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STATE OF FLORIDA
Governor's Red Ribbon Panel on AIDS

January 19, 1993

Dear Governor Chiles,

I am writing this letter on behalf of the members of the Red Ribbon Panel on AIDS and enclosing with it our report to you.

First, we all thank you for the privilege and opportunity to serve you and the State of Florida in our capacity as panel members. As Governor, your attention to the HIV/AIDS epidemic is crucial and appreciated.

You asked us to bring to you recommendations on how to improve HIV/AIDS prevention and education in Florida and how better to care for AIDS patients in more cost effective manners.

We are mindful that HIV infection spread for many years before we knew of its existence and that in order to prevent new infections we must promote behavior changes that are difficult at best.

And, regretfully, the fight against HIV/AIDS is further hindered by ignorance, prejudice, and political rhetoric. We are therefore especially grateful to your direction that we put emotion aside and save lives!

There is no vaccine, no cure, no law that can give us absolute protection from HIV infection. And, government's role is to encourage individual responsibility, not to take its place.

Although there are no easy solutions, we believe that there is much we can all do to stem the spread of HIV infection and to more effectively care for those persons already infected. Our report contains numerous strategies that must work together because in isolation they are not effective.

Finally, we will need the courage to face up to the truth of HIV/AIDS. The consequences of not doing so will continue to devastate too many young lives.

Respectfully,

Lois J. Frankel
Chair, Red Ribbon Panel on AIDS

GOVERNOR'S RED RIBBON PANEL ON AIDS

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/* We have left the table of contents as in the original; unfortunately, the page numbers no longer mean anything because of the reformatting necessary to have this document display through our program.*/

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EXECUTIVE SUMMARY

The recommendations of the Governor's Red Ribbon Panel on AIDS provide strategies for preventing the spread of HIV/AIDS in Florida and for improving the care of those already infected. Each recommendation is not meant to stand alone, but together they comprise a comprehensive approach for addressing the critical challenge of HIV/AIDS.

The following is a list of the major recommendations submitted by the Panel. More specific details of and the summary and rationale for the recommendations are included in the body of the report.

PREVENTION AND EDUCATION

(Rationale and more specific recommendations found on pages 8-15.)

- Comprehensive health and HIV/AIDS education in grades K through 12 should be a joint priority of the Department of Education and the local school boards. This education effort should be fully funded and should be taught by certified health educators. The state should set instructional guidelines and specific goals and outcomes for which the local school districts are accountable and below which local school boards may not go. Education should include emphasis on abstinence and monogamy; however, prevention

strategies should include non-penetration to penetration protection.

- Educators should be required to complete HIV/AIDS education.
- Parents should be educated about HIV/AIDS.
- A major initiative should be jointly undertaken by the government and the private sector to provide adult supervised after-school activities for adolescents.
- The number of school health services should be expanded.
- HIV/AIDS education should be required in Florida's universities and community colleges.
- Peer education should be promoted.
- Efforts to target HIV/AIDS prevention activities with sensitivity to cultural and language differences should be intensified.
- Promote AIDS/HIV education in the workplace.
- The development and distribution of state-of-the-art, culturally specific prevention materials should be pursued.
- Condoms and condom skill training combined with efforts to encourage peer acceptance must be made available wherever appropriate.
- Increase efforts to address HIV in women.
- HIV/AIDS education should be required for attorneys, judges, in-court and county jail personnel.
- HIV/AIDS education for health care providers should not be weakened, but should be coordinated.
- Funding for HIV/AIDS prevention and education efforts should be increased.

CARE AND TREATMENT AND LIVING WITH AIDS ISSUES

(Rationale and more specific recommendations found on pages 16-17.)

- Provide universal health care coverage for all Floridians.
- Increase the number of health care providers willing to provide medical and dental care for HIV-infected patients.

- Increase the number of nursing homes that accept HIV/AIDS patients and develop alternative housing arrangements for PWAs.
- Facilitate greater access to drug therapies for treatment and prevention therapy, including marijuana when medically indicated.
- Confront the issue of health care for illegal aliens.
- Promote nutrition counseling.
- Determine the best course for establishing pediatric and adolescent HIV/AIDS care statewide.
- Address the spread of tuberculosis among HIV-infected persons.
- Expand case management of patients and coordination of client services.
- Expand the AIDS Insurance Project statewide and continue the Medicaid Waiver Program.

COUNSELING, TESTING AND PARTNER NOTIFICATION

(Rationale and more specific recommendations found on pages 18-21.)

