked unless special efforts are made to evaluate the island's needs and the effects of its relationship with the federal government. At the local level this has created a sense of frustration. As one witness before the Commission stated:

> It is unfair to Puerto Ricans, as U.S. citizens, to have one of the highest rates of AIDS cases and not have the fiscal resources to deal with the epidemic as other states and cities on the mainland (Feliciano, 1990).

There are no simple solutions to the issues surrounding the relationship between Puerto Rico and the federal government. There are proponents on the island and the mainland of all forms of relationships. These range from continued, but enhanced, commonwealth status to statehood or independence, with the majority of Puerto Rico's residents favoring continued ties with the United States under commonwealth status or statehood (Congressional Research Service, 1990). Extensive congressional hearings about the status of Puerto Rico over the last two years and failed attempts to hold a plebiscite on this matter show that the people of Puerto Rico are still extremely divided on this issue. Consequently, a change of status is unlikely to take place in the near future. It is clear, however, that the people of Puerto Rico cannot wait for a resolution of the issue of status for the establishment of an overall and comprehensive response to the HIV epidemic in Puerto Rico.

The Commission recommends:

1. **That the issues confronted by the people of the Commonwealth of Puerto Rico be fully taken into consideration when establishing national policy and programs related to HIV infection and AIDS.**
2. **That the federal government and the Commonwealth of Puerto Rico urgently explore innovative approaches to partnerships, so that appropriate programs to respond to the HIV epidemic can be put in place with and for Puerto Ricans.**

The Commission believes that responses to the HIV epidemic are best understood in the context of the health systems in which they occur. Such an approach is equally appropriate when examining the responses to HIV/AIDS in Puerto Rico. However, the federal government currently lacks data on the health status of the people of Puerto Rico and the health services they receive. The Hispanic Health and Nutrition Examination Survey (HHNES), which assessed the health and nutritional status of Hispanic communities in the United States, did not include any sample of Commonwealth residents (GAO, 1992). In addition, the National Health and Nutrition Examination Survey (NHANES), the National Medical Expenditure Survey (NMES), and the National Health Interview Survey (NHIS) have never surveyed residents of Puerto Rico.

The Commission recommends:

3. **That Congress authorize the U.S. Department of Health and Human Services to conduct, in collaboration with the Commonwealth of Puerto Rico, a comprehensive study of the overall health status and services of people living in Puerto Rico. This study should also review the organization and delivery of health care in Puerto Rico and assess the federal role in assisting the people of Puerto Rico in addressing their most pressing health issues, particularly HIV disease. Consideration should also be given to including Puerto Rico in health surveys that cover the rest of the United States, such as NHANES, NMES, and NHIS, in such a manner that data on island residents can also be analyzed independently.**

Migration and Links Between Puerto Rican Communities

Puerto Rico is linked to the United States not only politically and economically, but also socially and culturally. Puerto Rico's shift from an agricultural to an industrial economy in the 1950s and 1960s brought about an increase in migration–from the island to the continental United States and, within Puerto Rico, from the countryside to the cities. About 700,000 residents of Puerto Rico migrated to the United States from 1947 to 1972. Net out-migration from Puerto Rico to the mainland from 1980 to 1988 is estimated at 280,000, and these migration patterns continue (GAO, 1990). As of 1990, approximately 2.7 million Puerto Ricans resided in the continental United States (National Puerto Rican Coalition, 1991). Migration between Puerto Rico and Puerto Rican communities on the U.S. mainland occurs for employment, educational, and family reasons. The active two-way movement of thousands of individuals each year between Puerto Rico and the United States–across the "air bridge"–has also tragically become a link between the HIV epidemic on the island and the HIV epidemic in mainland communities.

AIDS surveillance data collected by the Centers for Disease Control (CDC) does not distinguish between Hispanic subgroups. However, a study comparing the number of AIDS cases in non-mainland-born Hispanic subgroups found that Hispanics born in Puerto Rico have the highest number of AIDS cases of all Hispanic subgroups in the continental United States (Selik, Castro, and Pappaioanou, 1989). The study also found that the largest numbers of AIDS cases among Hispanics on the U.S. mainland were found in the Northeast, roughly matching the residence pattern of Puerto Ricans. As in Puerto Rico, a majority of Hispanics with AIDS in the Northeast are injection drug users. In addition, large Puerto Rican communities exist in Chicago and Miami, cities which have also been severely affected by the epidemic (National Council of La Raza, 1990). The disproportionate impact of the epidemic, in both the island and mainland Puerto Rican populations, is due in large part to the inextricable link between the HIV epidemic and the epidemics of poverty and drug use that have so tragically affected these communities.

The tremendous challenge of AIDS in Puerto Rico can not be successfully dealt with unless corresponding attention is given to Puerto Rican populations on the mainland and the implications of the ongoing in- and out-migration are fully and clearly understood.

As well as this ongoing migration, a new migration pattern seems to be emerging as a result of the HIV epidemic. People with AIDS in Puerto Rico have started to seek health care on the mainland, while others return to Puerto Rico to be with their loved

ones (Lambert, 1990). For many individuals this has resulted in disruption of the continuity of care–not an uncommon phenomenon for people who move from one community to another within the continental United States. Furthermore, in Puerto Rican communities, on both the island and the U.S. mainland, family ties–even to the extended family–are strong; hence, the social impact of the epidemic has extended far beyond those infected with HIV. Those moving to the mainland may have to leave their families behind to seek care in communities where they are often unfamiliar with the language, culture, and health care system. Those returning to the island to be with their families are particularly affected by the lack of a broader range of government resources for care and treatment compared with mainland programs.

In 1989 and 1990, the federal government, the Office of the Resident Commissioner of Puerto Rico, and the National Council of La Raza sponsored two "Think Tank Forums" (I and II) on "AIDS in Puerto Rico and Among the Puerto Rican Populations on the Mainland." These events brought together individuals from all levels of government in Puerto Rico and the states and localities with large Puerto Rican populations, as well as representatives of the private sector and community-based organizations. A major recommendation arising from these meetings has been for coordination of HIV prevention and health care services between these mainland and island communities to ensure continuity of care and appropriate patient and family follow-up and referral (National Council of La Raza, 1990).

The Commission recommends:

4. **That efforts be made at all levels of government and the private sector to identify and address the impact of the HIV epidemic on the Puerto Rican communities in the United States. Pilot projects, including case management coordination, linking HIV efforts on the U.S. mainland with those in Puerto Rico, should be developed where migration patterns warrant.**

While the Commission recognizes these powerful links between the communities and the necessity for cooperation and collaboration, the rest of this report focuses on the impact of the HIV/AIDS epidemic on the island of Puerto Rico. The Commission will be issuing a separate report on the impact of the epidemic on selected ethnic and racial populations, including Puerto Ricans, on the mainland.

CHAPTER II

Epidemiology of HIV/AIDS in Puerto Rico

AIDS in Puerto Rico is alarming both in its scope and its pattern. In 1991, the annual incidence of AIDS cases on the island was 50.9 per 100,000 population (CDC, 1992a). This rate is second only to that in the District of Columbia (120.4) and is followed by the incidence rates of new cases in New York State (45.3), Florida (41.9), and New Jersey (29.7) (CDC, 1992a). In this community of 3.5 million people, in 1990, four people are diagnosed with AIDS and three others die of AIDS-related complications every day (Rullan, 1990). In just a decade, AIDS became the leading cause of death in Puerto Rico for men between the ages of 25 and 44 years and for women between the ages of 25 and 34 years (Puerto Rico Department of Health, 1989).

San Juan, the capital of Puerto Rico and its major metropolitan area, has borne the brunt of the epidemic, ranking sixth in the rate of AIDS cases among United States metropolitan areas with populations of over half a million (CDC, 1992a). In 1992, in San Juan, nearly one of every 20 adults between the ages of 25 and 44 seen at the San Juan Municipal Hospital for non-AIDS-related illnesses was found to be HIV-infected (J. Rivera-Dueno, *Instituto del SIDA de San Juan*, San Juan, Puerto Rico, personal communication, April 1992).