- Increase and advertise the availability of confidential and anonymous testing. Testing should continue to be with informed consent and with pre- and post-test counseling.
- Avoid mandatory testing policies.
- Increase efforts to promote voluntary counseling and testing programs as part of primary health care, for child-bearing women and newborns, and in prisons.
- Partner notification should remain voluntary, confidential and without revealing the name of the source.
- Do not require mandatory name reporting by law, but increase efforts to encourage the use of the Department of Health and Rehabilitative Services (HRS) voluntary partner notification programs by the patients of private physicians.
- Maintain and expand laws which prohibit discrimination against persons with or perceived to be HIV infected.

- Develop mechanisms to clarify current Florida laws regarding testing, including allowing physicians to do anonymous testing in their offices.

SUBSTANCE ABUSE

(Rationale and more specific recommendations found on page 22.)

- Remove legal barriers which prevent clean needle exchange in conjunction with drug abuse treatment programs.
- Increase drug abuse treatment programs and strengthen education efforts for drug abuse and mental health counselors.

GOVERNMENTAL ACTION

(Rationale and more specific recommendations found on page 23.)

- Establish a permanent HIV/AIDS Advisory Panel and appoint an HIV/AIDS Policy Advisor.
- Increase ethnic minority participation in the HRS AIDS Program at the state level.
- The Governor should call a leadership conference on HIV/AIDS to educate Florida's leaders on the seriousness of HIV/AIDS prevention.
- Increase funding at all levels of HIV/AIDS prevention, education and care.

INTRODUCTION

HIV/AIDS is one of the most critical challenges facing the world today. It is especially tragic because it is striking young people during the most productive years of their lives. The proportions of this epidemic have created an urgent need for all of us to join together in the fight against the further spread of the disease.

Florida has seen more than its share of the HIV epidemic. Florida continues to rank third in the nation in the cumulative number of reported AIDS cases and second in the nation in pediatric cases. A cumulative total of 24,976 AIDS cases were reported in Florida as of December 31, 1992, with 8,742 of these persons presumed living and requiring care. In addition, an estimated two to three times as many persons require medical attention for HIV-related diseases. Based on 1990 estimates, 120,000 Floridians are currently living with HIV. Approximately 70-80% of these persons are thought to be unaware

of their infection.

HIV/AIDS has quickly become a statewide challenge. Although 60 percent of the adult cases in Florida have been reported from the southeastern counties of Dade, Broward, Palm Beach and Monroe, all of Florida's 67 counties have reported one or more cases of AIDS.

The face of AIDS is changing. State data show that the HIV/AIDS epidemic has disproportionately affected minorities. Although black and Hispanics compose only 25 percent of Florida's population, they represent 51 percent of all reported AIDS cases in the state.

Florida's AIDS cases differ in significant ways from the national averages. Six percent of the nationwide cases have been heterosexually transmitted compared with 17 percent in Florida. In addition, women represent ~ 1 percent of the total number of cases nationally compared to 16 percent in Florida.

In response to this increasing challenge, on November 24, 1992, Governor Lawton Chiles commissioned a Red Ribbon Panel to develop specific recommendations on ways to bolster the state's HIV/AIDS education and prevention programs, as well as to address the many needs of persons with HIV/AIDS and their families. Governor Chiles asked the Panel to put aside emotion and to be objective in its mission. The purpose of the report submitted by the Panel is not political, but is intended to present recommendations which will save lives.

The Governor's Red Ribbon Panel on AIDS represents a diverse and multidisciplinary group. This membership was intended to bring together a broad range of expertise, opinions and cultural experiences. The 11 members came from all parts of the state and included two physicians, three nurses (two of whom also have Master's Degrees in Public Health), two attorneys, two persons with HIV disease, an educator with a doctorate in sexology and two administrators of relevant patient service programs (one in patient medical services and the other in hospice services). With this solid and broad foundation on AIDS issues, the Panel went to the community for input on innovative and effective strategies for fighting this disease. The Panel held forums in Tallahassee, Jacksonville, Tampa and Ft. Lauderdale and received testimony on a wide range of issues. Written testimony was also received and considered.

The testimony received by the Panel gave clear and convincing evidence of the complexity and wide-ranging impact of HIV and AIDS on Florida's

communities. Testimony from throughout Florida reinforced the need to treat HIV and AIDS comprehensively. Fighting AIDS can not and should not be addressed in isolation from other social problems.

The Panel repeatedly heard testimony that HIV/AIDS educational efforts need to be more consistent, more accurate, and more intensive. Surveys indicate that even when people are informed about HIV, they do not always change behaviors to protect themselves from infection.

Without a vaccine, the key to preventing the further spread of HIV is education and prevention strategies that promote healthy behaviors and reduce risk-prone behaviors. Our reluctance to talk about sex and controversial lifestyles causes information to be withheld which can save lives.

From across the state, the Panel heard testimony about the problems in accessing health care. Many voiced concerns about long waiting lists and limited access to care. Although much has been done to provide care and treatment for persons with HIV infection, much more needs to be done.

Testimony heard by the Panel also emphasized the benefits of anonymous and confidential HIV counseling and testing services as an important tool in preventing the spread of HIV infection. The Panel heard repeated testimony on the reality of discrimination against persons with HIV infection and how the fear of discrimination may prevent a person from coming forward to be tested. Anonymous and confidential testing remove this obstacle.

Many persons involved with drug rehabilitation programs came forward with testimony for the Panel. With one exception, all testified that a clean needle exchange program should be part of a comprehensive drug abuse treatment program to break the link between dirty needles and HIV infection.

Although the government should play a major role in preventing the further spread of HIV/AIDS, there is no substitute for personal responsibility. There is no magic wand. Behavior change has been documented as very difficult to influence. Government can and should play a major role in facilitating conditions to encourage citizens to behave in ways that promote health and reduce the risk of contracting HIV/AIDS. There must be a united campaign both in the public and private sectors if we are to win this battle.

AIDS is a public health emergency and is different in many ways from other diseases. The implications of AIDS affect everyone. Although AIDS is a sexually transmitted disease, it is not like other sexually transmitted diseases. Just listen to the voices of Floridians who are infected with HIV. Unfounded fears and ignorance surround this disease and hinder our fight.

We must face up to HIV/AIDS with the courage to tell the truth and the strength to fight the disease, not people with the disease. Otherwise, the consequences will become increasingly more devastating.

PREVENTION AND EDUCATION STRATEGIES

SUMMARY AND RATIONALE

We do not know the cure for HIV/AIDS disease, but we do know that it is preventable. Transmission of HIV is the result of certain well-documented behaviors, to wit: exchange of infected body fluids (semen, vaginal secretions and blood) during sexual contact, sharing of HIV contaminate needles, from an HIV infected mother to her fetus and to her newborn by breast feeding, and through exposure to infected blood products or blood such as with serious needle sticks.

Therefore, if we can successfully prevent certain dangerous behavior, we can drastically reduce the number of new infections. The key to reducing the spread of HIV, at this time, is education, education, and more education.

When we say education, we mean more than the sharing of information. We are talking about education and prevention strategies that promote healthy behavior, that deter risk prone behavior, that promote a safe work environment, and that reduce the unfounded fears that lead to discrimination against persons with HIV/AIDS.

Our message must be clear that HIV/AIDS is everybody's problem. It is a disease that affects heterosexual men and women as well as gay men and IV drug users. It is a disease caused by behavior . . . not status, sex, skin color, sexual orientation, or age.

Our panel heard repeatedly from persons testifying that our education efforts need to be more consistent, more accurate, and more intensive. Our reticence to talk about sex, and to talk about controversial life-styles causes us to withhold lifesaving information even from those people we love the most: our children.

For us to have a chance to stop HIV infection, we must all join together and be willing to face the truth and tell the truth. Political, social, educational, religious and health leaders, schools, community based organizations, religious institutions, civic clubs, and media organizations must all play a role in our fight against HIV/AIDS.

And we must do more. The average lifetime cost of caring for one AIDS

patient is \$103,000. The money we spend now on prevention is well worth the cost. In the past decade, the average AIDS patient was likely to be well-educated and to have a career. As the epidemic affects more persons who are disenfranchised, a smaller proportion of these patients will be financially self-sufficient or insured, increasing the cost to state and local governments. Even persons with medical insurance, there may be treatments which are not covered by insurance. There will be loss of earnings and eventually complete disability. This imposes not only a financial cost to the patient, but to society when individuals can no longer perform as productive members of society. There are also non-treatment related costs incurred by health care providers, such as expenses for additional supplies, training, and testing.