However, the HIV epidemic in Puerto Rico is not limited to the major metropolitan areas. Large numbers of AIDS cases have also been reported in smaller cities such as Ponce and small towns such as Gurabo (Stubbe, 1991). As of January 1992, over 6,763 cases of AIDS had been reported on the island since the epidemic began (CDC, 1992a). A survey conducted by the Puerto Rico Department of Health in 1988 estimated that between 55,000 and 60,000 of the island residents were infected with HIV (Rullan, 1990). A study conducted by the Harvard Institute for International Development estimated that there are 12,000-14,000 HIV-infected individuals in the San Juan municipal area alone (Finlayson, Vargas, and Catasus, 1991).

Substance Use

Many of the AIDS cases in Puerto Rico are related to substance use. In few communities in the United States has there been a more dramatic link between the twin epidemics of substance use and HIV than in Puerto Rico. An estimated 74% of the cases of AIDS in Puerto Rico occur either directly from drug use or through sex with a partner infected through drug use. Fifty-seven percent of all reported AIDS cases in adults and adolescents in Puerto Rico have been in injection drug users, compared with 23% in the United States as a whole (CDC, 1992a). Nine percent of men with AIDS in Puerto Rico report both homosexual/bisexual and drug use behaviors (Puerto Rico Department of Health, 1992a). Eight percent of all AIDS cases are reported among sex partners of injection drug users. Because injection drug use is primarily linked with sexual transmission from men to women, and perinatal

transmission, Puerto Rico has seen an increasing number of women, children, and entire families wiped out by HIV disease.

Women

Within the United States and its territories, Puerto Rico has one of the highest percentages of AIDS cases in women. As of February 1992, 18% of the cumulative total of reported AIDS cases in Puerto Rico were in women, compared with 10% of the AIDS cases in the United States as a whole (CDC, 1992a). Of the total number of female AIDS patients in Puerto Rico, 47% were injection drug users. Forty-three percent of the women with HIV infection acquired the infection through heterosexual contact–up from 28% in 1988 (Puerto Rico Department of Health, 1992a). The majority of these women are known to be sex partners of injection drug users. AIDS surveillance data for the entire United States also shows that HIV transmission to female sex partners of injection drug users is increasing at an annual rate of 12%–much faster than the 8% increase in HIV-infected male drug users themselves (CDC, 1992a). Corresponding annual rates of increase in AIDS cases in Puerto Rico were 31% among female sex partners of injection drug users, and 0.9% for drug users themselves (Puerto Rico Department of Health, 1992a).

Infants and Children

Puerto Rico accounts for 6% of all reported pediatric AIDS cases in the United States (CDC, 1992a). Three percent of the cumulative number of AIDS cases in Puerto Rico are in children, compared with 1.7% of AIDS cases in the United States as a whole. Of the 196 pediatric AIDS cases reported in Puerto Rico as of February 1992, 95% were acquired through perinatal transmission (Puerto Rico Department of Health, 1992a). This contrasts with the average for the United States, where 85% of the pediatric cases occurring in children are acquired through perinatal transmission (CDC, 1992a).

Men Who Have Sex with Men

Eighteen percent of AIDS cases to date in Puerto Rico have been in men who have sex with men (homosexual and bisexual) but report no other risk factors (Puerto Rico Department of Health, 1992a). Although the proportion of cases in men who have sex with men is smaller in Puerto Rico than in the United States as a whole (58% nationwide), there may be substantial underreporting (CDC, 1992a) because Puerto Rico is a society in which homosexuality still carries a strong stigma. It is believed that many individuals may misrepresent themselves as injection drug users and hence be miscounted; some are treated by private physicians who agree not to reveal the individual's HIV status and, thus, are not counted at all (Babb, 1990; Castro, 1990). Although men who have sex with men represent a smaller percentage of AIDS cases than in the rest of the United States, this should in no way serve to minimize the tragic impact of the epidemic on this community or the need to prevent the further spread of the disease within this group.

Conclusions

The seeds of the future of the HIV/AIDS epidemic in Puerto Rico can be seen today. Trends indicate that, because injection drug users and their sex partners account for the largest proportion of AIDS cases on the island, heterosexual and perinatal transmission will continue to rise. The resulting situation, i.e., an almost equal ratio of

cases by gender, is already being seen in neighboring Caribbean countries. Without immediate action, this continuing rise in the number of cases in women as well as men will also lead to growing numbers of entire families infected with HIV, and the added tragedy of children left behind without parents to care for them. The Harvard Institute for International Development has estimated that in the city of San Juan alone between 1992 and 1996 there will be 1,300 children orphaned as a result of the HIV/AIDS epidemic (Finlayson, Vargas, and Catasus, 1991).

CHAPTER III

Access to Health Care in Puerto Rico

Because of the growing number of people needing care for HIV infection or AIDS, the health care system in Puerto Rico, as elsewhere in the world, has been overwhelmed by the cost. Since 1984, the hospitals under the administration of the Puerto Rico Department of Health have treated more than 3,000 people living with HIV disease at an approximate cost of $100 million (Torres, 1990). The Department of Health of Puerto Rico has estimated the cost of providing HIV-related services for fiscal year 1991-92 at $36 million, a 55% increase over fiscal year 1990-91 (Puerto Rico Federal Affairs Administration, 1991). If the current trend of utilization continues, by the year 2000 more than 50% of the budget for public hospitals will be devoted to the care of persons with HIV disease (Torres, 1990). Similarly, it has been estimated that the city of San Juan could spend between $459 and $550 million for health care for HIV-infected individuals in the five-year period 1992-96–an amount greater than the entire annual budget of the city (Finlayson, Vargas, and Catasus, 1991). Because Medicaid funds are capped, the Commonwealth of Puerto Rico receives only $79 million of federal funds to provide services to the estimated 1.8 million medically indigent individuals (Torres, 1990). The scarcity of resources has translated inevitably into fewer services and limited access to medications for people with HIV disease.

This section will look at the impact of the Medicaid cap in contributing to these shortfalls in the provision of care for people with HIV disease in Puerto Rico. This section will also highlight the delivery of health services for HIV-infected persons, Health Resources and Services Administration support, technical assistance needs, Ryan White CARE Act funding, and the paucity of clinical research and opportunities for access to experimental therapies; all of which are areas of concern in trying to improve access to care for people with HIV disease in Puerto Rico.

Effects of the Medicaid Cap on Health Care for Persons with HIV Disease

In the continental United States, Medicaid, the federal–state matching program that finances care for low-income persons, is the most important general source of financing for AIDS and HIV-related health care benefits. In 1990, it was estimated that Medicaid covered 40% of the persons with AIDS, including 90% of the children with AIDS (Davis et al., 1991). Eligibility criteria and types of benefits covered under Medicaid vary from state to state. All states cover a range of services for Medicaid-eligible individuals, including inpatient and outpatient services, physician and x-ray services, health screening, and follow-up services for children. In addition, all states must allow beneficiaries to obtain services from any qualified provider in the public as well as the private sector. For many people with AIDS in the United States, Medicaid has been the only vehicle for gaining access to needed care and treatment (Davis et al., 1991).

It has been estimated that 70% of individuals with HIV disease in Puerto Rico are medically indigent (Puerto Rico Federal Affairs Administration, 1991). As a result, the main burden of caring for these individuals falls on government programs. Because funds under Medicaid are capped for Puerto Rico at $79 million, its residents cannot fully benefit from the Medicaid program.

Medicaid funds are allocated by the Puerto Rico Department of Health to public hospitals and clinics that provide health services to the general population. In contrast with the program in the 50 states, Medicaid in Puerto Rico does not operate as a form of health insurance for the medically indigent. Medicaid in Puerto Rico does not authorize the use of private physicians or reimbursements to hospitals or clinics for the provision of services. Instead, Medicaid allows patients to receive health care and medication at designated public facilities.