Prevention and Education in Schools

Our hearings revealed that Comprehensive Health Education, including AIDS education required by Florida law, is inconsistent and of varying quality around the state. Local politics often interfere with providing our youth with the information, guidance, and skills that they need to live healthy productive lives.

Quality comprehensive health education programs, which include HIV/AIDS prevention as a component, are minimally 50 hours in length at each grade level and taught by trained certified health educators. One-time ("everyone to the auditorium") AIDS education by itself is not an effective means of fighting the spread of this disease because the prevention message needs to be constant and repetitive.

The Florida Youth Risk Behavior Survey Report issued in February 1992 presents an alarming picture of Florida students. Of those surveyed, approximately 47 percent of ninth graders and 80 percent of twelfth graders had had sexual intercourse. Less than 50 percent had used a condom the last time they had sexual intercourse.

These statistics, which are consistent with national surveys, mean that parents and teachers must take their heads out of the sand and face up to the reality of their children's activities. Therefore, although controversial, condoms and condom skill training, as well as specific prevention strategies which address the range of sexual activities (i.e., penetration vs. non-penetration), are necessary parts of a comprehensive health program. (By law in Florida, parents are allowed to opt their children out of comprehensive health education. Although we discourage parents from exercising this option, it should be available.)

Condoms should never be viewed as a substitute for education on abstinence and monogamy as first choices or as a substitute for the supervision of our children by responsible adults. A recent study by the Carnegie Council on

Adolescent Development reported that half of America's 20 million children between the ages of 10 and 15 go unsupervised after school, leaving too much time to join gangs, do drugs, and have sex. Florida currently has 750,000 children between the ages of 10 and 15. The more hours that our children are engaged in activities that promote healthy behavior such as sports, drama, debate clubs and community service, the less time they will have to be sexually active and at risk for HIV infection.

School based health services have also proven to be effective in promoting healthy children. Studies show that where students have access to primary health care at school they are healthier and more productive.

The recommendations of the Panel reflect the fact that as schools prepare for the 21st century, their academic role has enlarged to include consideration of social, health, mental health, and support services for children and families. Changed demographics, growing poverty, more people with multiple problems, and a rising demand for skills to survive in society, bring pressure to the system. Support for the role of schools in addressing these issues is justified for a variety of reasons: the adverse effect of non-school problems on school performance, the adverse impact of poor educational performance on individual and national economic success, and the high cost of public dependency resulting from education, health, and social deficits. However, schools do not operate in a vacuum and should not be expected to take on further services with no or even short-term discretionary funds. New approaches attempt to draw schools in as equal partners with health and social services agencies: each sector must contribute resources.

Research indicates that information alone or a fear based approach in education may increase knowledge, but is largely ineffective in changing behavior. Literature indicates only a modest relationship among changes in knowledge, attitudes, and behavior. When such programs lead to behavior change, the changes are often small and usually involve delaying the onset of a behavior, rather than preventing it altogether. Furthermore, studies show that neither provision of sexuality education nor of condoms through school-based health services results in the increase or earlier onset of sexual behavior.

These recommendations reflect over ten years of research which documents that achieving better outcomes for children and their families requires at least three elements: comprehensive services, increased involvement of parents, and changes to make schools and agencies more responsive to children and families. This research indicates how difficult it is to change behavior through traditional classroom-based approaches that do not include these three elements and shows that to employ these elements can lead to a change in student behavior.

The most up-to-date programs involve curricula that are based on social learning theories that provide students with information as well as training in social skills to resist pressures from peers, family, or the media; with skills to make thoughtful decisions about health behaviors; and with opportunities to role-play and practice their skills. When these more comprehensive programs have been combined with efforts to enlist parental, community, and media support, there is evidence that these broader initiatives are effective in reducing health risk behavior, including affecting problems related to sexual behavior.

Prevention and Education Activities in the Community

HIV/AIDS education is most effective when it is targeted, culturally specific and involving messengers (peer educators) who have the ability to bond with the receiver of their communication. Analysis of health indicators is useful in targeting education efforts toward populations most at risk. During testimony, the Panel heard some complaints that education materials were sometimes ineffective due to a reticence to use explicit materials.

There is a large segment of the population which is outside the mainstream of public and private school educational efforts. This is particularly true of our migrant communities, who are often geographically and socially isolated.

Education in the workplace can be a valuable tool, both in prevention and in fighting discrimination. Persons infected with HIV remain otherwise healthy and productive for many years until weakened by the disease. Workplace HIV/AIDS education would enable workers to learn lifesaving prevention strategies for use in their private and working lives (i.e., responding to an injured co-worker), as well as to minimize disruptions in the workplace.

Condom availability and skill training in usage are crucial prevention strategies. Mere knowledge that a condom reduces the risk of HIV transmission and the availability of condoms are not sufficient strategies alone. Knowledge and availability must be combined with peer influence and correct usage. Only when condom use becomes culturally accepted as required behavior for sexually active persons will safer sex become prevalent in our society.

Education in Health Care and Other Professions

Florida law requires HIV/AIDS education for numerous health care professionals and others such as cosmetologists, law enforcement officers, and drug abuse counselors. Testimony was heard concerning the need to coordinate these educational efforts.

Due to the changing face of HIV/AIDS and the increasing incidence of AIDS

cases, additional education for some and new requirements for other professions were recommended by persons testifying. There is a special urgency that health care workers who come into regular contact with women of child-bearing age be informed of the signs and symptoms of HIV disease in women and be alerted to counsel them on prevention. There was a concern expressed that due to the increasing number of legal issues related to HIV disease, lawyers, judges, in-court personnel, and jailers should be required to complete an HIV/AIDS education course. Educators should also be required to complete a HIV/AIDS education course.

Prevention and Education in Prisons

There is a higher proportion of infected persons in the prison population than in the general population. This is especially due to IV drug use among men and trading of sex for drugs by women. HIV/AIDS education in prisons is currently required by Florida law.

RECOMMENDATIONS FOR PREVENTION AND EDUCATION STRATEGIES

-The public and private sectors must face up to the seriousness of HIV disease by joining together in the fight against it. This will require a multitude of sustained efforts with a willingness to face up to the truth or be ready for devastating consequences.

-Comprehensive health and HIV/AIDS education as mandated by Florida law in grades K through 12 should be a joint priority of the Department of Education (DOE) and local school boards. In this regard:

It must remain mandated by state law;

It must be fully funded;

It must be taught by trained certified health educators;

It must be presented for an effective number of hours at every level;

The state must set instructional guidelines;

The state must set specific goals and student outcomes related to HIV prevention for which local school districts are accountable;

The DOE must provide technical assistance, training, and materials for local school boards and private schools;

-Parents must be made aware of the results of the Florida Youth Risk Behavior Survey report and the degree of youth involvement in at-risk

activities. Parents must understand the importance of prevention strategies and be educated to participate in prevention.

-The state must require HIV/AIDS education for all educators licensed by the state of Florida and other school board, community college, and university personnel who come into regular contact with students.

-A major initiative should be taken jointly by the government and private sector to provide adult supervised after school activities for children.

-The number of supplemental school health services should be expanded so that all of Florida's children are served. HIV/AIDS prevention plans should be required as part of participant applications.

- HIV/AIDS education should be required in Florida's universities and community colleges beyond the fliers or pamphlets currently distributed pursuant to the Omnibus AIDS Act of 1988.

- Peer education of all types, including AIDS awareness clubs on school campuses, must be encouraged.

- Peer education training should be established throughout the state.

- The use of pertinent health indicators as a tool in targeting HIV/AIDS prevention efforts should be expanded.

- Efforts to target education/prevention strategies at populations most at risk for HIV infection, with sensitivity given to cultural and language differences, should be expanded.

- Prevention strategies based upon knowledge gained from the Centers for Disease Control (CDC) AIDS Community Demonstration Projects and similar efforts should be supported.

- Prevention efforts to reach out-of-school youth (migrant, runaway, drop outs, homeless) should be intensified.

- Prevention outreach programs by community based organizations should be intensified and given the leeway to use non-judgmental, culturally sensitive strategies without undue restrictions based upon prejudice or paranoia.

- HIV/AIDS education prevention efforts in the work place should be promoted to reduce risk prone behavior and promote a non-hostile work atmosphere for HIV infected employees.

- The Department of Health and Rehabilitative Services should pursue state-of-the-art prevention materials and act as a facilitator for same.

- The CDC required review panel for HIV/AIDS prevention materials should include at least one person with HIV disease.

- Intensify efforts to make male and female condoms more available in various colors, including skin tone, and in such places as supermarkets, restaurants, hotels, laundromats, convenience stores, gas stations, doctors' offices, hospitals, counseling and testing sites, colleges and universities, drug abuse treatment centers, community based outreach programs, labor camps, community health centers, movie theaters, rest stops, public rest rooms, homeless shelters, bars, lounges, schools (should be part of a comprehensive health education program and health services), and prisons (should be part of a comprehensive HIV/AIDS prevention program for inmates in the Department of Corrections) and should be available upon discharge for both male and female inmates.