The problems associated with the limitation on Medicaid funding are further exacerbated by the unique legal obligation of the Department of Health to provide health care services to all residents of the island, regardless of their financial condition (Commonwealth of Puerto Rico Law, 1980). In 1991, 1.1 million island residents were eligible for health care services under the Medical Assistance Program (MAP) financed by the Commonwealth (Puerto Rico Federal Affairs Administration, 1991). To provide health care to these individuals the Commonwealth government spent $519 million in fiscal year 1990 in its Medicaid program–over six times the federal matching funds. If Puerto Rico operated under the same criteria as the 50 states it would have received $415 million in matching funds (Puerto Rico Federal Affairs Administration, 1991). The Commonwealth government spends 11% of its total budget for health care and hospitals, compared with an 8% average for the 50 states and the District of Columbia (GAO, 1990).

HIV-Related Services

Most HIV-related services are provided in public facilities administered by the two largest public health systems on the island, the Puerto Rico Department of Health and the city of San Juan Health Department. To respond to the HIV/AIDS epidemic, both systems have established an extensive network of regional and local HIV clinics, hospital units, and family centers for HIV/AIDS patients. The largest program is that of the Central Office of AIDS Affairs and Communicable Diseases, a division of the Puerto Rico Department of Health; this office allocates $7.4 million to AIDS activities. It is now in its second year of implementing a broad service network encompassing seven regional HIV clinics, community-based organizations (CBOs), prevention programs, hospitals, hospices, and shelters. Since the HIV clinics opened in October 1990, they have provided care to more than 5,000 patients (J. Rullan, Central Office of AIDS Affairs and Communicable Diseases, San Juan, Puerto Rico, personal communication, April 1992).

The city of San Juan Department of Health contracts with a nonprofit agency, the *Instituto del SIDA de San Juan* (San Juan AIDS Institute), to coordinate and fill the gaps in its model of integrated services for people with HIV infection. Current Institute responsibilities include meeting the health and social service needs of almost 30% of all people diagnosed with AIDS in Puerto Rico through nine community-based clinics known as Diagnostic Treatment Centers, as well as through dedicated facilities at the San Juan Municipal Hospital. The Institute's services include home, intermediate, and day care services. They also opened and operate the first government clinical trials unit (Rivera-Dueno, 1990).

The private sector has also been an important part of the response to the HIV/AIDS epidemic. Motivated by a sense of urgency, many volunteers have come forward to help those in need, with the additional support of over 30 community-based organizations involved in the areas of services, prevention, and treatment (Cunningham, Ramos, and Ortiz, 1991). In addition, some religious communities have been involved since early in the epidemic providing pastoral counseling and hospice and shelter care (Garcia, 1990).

Despite these efforts, persons with HIV disease who are dependent on government services have reported receiving limited health care services due to the lack of resources. Perhaps the most pressing issue the Commission encountered in its visit to Puerto Rico was the Commonwealth's policy of not authorizing the use of Medicaid funds for the financing of HIV-specific medications such as zidovudine (AZT) and pentamidine. Although it has been estimated that providing zidovudine alone to islanders would cost $60 million (Smith, 1990), in 1990, the only money available for purchasing drugs was $900,548 in federal funds from the AIDS Drug Reimbursement Program, a grant of the Health Resources and Service Administration (National AIDS Program Office, 1990). Thus, the government was providing HIV-specific medications to only 900 AIDS patients out of a potential pool of the 55,000 to 60,000 HIV-infected persons on the island (Rullan, 1990).

Greater challenges will be encountered as new medications become available for people with HIV disease. As explained to the Commission by a witness during the hearings:

> As life expectancies are extended with the privilege of access to [anti-retrovirals and other drugs to prevent opportunistic infections] we in Puerto Rico will be riding a steady and constant decline in comparative life expectancy. So when considering access issues in Puerto Rico, the inevitable approval of ddI and ddC will widen the gap between prolonging the life expectancy and expediting death. While the more privileged patients of the mainland will be extending their life expectancies, inversely, the relative death rate in Puerto Rico will skyrocket (Irizarry, 1990).

Commonwealth officials have stated that Medicaid funds are not being used to purchase medications because of the funding cap and have supported efforts to raise Medicaid funding in order to increase access to medications. Despite promises from federal officials to help increase Medicaid (Capo, 1990), no new funds were requested in the President's budget proposal for fiscal year 1993.

The Commission again recommends:

5. **That Congress and the Administration work together to raise the Medicaid cap on funds directed to the Commonwealth of Puerto Rico to ensure equal and adequate access to care and treatment.**

Health Resources and Services Administration Support

Because of the limited resources available for financing health care, federal funding in the form of grants for the establishment of HIV/AIDS programs to expand access to health care for persons with HIV disease has been of crucial importance for the Commonwealth of Puerto Rico. Most of this funding has come from the Public Health Service through the Health Resources and Services Administration (HRSA). For example, in 1987 HRSA funded the first AIDS-specific service demonstration projects

in Puerto Rico, one for adults and one for children. Until 1990, HRSA allocated the only funding available for HIV-specific medications and the only funding available for home health care (Otero, 1990). HRSA has recently funded an AIDS education training center in Puerto Rico, based at the University of Puerto Rico Medical Science Campus. In addition, HRSA funds 14 community and migrant health centers in Puerto Rico servicing over 300,000 patients per year. Although these facilities do not limit their services to HIV/AIDS patients, they have been crucial in bringing services to the medically indigent, including persons with HIV disease.

Technical Assistance

Despite the important contributions of the Public Health Service, Puerto Rico has not fared well in most of the federal programs for HIV-related services. In 1990, although Puerto Rico ranked sixth among the 57 states and territories in the cumulative total of AIDS cases, it ranked 20th in funding from the Public Health Service for AIDS-related programs per capita and 55th among the 57 states and territories in the total funding per reported case (National AIDS Program Office, 1990).

Public Health Service agencies allocate most of their funds through formula grants with specific state allocations established by law. They also allocate funds through the competitive grant process, basing awards on the strength of proposals with advice from review committees. Most of the money allocated to Puerto Rico by the Public Health Service has been through formula grants (National AIDS Program Office, 1992). Puerto Rico has not fared well when seeking federal funding through the competitive grant process. Technical, linguistic, and cultural differences have put the island commonwealth at a disadvantage when seeking funding. The government of Puerto Rico has lacked a cadre of grant proposal writers and the resources to utilize professionals in the private sector to respond to highly technical requests for proposals (Rullan, 1990). Linguistic differences have also contributed to difficulties in interpreting federal regulations.

Many of the federal funds allocated for HIV services present a radical departure from the traditional systems established for providing care in Puerto Rico. The Puerto Rico Department of Health and the municipal governments need technical assistance and time to build a new management infrastructure in order to disburse funds appropriately. Where federal funds allocated to the Commonwealth have not been used during the prescribed period, subsequent funding has decreased resulting in the failure of programs to thrive.

Community-based organizations (CBOs) have similar needs regarding technical assistance (Toro, 1990). The role of CBOs in responding to a public health crisis is a new phenomenon in Puerto Rico. Although most CBOs have only emerged in recent years, they play an important role in the private sector response to the epidemic. Because the epidemic has predominantly affected the drug-using population and a nascent gay community, CBOs have limited monetary and human resources to draw upon. However, CBOs have been instrumental in mobilizing community resources and volunteers, establishing prevention and education programs, providing case management services, running hospices, establishing homes for children with AIDS, and advocating for better services.

Because of the scope of the need in Puerto Rico, it is critical that every effort be made to assist Puerto Rico in improving its ability to secure necessary and available HIV funding. Current efforts in technical assistance also need to be augmented in order to encourage better communication among the agencies delivering services.