- Intensify efforts to promote safer sex and condom skill training with strategies that promote peer acceptance of usage. These efforts should be made whenever possible where condoms are made available, and, including but not limited to, testing and counseling sites, physicians' offices, at community outreach programs, civic clubs, health clubs, drug abuse treatment programs, colleges and universities, places of employment, labor camps, community health centers, schools (although controversial, this should be done as part of age appropriate, comprehensive health education in the schools where parents are allowed both participation and an ability to opt out their children), prisons (as part of comprehensive programs), and to prostitutes.

- Special attention should be given to the education of gynecologists, obstetricians and other health care providers on the need to counsel and test women for HIV infection and on the signs and symptoms of HIV disease in women. Endorsement of this proposal should be sought from the Black Nurses Association, the Florida Nurses Association, the Florida Medical Association and other related professional organizations.

- HIV/AIDS education should be required for attorneys, judges, in-court personnel and county jail personnel.

- Health care provider education requirements under Florida law should not be weakened. Health care providers should be better informed as to the public policy rationale for the AIDS laws to provide better acceptance by them.

- A panel with representatives from varied professions mandated to take

HIV/AIDS education courses under Florida law should be formed to coordinate educational efforts and develop a standard core curriculum.

-Funding for the AIDS Hotline should continue and services expanded for Haitian-Creole users.

-Funding for prevention and education efforts must be increased.

CARE AND TREATMENT AND LIVING WITH AIDS ISSUES

SUMMARY AND RATIONALE

The federal, state and local governments, community based organizations, and others have made major efforts to deal with the care and treatment of persons with HIV infection. Much more, however, needs to be done. Good programs should be expanded. Prejudices in the health care field need to be eliminated. In hearing after hearing, the Panel heard testimony about waiting lists for treatment and housing. We heard about doctors, dentists and nursing homes that refused patient care.

We also heard about successful efforts that should be expanded. The state Medicaid Waiver Program allows Medicaid dollars to be sent in cost effective manners which keep AIDS patients at home instead of in hospitals. Florida's AIDS Insurance Project, in which the state pays insurance premiums for some HIV patients, was praised as far more cost effective than having the state pay the full cost of a patient's care through Medicaid. Case management and coordinated client services were touted as more effective and less costly care for AIDS patients. We heard encouraging testimony concerning the use of nutrition programs in treating AIDS patients. We also heard about the potential for new drug therapies that were not being offered through the state Medicaid program.

There was testimony about new medical issues related to HIV/AIDS. This included great concern about the spread of tuberculosis (TB) due to its link to HIV. People with HIV infection are especially vulnerable to TB; they acquire TB infection more readily and TB often makes them sicker more quickly than persons with normal immune systems. In outbreaks of multidrug resistant (MDR-TB), many people with HIV infection have died only a short time after becoming ill. There was also increasing concern for children with AIDS. There was agreement by all that access to quality health care services for all Floridians would be a giant step in our fight against HIV infection.

RECOMMENDATIONS FOR CARE AND TREATMENT AND LIVING WITH AIDS

ISSUES

- Universal health care coverage should be provided for all persons living in Florida to ensure access to quality health care services.
- Patient care funding must be increased.
- Intensify efforts to broaden the number of medical and dental health care providers willing to care for HIV-infected patients.
- Increase efforts to make nursing homes comply with state and federal laws which require that they accept HIV/AIDS patients.
- The state should facilitate greater access to drug therapies for treatment as well as preventive therapy. This should include access to marijuana when medically indicated.
- The state must continue and expand its Medicaid Waiver Program.
- The state must confront the issue of health care for illegal aliens.
- Nutrition counseling should be encouraged as part of post-test counseling and part of treatment for those who test HIV positive.
- A task force should be created to determine the best course for establishing pediatric and adolescent AIDS care statewide.
- The increased spread of tuberculosis among HIV-infected persons must be confronted. There should be efforts to educate persons providing services for HIV patients about TB and efforts to resume direct observation of medication intake by TB patients.
- Case management of patients and coordination of client services should be encouraged as less costly and more effective care for AIDS patients.
- The state should expand the AIDS Insurance Project statewide as it has proven to be cost effective.
- Develop alternative housing arrangements for PWAs and coordinate those efforts already in place.

COUNSELING, TESTING AND PARTNER NOTIFICATION

SUMMARY AND RATIONALE

Counseling and testing is an important tool in preventing the spread of HIV infection. With rare exception, testing should be voluntary, by informed consent, involve pre- and post-test counseling, and be confidential or anonymous.

Testing by itself is not an effective prevention tool because behavior change requires education. That is why pre- and post-test counseling are so important. The pre- and post-test counseling requirements by Florida law are often the only time a person receives individual, one-on-one, counseling concerning the transmission of HIV infection. Although counseling lengthens a patient's visit to a physician's office, this is a lifesaving strategy which should not be eliminated.

Counseling effectiveness is increased when it is done in a person's primary language and by a peer. Establishing a bond of trust is often a pre-condition of opening the ears and mind of the listener, making the messenger sometimes as important as the message. The availability of male and female condoms, as well as condom skill training by trained counselors, should be part of the counseling.

Confidentiality is also important. One only has to be reminded of the shameful burning of the home of the Ray family when they disclosed that their three sons were HIV infected. Our Panel heard repeated testimony about the fears of discrimination as well as actual discrimination against persons with HIV. Fear of discrimination may be an obstacle preventing a person from coming forward to be tested. Confidentiality or anonymity in testing removes that obstacle.

Florida's anti-discrimination laws are also important prevention tools in the fight to stop the spread of HIV infection. Despite political rhetoric to the contrary, protecting civil rights and stopping the spread of HIV/AIDS are compatible. In fact, this was recognized by President Reagan's Presidential Commission on the Human Immunodeficiency Virus Epidemic in 1988. That commission recommended strong laws protecting persons with HIV from discrimination in all aspects of life including employment, housing, and public accommodations.

The reason for this is two-fold. First, anti-discrimination laws (along with confidentiality) allow people to feel secure about being tested without losing an important part of their life, such as their job or their insurance, should they test positive. Second, if persons with HIV are taken out of the mainstream of society due to discrimination while they are still productive, the tragedy of HIV infection is compounded both for the individual and for the community.

Mandatory testing policies, although often thought of as a good idea on the surface, are not cost effective and are contrary to public health efforts, as well as to a democratic society. For example, mandatory testing of all health care workers, while not only ineffective in terms of cost, could lead to health care workers refusing to treat HIV infected persons, and could cause a relaxation of their use of universal precautions. Instead, routine, voluntary counseling and testing programs may be effective in a variety of circumstances. These efforts should be intensified in all prisons. Physicians should be encouraged to counsel and test women of childbearing age, their newborns, persons who are sexually active, and drug users. HIV counseling and voluntary testing, where appropriate, should be offered with all primary care visits and entry into health care facilities.

Public health officials testified that voluntary partner notification efforts have been relatively successful in Florida. Currently in Florida, all persons who are tested in the public sector and found to be HIV positive are offered assistance with contacting their partners. This is a voluntary service that is done confidentially and without naming partner source. Increased efforts are appropriate to ensure that Florida physicians are fully aware of the legal requirements to notify their patients of this service and to encourage the use of it.

The issue of mandatory name reporting of HIV infected persons is controversial. Those who favor reporting want to collect epidemiological data and to expand partner notification activities for private patients of physicians. The opponents of HIV reporting are concerned that name reporting would deter persons from being tested and that this would have the effect of the disease going underground. Other opponents argue that mandatory reporting is too great an intrusion by government into individual privacy without substantial benefit to the public. The Panel unanimously rejected mandatory name reporting, finding that both epidemiological analysis as well as expansion of voluntary partner notification services were possible without name reporting.

RECOMMENDATIONS FOR COUNSELING, TESTING AND PARTNER NOTIFICATION

- Increase and advertise the availability of confidential and particularly anonymous testing.
- Testing should continue to be by informed consent, voluntary, confidential or anonymous, with pre- and post-test counseling.