The Commission recommends:

6. **That the U.S. Department of Health and Human Services, in collaboration with the government of the Commonwealth of Puerto Rico, seek ways to strengthen the technical, administrative, and coordinating capabilities of the Puerto Rico Department of Health. Similar support should also be provided directly to other health, social service and housing agencies, and community-based organizations in Puerto Rico. Technical assistance provided in these areas should be on-site and ongoing.**

The Ryan White CARE Act

In 1991, the city of San Juan and the Commonwealth Health Department were recipients of HRSA funding allocated under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This new funding has raised the hopes of those whose lives are touched by HIV disease. Resources allocated under the CARE Act will be used to coordinate services and provide medication for persons with HIV disease. Funds allocated under Title I of the CARE Act provide aid to cities severely affected by the HIV/AIDS epidemic. Under Title I the San Juan Metropolitan Area will receive $3.5 million for fiscal year 1992. Funds allocated under Title II provide aid to the 50 states, the District of Columbia, and the Commonwealth of Puerto Rico. Under Title II the Puerto Rico Department of Health will receive $5.8 million for fiscal year 1992. Funds under Title III provide monies to community-based programs for early intervention services; five programs (Puerto Rico CONCRA; *Centro de Salud de Lares*; *Consejo de Salud de la Comunidad Playa de Ponce*; Rider Memorial Hospital, Humacao; Advance Community Health Services, *Instituto del SIDA de San Juan*) have been funded in Puerto Rico with total funding of $2.4 million. Recipients of funds have identified HIV treatment drugs and case management as priorities. The Puerto Rico Department of Health reserved $1.8 million of the $5 million funding for the purchase of drugs alone (National AIDS Program Office, 1992). Under the CARE Act, HRSA has also provided short-term technical assistance in project planning to Puerto Rico.

Puerto Rico's situation illustrates the need to allocate full funding for the CARE Act. Because of the limited resources allocated to Puerto Rico under Medicaid, funding under the CARE Act has assured unprecedented access to treatment and care. Such support must continue. CARE Act funding, however, cannot be seen by federal officials as a substitute for the need to increase Medicaid funds. Compared with the estimated $60 million needed to purchase zidovudine alone, the $11.7 million provided under the CARE Act will not be sufficient to overcome this and other pressing issues faced by the people of Puerto Rico in response to the HIV epidemic.

Clinical Research and Access to Experimental Treatments

The clinical consequences of HIV infection are known to vary between communities and regions depending on the locally prevalent challenges to the immune system. Therefore, clinical research to characterize the manifestations of HIV-related diseases in Puerto Rico is necessary to ensure an adequate base of knowledge for local clinical-care providers. Such research should be designed to anticipate shifts in the population affected, such as the increasing number of cases in women, infants, and children.

With a new disease such as AIDS where there are no recognized standard care protocols, a flexible view is needed in regard to treatment options. The Commission

believes access to experimental treatment is an essential component of health care services for all people with HIV disease (National Commission on AIDS, 1991). In addition to the limitations on access to standard medications (e.g., for opportunistic infections) due to the lack of resources, the Commission found that persons living with HIV disease in Puerto Rico had poor access to, and a scarcity of, experimental treatment options.

The Commission has also strongly supported the expansion of clinical research efforts among underrepresented populations, particularly African-Americans, Hispanics, and women. Despite the fact that the residents of Puerto Rico represent 20% of all reported AIDS cases in Hispanics, and that the island ranks sixth in the total number of cases in the United States, Puerto Rico ranked 51st among the states and territories in allocation of money for HIV treatment research by the National Institutes of Health (National AIDS Program Office, 1990).

In fiscal year 1990, funding was approved for an AIDS Minority Infrastructure award from the National Institute of Allergy and Infectious Diseases (NIAID) to the University of Puerto Rico School of Medicine. The purpose of this 3-year award was to support the necessary infrastructure in terms of equipment and personnel in order to have a maximum opportunity to successfully compete to become an AIDS Clinical Trials Unit. It is anticipated that the first patients will be enrolled at the site in 1992. In the continental United States, NIH has used the Community Programs for Clinical Research on AIDS (CPCRA) to facilitate access to trials for underrepresented communities. Puerto Rico does not have a CPCRA program. The only community-based clinical research initiatives on the island have been undertaken by the American Foundation for AIDS Research, which has granted seed money to the *Fundacion SIDA* to begin efforts to establish a community-based research initiative. In 1990, the NIAID funded an HIV-related clinical trial for HIV-infected children and adolescents (known as *Proyecto GAMMA*) under a grant given to the University of Puerto Rico Children's Hospital. The University of Puerto Rico is also a site in a multi-center women-and-infants-transmission (WITS) study. The Commission was pleased to learn in January 1992 that the University of Puerto Rico was selected as one of nine new sites receiving a new 5-year award as a Pediatric AIDS Clinical Trials Unit.

The Department of Veterans' Affairs and the *Instituto del SIDA de San Juan* have taken the lead in integrating clinical research as part of their AIDS services. The Veterans' Affairs Medical Center in San Juan has one of the few medical units in Puerto Rico that includes clinical trials as part of the therapy provided for HIV-infected persons. The unit is part of the Infectious Disease Research Laboratory and is treating over 200 HIV-infected veterans with various therapeutic alternatives. It is also conducting trials on the efficacy of zidovudine, ddI, and ddC and one trial on an opportunistic infection, cryptococcal meningitis (Ramirez-Ronda, 1991). The *Instituto del SIDA de San Juan* in collaboration with the Veterans' Affairs Medical Center also has an AIDS clinical studies unit conducting research with 100 patients on alternatives similar to those described above.

Puerto Rico is home to a large number of pharmaceutical companies, attracted there by federal tax exemptions. These pharmaceutical companies include some manufacturers of AIDS-specific medications. This makes the difficulties in obtaining drugs that persons in Puerto Rico encounter particularly ironic. Pharmaceutical companies have played a crucial role in the continental United States in increasing the availability of drugs necessary for HIV/AIDS care and treatment and must be encouraged to continue these efforts. This role is no less important in Puerto Rico than

on the mainland; yet the Commission was informed that very few clinical trials have been sponsored in Puerto Rico by the pharmaceutical industry (Ramirez-Ronda, 1990).

The Commission recommends:

7. **That approaches to expanding clinical research, as well as increasing access to experimental therapies (via clinical trials or expanded access programs) be explored by all involved in the HIV epidemic in Puerto Rico, including the federal, commonwealth, and municipal governments, as well as the private sector.**

CHAPTER IV

Discrimination Against HIV-Infected Persons

The Commission was profoundly disturbed by testimony describing the stigmatization and discrimination faced by HIV-infected individuals when seeking housing, employment, and health care in Puerto Rico. There were also alarming reports of refusals by doctors, laboratory technicians, emergency medical personnel, and officers in correctional settings to assist persons with AIDS (Maldonado, 1990; Vargas, 1990).

Communitywide Education Efforts

Efforts to fight discrimination against persons with HIV disease need to be seen as an integral part of the endeavors to expand access to care and to establish effective prevention efforts. While discrimination is a complicated issue, education of health care professionals and others is key to combatting it and should be central to both these efforts. First, because there will never be adequate care if the majority of health care providers refuse or are reluctant to care for persons with HIV disease. And second, because individuals consistently turn to their health care providers for reliable information about AIDS. A recent survey of 750 residents of San Juan conducted by the *Instituto del SIDA de San Juan* indicates that over 85% believe that health care professionals, over all others, provide the most trustworthy information about AIDS (Instituto del SIDA de San Juan, 1991). Therefore education of health care professionals can positively affect discrimination not only within the health care setting, but in the larger community as well.

Additional aggressive communitywide education about how HIV is and is not transmitted is necessary in order to create a less hostile environment for HIV-infected individuals. Government agencies must work to educate communities and at the same time protect persons with HIV disease from discrimination.

Legal Mechanisms

All federal laws providing protection against discrimination for persons with HIV disease apply to Puerto Rico. Section 504 of the Rehabilitation Act, as well as the Fair Housing Act are sources of legal protection for persons with HIV disease on the island. Additionally, Commonwealth Law 44 (Commonwealth of Puerto Rico Law, 1985) may offer some protection against employment discrimination for persons with HIV disease who meet the statute's disability criteria.

The Commission had the opportunity to visit a shelter for persons with AIDS that had recently opened after a federal court ruled that the denial of a permit to operate a shelter by the Commonwealth Permit Administration violated the Fair Housing Act (Association of Friends and Relatives of AIDS Patients v. Regulations and Permits Administration, 1990). However, the Commission found that individuals with HIV disease in Puerto Rico, in general, encountered major difficulties in seeking legal

protection against discrimination. First, there are limited resources available for persons with HIV disease in need of legal representation. There is simply not a sufficient number of attorneys who are willing to represent persons with HIV disease, particularly if they are indigent, as most of the people with HIV disease in Puerto Rico are.

Second, there are significant obstacles to successfully bringing federal discrimination suits, particularly under current federal administrative and judicial processes. For example, Fair Housing Act complaints must be submitted to the Federal District Court in San Juan, which conducts its business in English and requires a special license for attorneys to practice; these requirements limit the number of attorneys who can bring cases to this court and thus further restrict access to federal anti-discrimination protections (Lavin, 1990). A complaint under Section 504 of the Rehabilitation Act, based in Puerto Rico, must be filed in the U.S. Department of Health and Human Services Regional Office in New York City. Because of the geographical distance and the failure to consistently educate the community about federal protections, only five AIDS-related complaints originating from Puerto Rico were filed at this office between 1990 and 1992 (J. Kennedy, Region II Civil Rights Office for the Department of Health and Human Services, New York, New York, personal communication, February 21, 1992).

Third, the local statute protecting disabled individuals from discrimination provides remedies for only those with grievances against government employers or Commonwealth-funded organizations (Gonzalez and Pizarro, 1991). As of February 1992, only three complaints relating to AIDS discrimination had been filed at the Disability Office in Puerto Rico (W. Peyot, Office of the Disability Ombudsman for the Commonwealth of Puerto Rico, San Juan, Puerto Rico, personal communication, February 1992). This is a dramatically low number of administrative cases compared with the 628 cases processed by the New York City Human Rights Office in the fiscal year between 1990 and 1991 alone (Dinkins, Steisel, and Robin, 1991).

Fourth, Puerto Rico has been slow to develop an advocacy infrastructure adept at handling issues concerning civil rights. Because of cultural homogeneity, traditional areas of anti-discrimination protection were not immediately identified as relevant issues for Puerto Rico. Accordingly, it was not until 1976 that the Puerto Rico Department of Labor opened an Anti-Discrimination Division to enforce Title VII of the Civil Rights Act of 1964. And it was not until this locally based mechanism was put in place that race- and gender-based employment discrimination claims were pursued in court. In 1975, the Anti-Discrimination Office processed only 40 complaints. With a better established civil rights infrastructure, growing awareness of discrimination problems, and increased availability of remedies, over 411 discrimination cases were processed in 1991 alone (Lugo, 1992).

Lessons from the history of anti-discrimination efforts in Puerto Rico can aid the current struggle to ensure that anti-discrimination protections for persons with HIV are fully enforced. To ensure that individuals are protected, AIDS discrimination in Puerto Rico must be recognized as a present reality that should not be tolerated, people must be educated regarding their rights, and resources must be directed at developing the appropriate processes to facilitate the filing of complaints and their appropriate resolution. These activities are of critical importance to the implementation of the Americans with Disabilities Act (ADA), which extends anti-discrimination protections in the two areas that have been most troublesome for persons with AIDS–private employment and private health care.

Efforts need to be undertaken not only to educate people about the ADA, but to build adequate mechanisms to facilitate the implementation of the law. The Commission is aware that a local law was enacted expanding the legal protections against employment discrimination for persons with disability in public and private settings (Commonwealth of Puerto Rico Law, 1991). The intent of the law is to facilitate the implementation of Title I (Employment) of the ADA by providing both federal and local remedies and authorizing claimants to submit grievances at the local level. Similar efforts need to be undertaken in order to facilitate the implementation of Titles II and III, which cover Transportation and Public Accommodation, respectively. The public accommodation provision is of special importance for those fighting to eradicate HIV-related discrimination in the health care setting. For the purposes of the ADA, professional offices of health care providers and hospitals are considered places of public accommodation. In the ADA Report language (United States Senate, 1989), Congress specifically states that treatment cannot be denied if the health care provider treats nondisabled individuals for the same condition, e.g., a drug rehabilitation clinic could refuse to treat a person who was not a drug addict, but could not refuse to treat a person who was a drug addict simply because he or she tested HIV-antibody-positive.

The Commission recommends:

8. **That special efforts be undertaken in Puerto Rico to educate the community and advocates for persons infected with HIV about the provisions of and rationale for anti-discrimination laws, such as the Americans with Disabilities Act, and to build adequate mechanisms to facilitate the enforcement of these laws. These efforts should be undertaken jointly by the federal government and the government of the Commonwealth of Puerto Rico. The Commonwealth government may wish to consider the possibility of establishing an HIV/AIDS anti-discrimination office similar to those found in cities such as Los Angeles and San Francisco.**

CHAPTER V

Prevention

Efforts to prevent the spread of HIV infection in Puerto Rico have been impeded by the lack of resources of those most affected by HIV disease, as well as by religious, cultural, and social taboos that may be more restrictive than in most of the continental United States. The lack of resources to provide health-related services and the discrimination experienced by individuals with HIV disease have also created major disincentives to getting tested and seeking counseling on HIV-prevention methods.

Poverty

Poverty undoubtedly has magnified the difficulties of meeting the challenges of HIV disease in Puerto Rico. The per capita income of the island is less than half that of Mississippi, which has the lowest per capita income of the 50 states (GAO, 1990). Chronic unemployment has taken its toll on the health status and social well-being of this community, creating an environment where individuals are at a greater risk of HIV infection. For decades Puerto Rico has experienced an increasing wave of violent crime and high rates of illicit drug use, alcoholism, mental illness, sexually transmitted diseases, and teenage pregnancy (GAO, 1990). Although the education level of the population has dramatically risen in the last 50 years, the public high school graduation rate was still 63.2% in school year 1987-88, compared with 72.6% in the United States as a whole (GAO, 1990). Only two states and the District of Columbia had a lower graduation rate.

Cultural and Socio-Political Aspects

Cultural and socio-political objections have presented serious obstacles to the establishment of effective islandwide HIV prevention programs. In this conservative Hispanic community, where 75% of the population identify themselves as Roman Catholic, messages about safer sex practices, particularly condom use, which are central to HIV prevention programs, have been the subject of intense debate by church and political leaders (Cunningham, Ramos, and Ortiz, 1991). During the Commission's visit in November 1990, condom distribution on the government level was taking place only in programs targeting high-risk behavior and in family planning clinics (Nieves, 1990). An HIV-infected witness told the Commissioners about her frustration:

> Many times I have gone to the Office of Family Planning to receive the contraception methods, condoms, and I have to wait two to three days in asking them for condoms because they do not have them available (Woman with HIV, 1990).

Although community-based organizations have been distributing condoms since early in the epidemic, it was not until September 1991, a decade into the HIV/AIDS

epidemic, that the government of Puerto Rico publicly endorsed condom use as an intervention in its HIV education and prevention campaign for the general public (Pedro Ramos, Office of AIDS Affairs and Communicable Diseases, San Juan, Puerto Rico, personal communication, 1992).

The federal government, in partnership with the Commonwealth and municipal governments, has played an instrumental role in HIV prevention and education efforts in Puerto Rico. For example, in 1990 the Centers for Disease Control (CDC) was the principal source of funding for more than 55 counseling and testing sites and played a crucial role in the development and design of risk reduction programs, public information efforts, and AIDS education curriculum development in the public school system (Nieves, 1990).

The Commission found that Puerto Rico faces great challenges in establishing prevention programs, particularly those targeting individuals who engage in high-risk behavior. For the purposes of analysis, the following sections will look at HIV transmission among adolescents; incarcerated populations; men who have sex with men; substance users; and women. However, individuals may engage in more than one risk behavior, and behavior may change over time.

Adolescents

Adolescents and young adults in Puerto Rico are at a high risk of HIV infection. As the New York State Department of Health AIDS Institute reports:

> The federal seroprevalence studies among applicants for military service allows for comparison between applicants from Puerto Rico, where 0.51% of all applicants were HIV-positive, and the rest of the United States, which averaged 0.12% seroprevalence. Only the District of Columbia had a higher rate than Puerto Rico. Among female military applicants, Puerto Rico had the highest rate of HIV infection (0.35%) (New York State Department of Health AIDS Institute, 1992).