- Mandatory testing policies are rejected as non cost effective, contrary to public health efforts, and adverse to a democratic society. This includes, but is not limited to, mandatory testing of all health care workers, marriage applicants, prisoners, and patients admitted to health care facilities.
- Routine, voluntary counseling and testing programs should be continued and intensified in all prisons.
- Intensify efforts to promote counseling and voluntary HIV testing where appropriate as part of primary health care and entry into health care facilities.
- Intensify efforts to promote voluntary counseling and testing for child-bearing age women and newborns.
- Offer routine, voluntary testing of pregnant women giving birth in Florida. Routine and voluntary HIV screening of heel-stick blood from newborns should be studied expediently by an appropriate panel of experts. Such a program should be funded and initiated if so advised by the panel.
- Partner notification efforts should remain voluntary, confidential, and without identification of the named source.
- The private sector should be encouraged to participate in voluntary partner notification activities with assistance by public health personnel. HRS should step up efforts to work with private physicians and their patients, taking advantage of CDC funding.
- Voluntary partner notification efforts should be based upon physician diagnosis and done after consultation with a patient's doctor.
- Mandatory name reporting of HIV infected persons should not be required by law. The state should collect non-identifying data on seroprevalence testing in the private sector and should implement stronger measures to encourage private physicians to make use of voluntary partner notification services provided by public health personnel. This could be done, for example, by allowing doctors to put patients in touch with health officials on a voluntary basis during the post-test counseling.
- Counseling should be offered whenever possible in the person's primary language and by a peer. Establishing a bond of trust is often a pre-condition of opening the ears and mind of the listener, making the messenger sometimes as important as the message.
- Condoms and condom skill training should be made available during pre- and post-test counseling by trained counselors.

- Amend s. 381.004(3)(f)11., F.S., to include in the list of persons with a "need to know," those residential programs and day programs licensed or funded pursuant to ch. 393 F.S.
- Conform the Omnibus AIDS Act to the provisions of the Florida Civil Rights Act as it relates to damages.
- Policy information provided to insureds by an insurer should be required to be revised not less often than every two years to take into account differences between Florida and other jurisdictions.
- Require confidentiality by insurers as to a person having taken or having refused to take an HIV test or having refused to authorize release of the results.

SUBSTANCE ABUSE AND PREVENTION

SUMMARY AND RATIONALE

The transmission of HIV among intravenous drug users has been well documented. Regretfully, funding for drug abuse treatment programs has been dismal. However, even with the availability of a rehabilitative program, drug users often stay involved with drugs for many years before seeking or completing treatment.

There is a definite link between dirty needles and HIV transmission. The panel heard the testimony of many persons involved with drug rehabilitation programs. With rare exception, none believed that distributing clean needles would promote drug-use. All were in agreement that clean needle programs should not be considered substitutes for drug rehabilitation programs. However, clean needle exchange as part of a comprehensive drug abuse treatment program would be a way to reduce the harm of drug use until the drug user could be rehabilitated.

It is important that persons working with drug users be fully educated in a variety of HIV/AIDS education issues. HIV/AIDS education is an important part of their counseling and outreach efforts to drug users.

RECOMMENDATIONS FOR SUBSTANCE ABUSE AND PREVENTION

- More drug abuse treatment programs must be made available.
- Break the link between dirty needles and HIV infection by

implementing clean needle programs in conjunction with drug abuse treatment programs. This requires removing certain legal barriers.

- Strengthen educational efforts for drug abuse and mental health counselors.

GOVERNMENTAL ACTION

SUMMARY AND RATIONALE

Although there are many HIV/AIDS prevention and care activities ongoing in the state of Florida, there does not seem to be a comprehensive, coordinated effort. A permanent AIDS advisory council and AIDS policy advisor to the Governor would have the dual effect of elevating the importance of our fight against HIV/AIDS infection, as well as effecting a statewide comprehensive plan.

Due to the changing face of AIDS and to the disproportionate amount of infection in the ethnic minority communities, it is important that ethnic minorities be included in both policy making and advisory positions at all levels in the fight against HIV/AIDS infection.

The cost of caring for AIDS patients combined with the epidemiological predictions are dismal. Increased funding now both for prevention and care will save dollars later. Florida's leaders have a need to know and understand the seriousness of the HIV/AIDS epidemic so that they will support increased funding efforts.

RECOMMENDATIONS FOR GOVERNMENTAL ACTION

- A permanent HIV/AIDS Advisory Panel should be established with the potential for sub panel task committees. The panel should be diverse with special sensitivity to infected populations.
- The Governor should appoint an HIV/AIDS Policy Advisor.
- Increase ethnic minority participation in the HRS AIDS program at the state level.
- The Governor should call a leadership conference on HIV/AIDS to educate Florida's leaders on the seriousness of HIV prevention.
- Increase funding at all levels of HIV/AIDS prevention, education, and care.

- Don't put these recommendations on the shelf. Face the truth or suffer the consequences!