These numbers may be low, however, because the military does not accept HIV-positive individuals or gay men and lesbians, and there is thought to be considerable self-deferral by individuals who know they are at risk of HIV. In addition, the fact that Puerto Rico has a high rate of teenage pregnancy demonstrates the need to aggressively target adolescents with sex education, including HIV prevention messages.

The Commission is aware that the Commonwealth's legislature has passed laws authorizing HIV prevention messages targeting adolescents and young adults in the public school system (Puerto Rico Department of Health, 1990). An AIDS program was incorporated into the health program for the school year 1987-88 (Nieves, 1990). The Commission is aware of one program, *Fundacion SIDA's Proyecto de Pares*, that has been put in place to reach out-of-school adolescents. To the Commission's knowledge, no government programs have been put in place to reach this population, despite the fact that studies conducted by the Research Institute of the Department of Anti-Addiction Services found that over 50% of injection drug users leave school before graduating (Colon, Robles, and Hardeo, 1991).

Moreover, providing only general information about HIV risk to adolescents and young adults has proven insufficient. Two large surveys involving thousands of students at the University of Puerto Rico found over 95% of those surveyed were knowledgeable about modes of transmission and the usefulness of condoms as a means

of protection. Yet only 11% of sexually active students in the same survey reported always using condoms; more than 40% never use condoms at all (Cunningham and Rodriguez, 1991).

This survey of AIDS knowledge, attitude, beliefs, and behavior is the kind of project that is needed to gain better understanding of what works and does not work in prevention efforts among a particular group of adolescents and young adults. We do know, however, that HIV education and prevention messages must be clear, realistic, and unequivocal about the risk of HIV transmission in order to provide adolescents and young adults with the necessary tools to reduce high-risk behavior. For the future of Puerto Rico, such prevention messages must be made a priority.

Incarcerated Populations

HIV disease is a profound problem in Puerto Rico's correctional facilities. As of October 1, 1990, officials in Puerto Rico reported having had at least 393 inmates with AIDS in the correctional system, of whom 149 had died; however, these numbers are recognized as possible underestimations. In addition, prisons in Puerto Rico contain a disproportionate number of people at risk of, or infected with, HIV. Public health agencies should make interventions in this setting a high priority and should work closely with corrections officials to bring successful public health strategies to bear in prisons and jails on the island.

The availability and effectiveness of education programs in Puerto Rico for inmates and corrections personnel is an area of grave concern. For, although corrections officials in Puerto Rico reported (in a survey conducted by the National Institute of Justice) providing face-to-face HIV education in addition to written materials to inmates at all of their institutions, they also indicated that no training on safer sex practices or methods of cleaning drug equipment was provided. In addition, officials could not determine how many individuals had received AIDS education because attendance at AIDS education programs was voluntary for both inmates and staff. In reviewing AIDS education programs in Puerto Rico in 1990, the Office of the Court Monitor reported:

> On-site education to inmates about the symptoms, transmission, and prevention of Human Immunodeficiency Virus (HIV) infection is virtually nonexistent. Infrequent, poorly attended sessions have been presented in some correctional facilities. The knowledge level of the incarcerated population concerning HIV infection is horribly inadequate. The current system of referring all inmates to *Centro Latinoamericano de Enfermedades de Transmision Sexual* (CLETS) for HIV counseling is logistically impossible, burdensome to the correctional staff, and a major barrier to the dissemination of information about AIDS and its prevention to the incarcerated population. Given the enormous problem that HIV infection has caused within the Administration of Corrections and in the Commonwealth of Puerto Rico, the current plan to hire 4 (AIDS) educators to work in correctional facilities is grossly inadequate (Office of the Court Monitor, 1990).

HIV education programs are critical to reducing the spread of HIV infection. Education for prevention, however, is of no use if it is not delivered diligently.

Inmates, like others in our society, have the right to be protected from life-threatening illnesses. To prevent the spread of HIV infection, inmates and staff need

to be taught how to reduce or eliminate their risk of HIV infection. In failing to provide adequately for the public health needs of persons who are incarcerated, the government is missing opportunities to educate people at high risk of HIV infection for preventing further spread of HIV, as well as other important preventable diseases. In addition, since most incarcerated individuals will go back into the community, efforts should also be made to educate the family and friends of inmates. HIV/AIDS education programs remain the single most effective strategy for slowing the spread of HIV infection. For legal, moral, and public health reasons, effective and comprehensive HIV/AIDS education programs should have a high priority in all correctional facilities, including those of Puerto Rico.

Men Who Have Sex with Men

During the visit to Puerto Rico, the Commission found relatively few HIV prevention initiatives targeted at gay and bisexual men or at men who have sex with men but do not self-identify as part of the gay or bisexual community. The lack of efforts to reach these individuals, despite the fact that 18% of the reported AIDS cases on the island are in men who have sex with men, is the most glaring example of the impact of sexual taboos on Puerto Rico's response to the HIV epidemic (Puerto Rico Department of Health, 1992a). As stated by one witness:

> The bisexual and homosexual community in our country [Puerto Rico] is under a veil of persecution and attack that we know as "homophobia." The principal areas of the government sadly manifest this prejudice, and as a consequence, at the present time, the programs on education and prevention of AIDS in Puerto Rico do not include in their work, plans to reach our community (Santiago, 1990).

Although there are many informal gathering places for gay men in Puerto Rico, there are very few identifiably gay organizations, such as are found in New York and San Francisco (Cunningham, 1989). Because of the existing stigma associated with homosexuality, gay advocacy around HIV/AIDS issues has not been as strong or evident as in some mainland communities. The first organization to mobilize against AIDS in Puerto Rico was *Fundacion SIDA*. Although initially it was affiliated with the gay community, today 70% of its clients are substance users, and it is recognized primarily as an AIDS service organization (Toro, 1990), rather than as an organization specifically focusing on the problems of the gay community.

In 1990, the Commission was aware of only one prevention program, *Alto al SIDA*, that specifically targeted HIV prevention efforts to men who have sex with men; this program is funded by the Robert Wood Johnson Foundation through the Puerto Rico Community Foundation (Santiago, 1990). Neither the Commonwealth nor the municipal government had allocated resources specifically targeted for HIV prevention among men who have sex with men (Babb, 1990; Santiago, 1990).

The lack of a more coordinated effort to implement HIV prevention programs for this community has meant that in Puerto Rico it has not exhibited the profound behavioral changes seen on the U.S. mainland among men who have sex with men, a change particularly driven by the openly gay community. A survey of knowledge, attitudes, and behaviors of 207 men in San Juan helps to document this issue. Over 60% of the overall sample reported having had sex with at least one man in the past three months. Of these men, 33.9% reported that they did not always use condoms

with their male partners, and 17.7% reported never using condoms with their male partners (Crandon, 1991).

This lack of coordinated efforts is also reflected in the rates of increase in AIDS cases in men who have sex with men in Puerto Rico; between 1981 and 1990, there were 1,348 reported cases of AIDS in men who have sex with men on the island. Between 1988 and 1990, the number of AIDS cases within this same group increased by 394, (Puerto Rico Department of Health, 1992b). This 42% increase compares unfavorably with the comparative rate of increase of 36% of AIDS cases in men who have sex with men for the entire United States in the same 2 years (CDC, 1992a).

Experience in the mainland United States suggests that interventions by local community-based agencies undertaking HIV prevention efforts among self-identified gay and bisexual men, as well as among men who have sex with men but do not self-identify as such, have been effective. Other community-based efforts already in progress, particularly those utilizing "peer counseling" programs, can serve as potential models.

Substance Users

Puerto Rico has been devastated by the twin epidemics of HIV and substance use: a dynamic that has been nourished by the social and economic deprivation of those caught in this human tragedy. Only cities such as New York, Newark, and Jersey City have reported such high percentages of substance users among persons with AIDS. HIV prevention among substance users must be a priority if efforts to stem the tide of HIV transmission in Puerto Rico are to be successful.

This section will primarily document the impact of the HIV epidemic among injection drug users in Puerto Rico. However, alcohol consumption and the use of noninjection drugs also put individuals at risk of HIV infection by impairing judgment, which interferes with the use of protection during sexual intercourse. Puerto Rico has a high rate of alcoholism and use of noninjection drugs; however, most of the research on HIV and substance use has not covered these issues. The Commission encourages further research on the impact of alcohol and noninjection drugs in the spread of HIV in Puerto Rico.

Injection drug users (IDUs) in Puerto Rico are mostly young (60% under 35 years old) and predominantly male (78% male); over 50% have not finished high school and only 18% report regular employment as their source of income (Colon, Robles, and Hardeo, 1991). The sex partners of IDUs have a similar profile except that they are predominantly female. A study of 385 female sex partners of IDUs found that 51.3% were 20-29 years old, 59% had left high school before graduating, and 72% reported government programs as their sole source of income (Robles et al., 1990).

HIV infection rates among IDUs in Puerto Rico have been found to be very high, ranging from 45% to 60% (Colon et al., 1991). Factors believed to contribute to these high rates include long-term–more than five years–drug injecting, widespread use of "shooting galleries," the high frequency of drug injection that includes "speedballing" (injecting a combination of heroin and cocaine) and the use of heroin alone, the pervasive sharing of "cookers," and the high rates of syphilis and other sexually transmitted diseases within this group.

The Commonwealth government has responded to the spread of HIV among drug users by expanding access to treatment and providing information about HIV/AIDS in treatment facilities and mobile units. In 1990, the Department of Anti-Addiction Services (DESCA), the commonwealth branch in charge of all prevention and

treatment services for both drugs and alcohol, provided services to over 22,000 illicit drug users (Suliveres de Martinez, 1990). Working in cooperation with the AIDS Central Office of the Puerto Rico Department of Health, DESCA also coordinated HIV testing, counseling, and prevention programs in its treatment facilities. Similar efforts have been undertaken by the municipality of San Juan through the *Instituto del SIDA de San Juan*. The private sector has also played an important role. The Commission had the opportunity to visit *Hogares Crea*, the largest nongovernmental treatment program on the island providing services to over 4,000 substance users, mostly youth, islandwide.

The Commission is particularly concerned by the lack of services for women, especially pregnant women. As of September 1989, only 8.3% of people in public and private treatment facilities were women, despite the fact that women are estimated to represent 20% of drug users in Puerto Rico. In addition, a larger number of women live with their children, thus treatment programs need to take this into account (Robles, 1989).

The effort to provide accessible, comprehensive, long-term treatment for substance users and their families is an effective policy and must continue. Strategies to stop the further spread of HIV among substance users, however, must also take into consideration the complexities of substance use as a disease. Because of the well-documented recidivism, it is important to recognize the need to promote knowledge and adoption of safer injection practices among those who continue to inject. The use of sterile needles and bleach to prevent HIV transmission is complementary to efforts to reduce or eliminate drug injection habits.

In testimony to the Commission, the Secretary of Anti-Addiction Services acknowledged the lack of funding for the implementation of badly needed outreach efforts to follow-up on IDUs who have abandoned treatment and to assist others in avoiding relapse. A study of treatment utilization of over 1,600 IDUs in Puerto Rico found that 66% had at some point been treated for addiction, but usually not before they had an average of 10 years of drug use and suffered from a variety of health problems, making it difficult to succeed in recovery (Suliveres de Martinez, 1990).

In addition, as of November 1990, neither the Commonwealth government nor the municipality of San Juan had sponsored a needle exchange, bleach distribution, or condom distribution program for IDUs. Not surprisingly, an ethnographic study comparing 1,308 IDUs on the island, 1,383 Puerto Rican IDUs on the mainland, and 702 white IDUs on the mainland found that island Puerto Ricans scored lowest in the HIV knowledge test. Fifty percent of IDUs in Puerto Rico reported sharing their cookers and rinse water, and, of all the groups, island Puerto Ricans were the least likely (91.8%) to use bleach to clean needles and the least likely (88%) to always use condoms (Robles et al., 1991).

Despite the tragic situation faced by these individuals, efforts to reach IDUs have demonstrated that there is hope. A study on high-risk behavior among IDUs in San Juan found that they were willing to change high-risk behavior to prevent the transmission of HIV. After 778 IDUs were provided with HIV testing and counseling, referral to drug treatment programs, and information about HIV/AIDS service programs, 50% of the participants reduced their sharing of needles and other drug paraphernalia including cookers, 19.3% stopped using shooting galleries, and 8.5% stopped injecting altogether (Colon et al., 1991).

The need for resources to stop the spread of HIV among IDUs, their sex partners, and their children is urgent. Efforts to provide accessible, comprehensive, and long-

term treatment for addicted persons and their families must continue. In addition, efforts must be made to encourage and enable drug users to sterilize their injection apparatus with bleach and to educate them about clean needle/syringe programs if they are unable to stop using drugs.

The Commission recommends:

9. **That the Department of Anti-Addiction Services, the Puerto Rico Department of Health, nongovernmental organizations, and the federal government work together to create a strong, coordinated response to the twin epidemics of substance use and HIV. This response should include the expansion of treatment programs and establishment of bleach and clean needle/syringe programs.**

Women

Puerto Rico has one of the highest percentages of reported AIDS cases among women of all jurisdictions in the United States. Alarming indicators of the growing risk to women are the rates of HIV infection seen by the San Juan Municipal Hospital sentinel surveillance program. The percentage of infected women among those giving birth doubled in one year–from 1.87 in 1989 to 3.86 in 1990. One out of every 26 women giving birth at Municipal Hospital was HIV-infected (Feliciano, 1990).

Yet despite the high proportion of women with HIV infection in Puerto Rico, the Commission found at the time of its hearing that neither the Commonwealth nor the city of San Juan had prevention efforts targeting women specifically. Current efforts are centered in prenatal-care settings or in childbirth services and, although important programs, do not reach all women at risk.

Women who are injection drug users are obviously at risk and need to be aggressively targeted in prevention efforts. However, like the rest of the nation, Puerto Rico has limited drug treatment facilities for women.

Sex partners, typically women, of IDUs also need special attention. The previously mentioned study of 385 female sex partners of IDUs revealed that these women failed to assert and protect themselves from their drug using partners because of a profound sense of powerlessness. Although 84% reported recognizing that they had at least a chance of developing AIDS, 90% reported having had unprotected vaginal intercourse, with 52.6% citing their partners' discomfort as the reason for not using condoms (Robles et al., 1990).

Men who engage in unprotected bisexual practices place their partners at risk. In a survey of Hispanic men who have sex with men in the northeastern region of the United States and Puerto Rico, 28% of the 284 participants reported having had unprotected sex with a woman in the previous year (Amaro and Gornemann, 1992). Moreover, heterosexual anal intercourse, because it is not associated with the risk of pregnancy, is unlikely to involve the use of condoms unless specific HIV risk reduction behaviors are being practiced. A recent survey of the knowledge, attitudes, and behaviors of 3,901 students at the University of Puerto Rico found that of the sexually active students 30.9% of women having sex with men engaged in unprotected anal intercourse (Cunningham and Rodriguez, 1991).

Finally, their choice of contraception methods influences the need for targeted education efforts for some women. One study indicates that in Puerto Rico 58% of all contraceptive decisions involved female sterilization, whereas in the United States as a whole the comparable rate is 26% (Robles et al., 1988). The large percentage of Puerto Rican women who have been sterilized exacerbates the difficulties of

HIV/AIDS prevention. These women obviously need not avail themselves of condoms or other barrier methods of protection as a means of preventing pregnancy, yet these same measures would lower their risk of HIV transmission. Moreover, women who have been sterilized have no need to attend family planning clinics, a critical venue of education about sexual risk-taking and disease transmission (CDC, 1992b).

The women of Puerto Rico are living under circumstances which make them extremely vulnerable to HIV disease. During the Commission's visit, community advocates recommended a massive education and prevention initiative among women–from adolescence onwards–as essential to stemming the tide of further HIV transmission. Communitywide prevention efforts to provide explicit knowledge, behavioral change, and empowerment strategies to help women protect themselves must be part of these efforts.

The Commission recommends:

10. **That the Public Health Service, the Commonwealth of Puerto Rico, and community-based organizations continue, coordinate, and intensify existing prevention efforts. Additionally, these entities should develop ways to establish and expand prevention initiatives specifically targeted at adolescents; incarcerated populations; men who have sex with men; substance users; and women.**

CONCLUSION

The Commission is proud to have provided the forum for a public hearing on the impact of the HIV epidemic in Puerto Rico. The participation of over 30 invited witnesses and 20 individuals during the public comment period is testimony of the community awareness and concern about the HIV epidemic. As a national advisory body, the Commission's recommendations have focused on issues that need to be addressed in partnership between the people of Puerto Rico and the federal government. However, this report and the implementation of its recommendations ultimately belong to the people of Puerto Rico.

The Commission hopes that–in concert with the federal government–the Commonwealth and municipal governments, as well as community-based organizations already involved in the epidemic, look at these recommendations as incentives to continue their efforts and enhance their collaboration. Nevertheless, an effective response will not take place unless all sectors of the community, including government agencies beyond the health departments, are equally involved with a sense of urgency and willingness to allocate the resources necessary to adequately respond to the epidemic. The Commission calls for community-based organizations, churches and religious organizations, organized labor, trade associations, professional associations, small businesses, corporations, and others to join forces in responding to this crisis. To further communication and coordination, the Commonwealth government may wish to consider creating a forum in which all sectors of the community can come together to be part of the response to the epidemic. Only through a massive effort and coming together of numerous agendas can Puerto Rico respond to and survive this great challenge.

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APPENDIX

NATIONAL COMMISSION ON AIDS
AGENDA
HEARING OF NOVEMBER 27-28, 1990
SAN JUAN, PUERTO RICO
GOLD ROOM - RADISSON NORMANDIE HOTEL
Corner of Munoz Rivera Avenue and Rosales Street
TUESDAY, NOVEMBER 27, 1990

8:15 a.m. OPENING REMARKS

June E. Osborn, M.D., Chairman

GREETINGS

Antonia Novello, M.D., M.P.H., U.S. Surgeon General

WELCOME

Angela Hernandez de Freer, M.D., Acting Secretary of Health, Puerto Rico Department of Health (PRDH)

8:30 a.m. HIV/AIDS SERVICES IN PUERTO RICO

Kenneth Castro, M.D., M.P.H., Assistant Chief, Epidemiology Branch, Division of HIV/AIDS, Centers for Disease Control, Atlanta, Georgia
Johnny Rullan, M.D., M.P.H., Executive Director, AIDS Central Office, (PRDH)
Pedro Borras, M.D., Director, Department of Health, City of San Juan
Luis Maldonado, Person living with AIDS and Director, Proyecto Corazon, Ponce, Puerto Rico

9:30 a.m. FINANCING OF CARE

Laura E. Torres, Acting Director, Health Facilities and Services Administration, (PRDH)
Guillermo Otero, M.D., Sub-Regional Director, U.S. Public Health Service, Puerto Rico
Jaime Rivera-Dueno, M.D., Executive Director, Instituto del SIDA de San Juan

10:30 a.m. Break

10:45 a.m. AVAILABILITY OF CLINICAL TRIALS AND EXPERIMENTAL DRUGS

Carlos H. Ramirez Ronda, M.D., F.A.C.P., Associate Chief of Staff for Research and Development, Veteran Affairs Medical Center, San Juan, Puerto Rico
Jorge Irizarry, Person living with HIV

11:15 a.m. HIV/AIDS AND SUBSTANCE USE

The Honorable Isabel Suliveres de Martinez, Secretary, P.R. Department of Anti-Addiction Services, (DAAS)
Lydia Santiago and Henry Bodhwell, Residents, Hogar Crea las Americas

11:45 a.m. The Honorable Hector Luis Acevedo, Mayor, City of San Juan

11:55 a.m. LEGAL AND ADVOCACY ISSUES

Lydia Platon, Special Assistant, Disability Ombusdman for the Commonwealth of Puerto Rico
Nora Vargas, Esq., Sabana AIDS Litigation and Civil Rights Project, San Juan, Puerto Rico
Raul Villalobos, M.D., Executive Director, Correctional Health Program, (PRDH)
Trina Rivera de Rios, Ph.D., President, Comite de Amigos y Familiares de Confinados, Inc.

12:45 p.m. Commission's Press Conference, Radisson Normandie Hotel - Gold Room

1:15 p.m. Lunch

2:00 p.m. Site visits to facilities in the San Juan Metropolitan Area

7:00 p.m. Reception for the National Commission on AIDS offered by the Honorable Rafael Hernandez Colon, Governor of Puerto Rico, at La Fortaleza (the Governor's Mansion)

WEDNESDAY, NOVEMBER 28, 1990

8:15 a.m. MIGRATION PATTERNS AND THE HIV EPIDEMIC

Eunice Diaz, M.S., M.P.H., Member, National Commission on AIDS

8:30 a.m. HUMAN AND SOCIAL SERVICES

Gladys Altieri, Ph.D., Special Assistant to the Secretary of the Department of Social Services
Jose Nunez Lopez, M.D., Assistant Secretary for Mental Health, (PRDH)
Joaquin Fernandez Dumont, Liaison, Community Based Organization, AIDS Central Office, (PRDH)
Family living with AIDS, Clinica de Servicios Pediatricos, Proyecto Amistad, Instituto del SIDA de San Juan, Departamento de Salud de la Capital
Jose Toro, Ph.D., Executive Director, Fundacion SIDA, San Juan, Puerto Rico
The Reverend Francisco Garcia, Albergue la Providencia, Ponce, Puerto Rico

9:40 a.m. SPECIAL ISSUES FOR WOMEN AND CHILDREN WITH HIV/AIDS

Carmen Feliciano de Melecio, M.D., Director, Federal Programs, Department of Health, City of San Juan
Carmen Zorilla, M.D., Co-Investigator, WITS Project, University Hospital, University of Puerto Rico (UPR), Medical Sciences Campus (MSC)
Clemente Diaz, M.D., Principal Investigator, Proyecto Gamma, Children's Hospital, (UPR) (MSC)
Nancy Santiago, M.D., Director, HRSA Pediatric AIDS Service Demonstration Project, (PRDH)
Maria de los Angeles Calderon, Proyecto Tu, Mujer, (DAAS)

10:35 a.m. Break

10:50 a.m. PREVENTION AND EDUCATION EFFORTS

Juan Morales, M.P.H.E., Coordinator, Education Programs, AIDS Central Office, (PRDH)
Daisy Gely, M.P.H.E., Director, AIDS Education and Training Center, (UPR)
Enrique Nieves, M.S., Coordinator, HIV/AIDS Prevention Program, (PRDH)
Wilfredo Santiago, Director, Alto al SIDA, San Juan, Puerto Rico

11:45 a.m. Public Comments

12:15 p.m. Lunch

1:00 p.m. Site visits to facilities throughout the Island

NATIONAL COMMISSION ON AIDS

SITE VISITS
PUERTO RICO
NOVEMBER 27-28, 1990

1. Hogar Crea las Americas

   Juan Jose Garcia, President
   Hogares Crea de Puerto Rico
   Calle Teniente Cesar Gonzalez
   1105 Villas Nevares
   Rio Piedras, Puerto Rico 00927

2. Instituto del SIDA de San Juan

   Jaime Rivera Dueno, MD, Director
   Jeannette Sotomayor, Esq., MPH, Administrator
   Instituto del SIDA de San Juan
   P.O.Box 13964
   Santurce, Puerto Rico 00903

3. Latin American Center for Sexually-Transmitted Diseases, CLETS

   Carlos Gadea, MD, Director
   Primer Piso Casa de Salud
   Medical Center
   Rio Piedras, Puerto Rico 00936-1423

4. Fundacion SIDA de Puerto Rico

   Jose Toro, Ph.D., Executive Director
   Calle 16 Esq. 15, 1200 S.E.
   Caparra Terrace, Puerto Rico

5. Proyecto Amor

   Marisa Blay, Director
   Barrio Caimito
   Rio Piedras, Puerto Rico 00926

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10. Centro de Diagnostico y Tratamiento de la Playa de Ponce

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